



# Improving Quality of Care in Rheumatoid Arthritis and associated comorbidities



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## **Terms of reference:**

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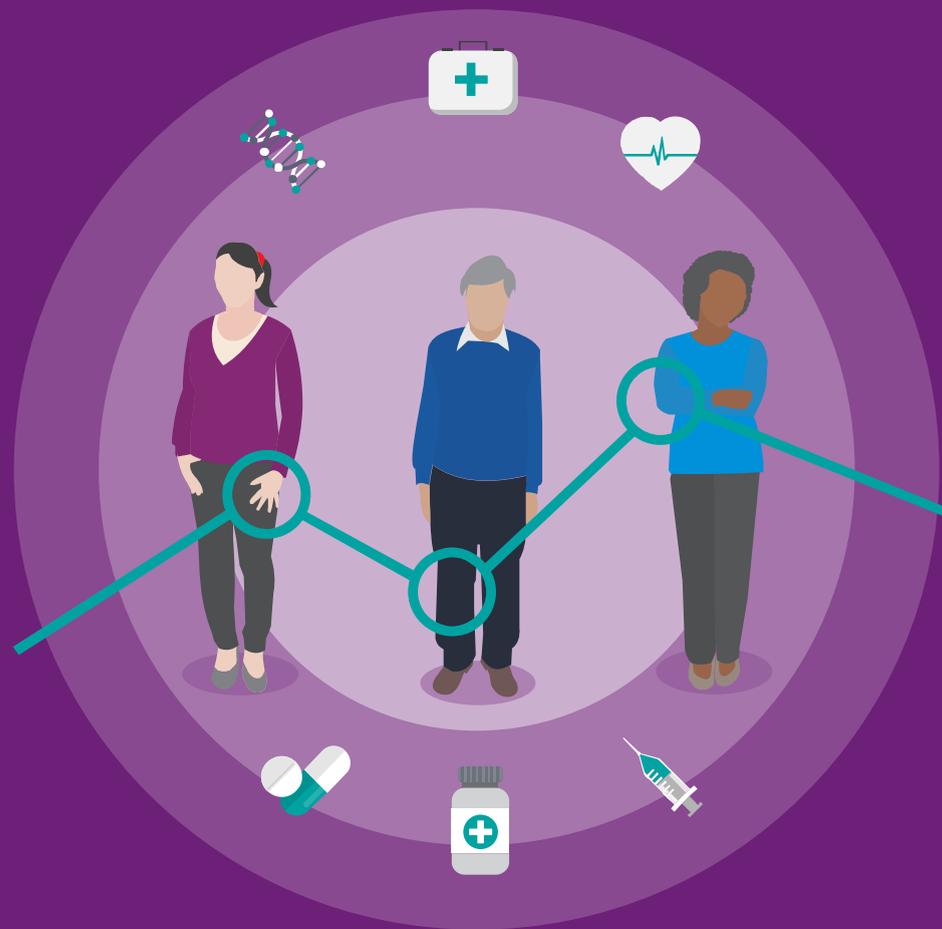
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Note: See page 106 for contributor roles and responsibilities





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# Foreword



# Foreword

Although rheumatoid arthritis (RA) care has seen significant improvements over the last decades, challenges still remain. This is especially true for the management of associated comorbidities as it requires collaboration across specialties and care settings. Other challenges exist such as delayed referrals and late diagnosis of RA.



This initiative highlights good practice interventions observed in selected centres across Europe which address these.

I am proud to have chaired a multidisciplinary group of rheumatologists, comorbidity specialists, a patient representative and a nurse to ensure that the findings documented were as relevant as possible to the entire rheumatology community.

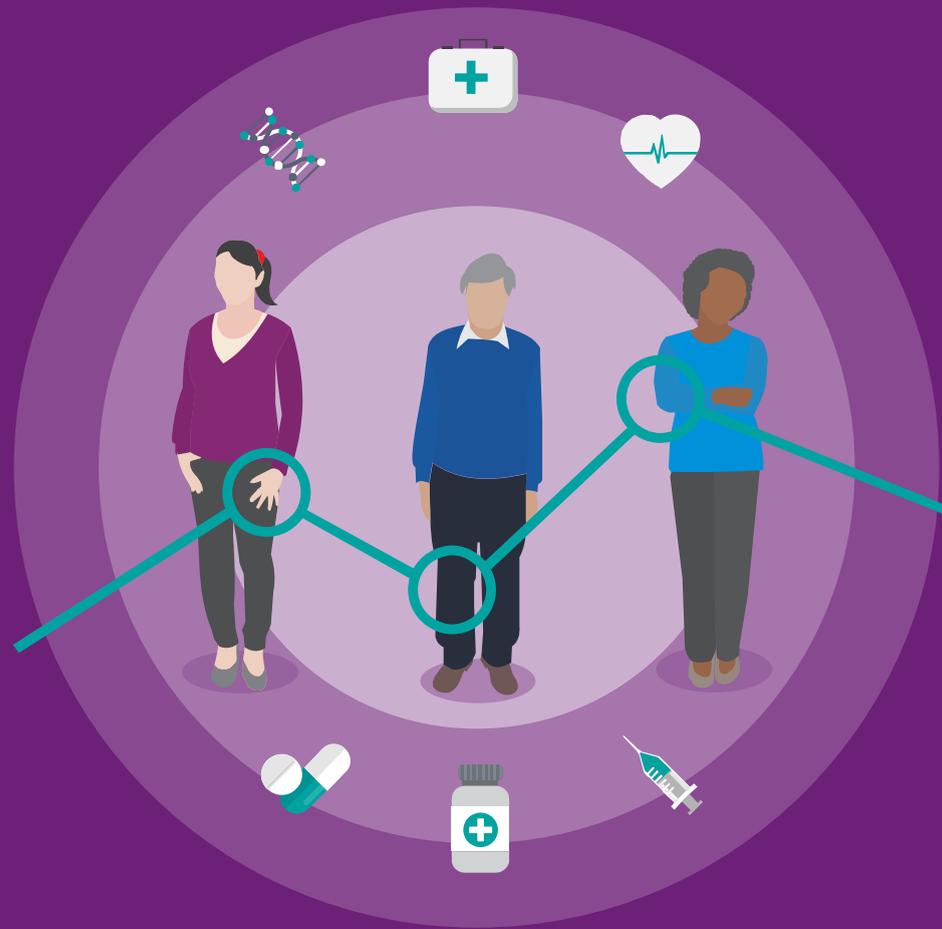
My hope is that these results will give inspiration to other rheumatology teams and provide them with interesting thoughts to reflect upon. We all aim to provide our patients with the best care possible and I strongly believe that this report can help achieve this goal regardless of country or health system.

I look forward to seeing our findings implemented around Europe and the positive outcomes achieved.

**Tore Kvien**

Chair of Steering Committee







# Executive summary



# Our initiative aims to improve the management and care of patients with RA and associated comorbidities across Europe

## Aims

To develop a set of guiding principles, supporting treat-to-target (T2T) ambitions, for the future of patient centred, holistic rheumatoid arthritis (RA) and associated comorbidities care in Europe



Drive improvements in patient quality of care



Encourage greater collaboration between rheumatologists, other specialties, and other healthcare disciplines e.g. nursing



Promote the delivery of consistent care across geographies and care settings



Increase levels of active patient participation in disease management



Establish a dialogue between centres of care to enable sharing of best practices



Raise awareness of the current challenges in care





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EXECUTIVE SUMMARY

# We combined primary and secondary research with guidance from experts in RA and associated comorbidities

## Key steps to arrive at report findings



 **1 Conduct literature review**

— Review key available evidence on recommended good practice care and management, e.g. local and international guidance, EULAR / ACR recommendations

 **2 Visit centres**

— Observe and document good practice interventions

 **3 Synthesise findings**

— Identify key themes in challenges and good practice interventions

 **4 Review with expert Steering Committee**

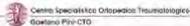
— Ensure findings are representative and accurate

 **5 Finalise report**

— Document findings and recommendations of expert Steering Committee

# We selected a number of centres demonstrating features of good practice to visit across Europe

We selected centres according to whether they could demonstrate examples of innovation in RA care, and expertise in managing comorbidities. We also picked centres that were broadly representative of the healthcare system in that country

	Cliniques Universitaires Saint-Luc, Brussels, Belgium	
	Institute of Rheumatology, Prague, Czech Republic	
	Rigshospitalet, Copenhagen, Denmark	
	Hôpital Cochin, Paris, France	
	Istituto Ortopedico Gaetano-Pini, Milan, Italy	
	Sint Maartenskliniek, Nijmegen, Netherlands	
	Diakonhjemmet Hospital, Oslo, Norway	
	Hospital de Santa Maria, Lisbon, Portugal	
	Hospital Universitario La Paz, Madrid, Spain	
	Karolinska University Hospital, Stockholm, Sweden	
	Geneva University Hospitals, Geneva, Switzerland	
	Leeds Teaching Hospitals, Leeds, United Kingdom	



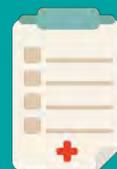


# Patient pathway



## 1. Awareness & Prevention

Awareness in patients and especially in primary care physicians (PCPs) to detect possible inflammatory arthritis and associated comorbidities



## 2. Referral

Referral via the following avenues:

- Primary care
- Self-referral
- Another specialty to secondary care for specialist assessment

## 3. Diagnosis

Initial screening by rheumatology or comorbidity specialist

Investigations and review by specialist

Confirmation of diagnosis



## 4a. Treatment & management

### Pharmacological management

Management of RA using conventional and targeted synthetic or biological drug therapies

Management of RA and associated comorbidities by rheumatologists and comorbidity specialists e.g. cardiologist, diabetologist, lung specialist, psychiatrist

## 4b. Treatment & management

### Non-pharmacological management

Physiotherapist  
Occupational therapist  
Psychologist  
Rheumatology nurse  
Social worker



## 5. Follow-up

Programmed or patient-initiated follow-up

Rheumatologist, rheumatology nurse and comorbidity specialist periodic review

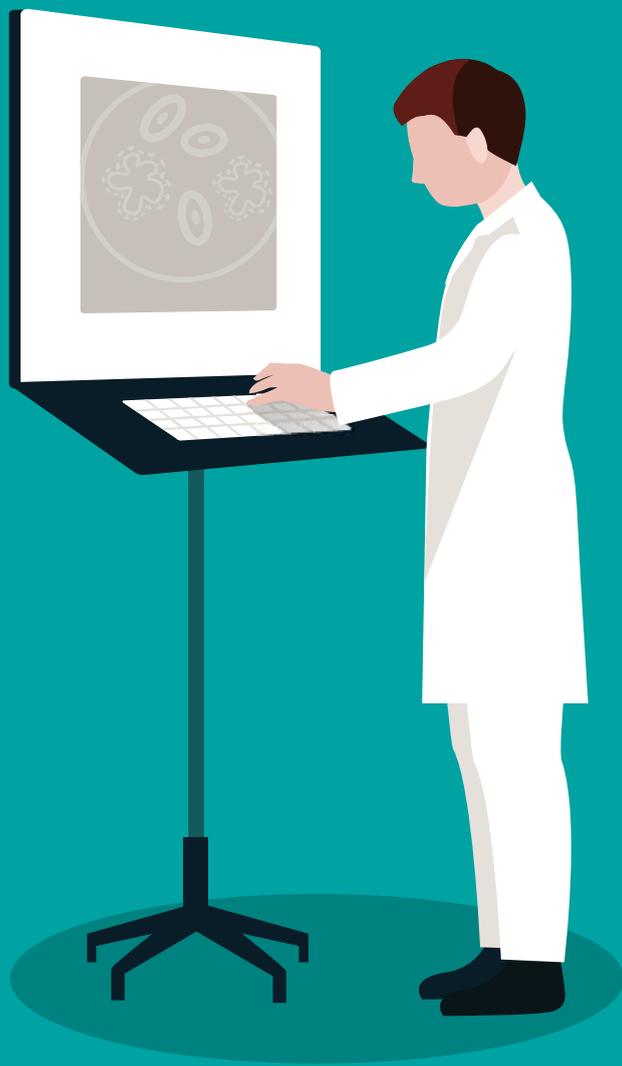


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EXECUTIVE SUMMARY

# We identified key challenges in RA care along the patient pathway

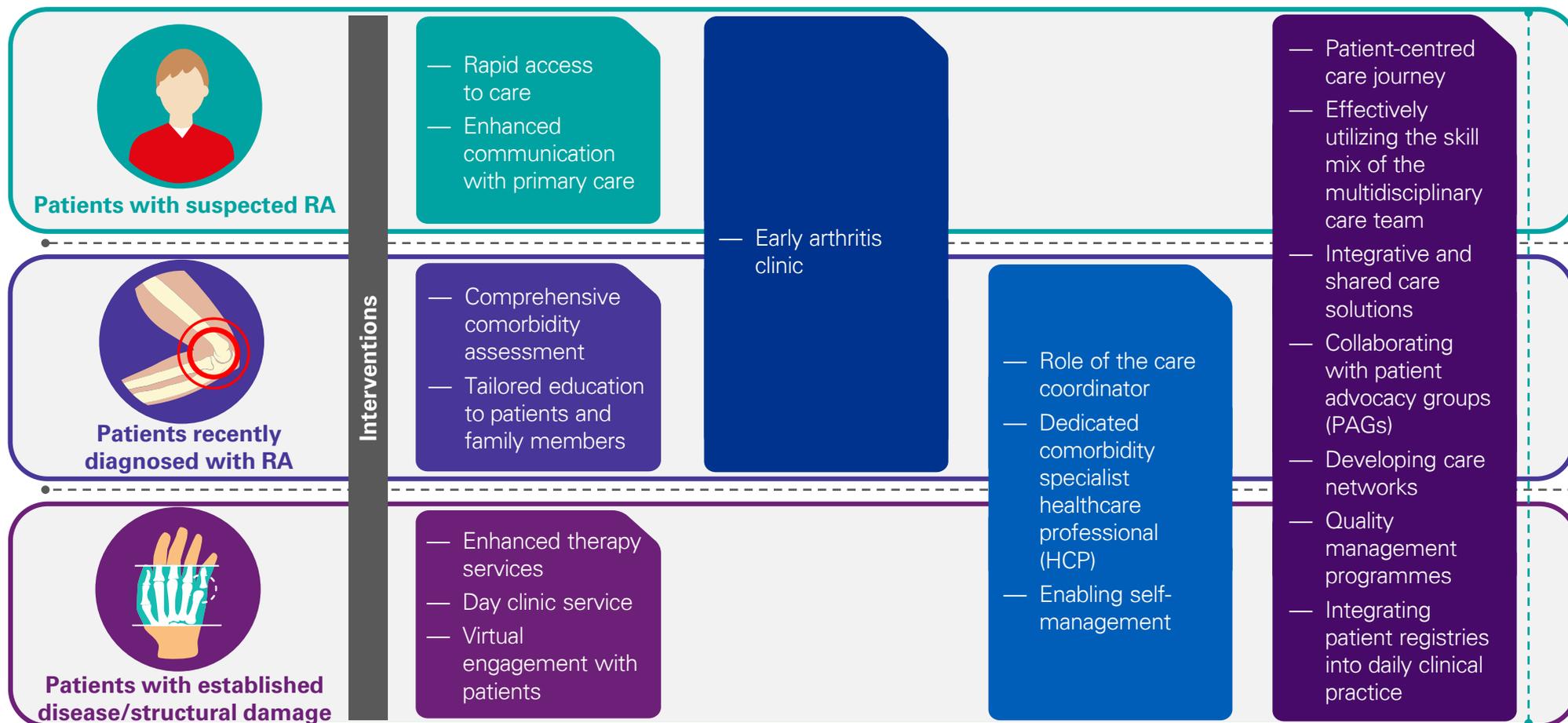


## Challenges

- During our research we identified a number of challenges to providing high-quality RA care that exist across the patient pathway
- The findings from our secondary research were reinforced by our fieldwork and were relatively consistent over the different countries we visited across Europe. For each site visit, a centre-specific report was produced which was reviewed and approved by all centres
- Despite these barriers, which included lack of funding, resources or workforce issues, we found many examples of good practice interventions that could help centres aiming to improve their care

# The Steering Committee prioritised 18 good practice interventions which meet the needs of three distinct patient profiles

Guided by our Steering Committee, we identified 3 groups of patients across the RA care continuum. Across the patient profiles, we identified 18 good practice interventions in RA care that together create a holistic overview of good practice care. We have described 53 case studies across all of the centres we visited, demonstrating the different ways good practice interventions were delivered in different health systems / local circumstances.



# We also found examples of good practice that directly meet guidelines / recommendations on comorbidity care

We focused on the care of five comorbidities because they are collectively found in a large proportion of all patients with RA: cardiovascular disease (CVD); diabetes; depression; osteoporosis; interstitial lung disease (pulmonary).

Comorbidity	Published guidelines / recommendations sources	Case studies / examples targeting specific comorbidity	Case studies / examples addressing all comorbidities
 <b>CVD</b>	(a), (b), (c)	<b>Preventive cardio-rheuma clinic</b>	<b>COMorbidities Education in Rheumatoid Arthritis – COMEDRA</b> <b>Joint comorbidity services</b> <b>Dedicated comorbidity care services</b> <b>Education Programme for Patients and caregivers: ETP</b> <b>Comorbidity research programme</b> <b>Role of the pharmacist</b> <b>Comorbidities monitoring on SQCM</b>
 <b>Diabetes</b>	(c) (not specific to diabetes alone)	<b>Dedicated primary care coordinator</b>	
 <b>Depression</b>	(c)	<b>Dedicated psychologist</b> <b>Sleep outpatient clinic</b> <b>Learning and coping centre</b>	
 <b>Osteoporosis</b>	(d)	<b>Measuring tracking and improving for better care</b> <b>Dedicated comorbidity care services</b> <b>Investigations and procedures unit</b> <b>Systematic inflammatory osteoporosis screening</b>	
 <b>Pulmonary</b>	(e)	<b>Joint rheuma-respiratory clinic</b> <b>Combined clinic for comorbid ILD</b>	

**Sources:** (a) Agca et al. 2017. EULAR recommendations for CVD risk management in patients with RA and other forms of inflammatory joint disorders: 2015/2016 update (b) Peters et al. 2010. EULAR evidence-based recommendations for CVD risk management in patients with RA and other forms of inflammatory arthritis (c) Baillet et al. 2016. Points to consider for reporting, screening for and preventing selected comorbidities in chronic inflammatory rheumatic diseases in daily practice: a EULAR intervention (d) Hoes et al. 2015. Management of osteoporosis in rheumatoid arthritis patients (e) Bluett et al. 2017. Practical Management of Respiratory Comorbidities in Patients with Rheumatoid Arthritis

# We propose the following considerations for potential implementation of our report findings to improve RA care delivery

## Develop programme of service improvement

Design a programme that addresses the gaps in care, drawing on the interventions identified in this report

## Identify local gaps and challenges

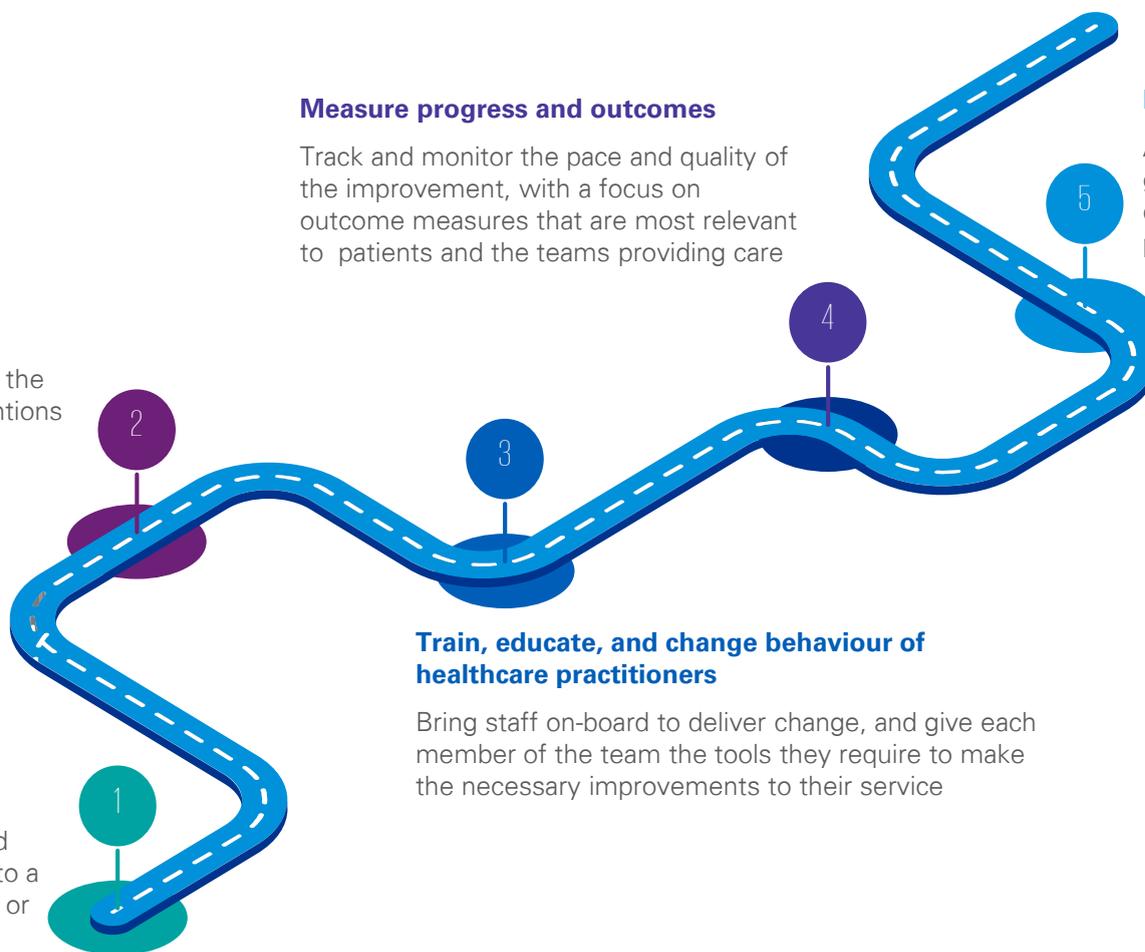
Assess where the common gaps and challenges we have identified apply to a particular RA and comorbidity centre or service

## Measure progress and outcomes

Track and monitor the pace and quality of the improvement, with a focus on outcome measures that are most relevant to patients and the teams providing care

## Evaluate and redesign

Analyse and reflect on which changes are going well and what requires development, then modify the programme accordingly





# Context



# Rheumatoid arthritis is a chronic inflammatory autoimmune condition, with a wide impact on morbidity



## Definition

Rheumatoid arthritis (RA) is a chronic inflammatory disease characterised by joint swelling, joint tenderness, and destruction of synovial joints, with a severe disability, comorbidity and mortality impact<sup>(a)</sup>



## Prevalence

- RA is the most common inflammatory arthritis and affects about 1% of the population<sup>(b)</sup>
- It is more common in women and in developed countries
- The incidence increases up to 60 years old and plateaus after that



## Causes

RA is caused by a combination of genetic and environmental factors<sup>(c)</sup>



## Symptoms

Symptoms present in the joints, connective tissues, muscle, tendons, and fibrous tissue in a characteristic symmetric pattern<sup>(a,d)</sup>



## Diagnosing RA

'Diagnosed RA' is supported by following classification criteria<sup>(a)</sup>:

- Confirmed presence of synovitis in at least 1 joint
- Absence of an alternative diagnosis
- A total score  $\geq 6 / 10$  from the following 4 domains:
  1. Number and site of involved joints (0-5)
  2. Serologic abnormality (0-3)
  3. Elevated acute-phase response (0-1)
  4. Symptom duration (2 levels; 0-1)



## Burden

- RA was ranked as the 42nd highest contributor to global disability<sup>(b)</sup>
- It is a chronic disabling condition often causing pain and deformity
- Within 10 years of onset, at least 50% of patients in developed countries are unable to hold down a full-time job<sup>(c)</sup>

# People are living for longer with RA, resulting in a growing global burden on patients, caregivers, and healthcare systems

The global burden of RA has risen, despite no significant change in prevalence

## Drivers of RA burden:



Growing prevalence of comorbidities such as cardiovascular disease and diabetes



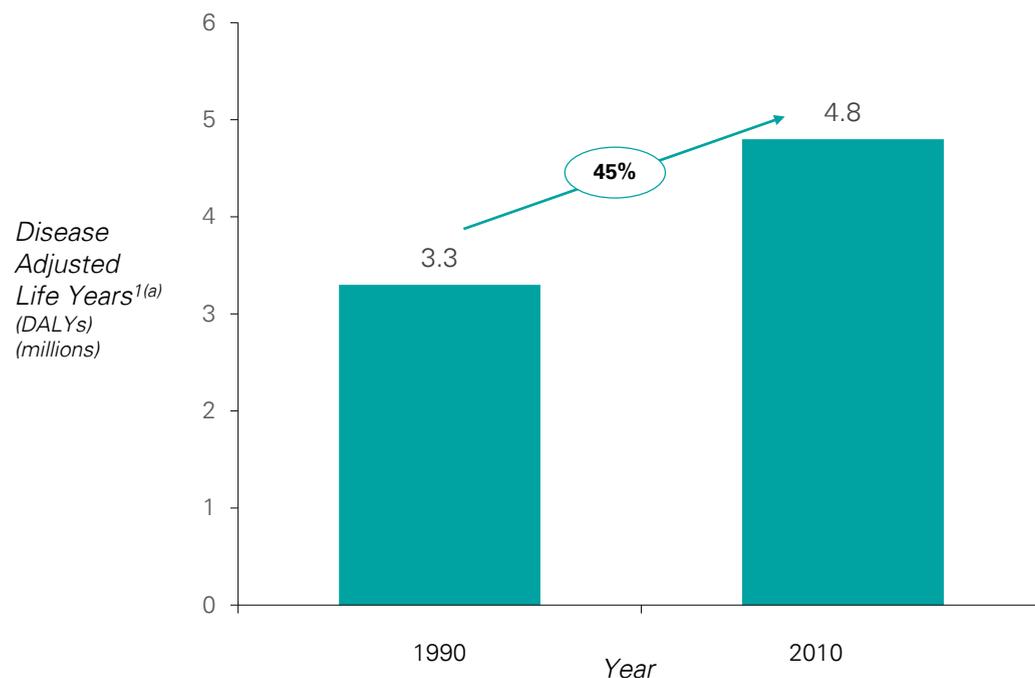
Ageing population and changing lifestyle



Longer exposure to risk factors due to prolonged patient life through advancements in treatment options



Economic and personal impact of treatment with existing therapeutic options



**Notes:** 1. Years of life lived with disability (YLDs), added to the years of life lost due to premature mortality to estimate the overall burden (disability-adjusted life years (DALYs))  
**Sources:** (a) Cross et al. 2013. The global burden of rheumatoid arthritis: estimates from the global burden of disease 2010 study

# RA has a significant economic impact, putting pressure on families, providers and society across Europe

## Burden of RA across Europe<sup>(a)</sup>

More than 2.3 million individuals are diagnosed in total with RA in Europe, generating an annual cost of management of over €45 billion



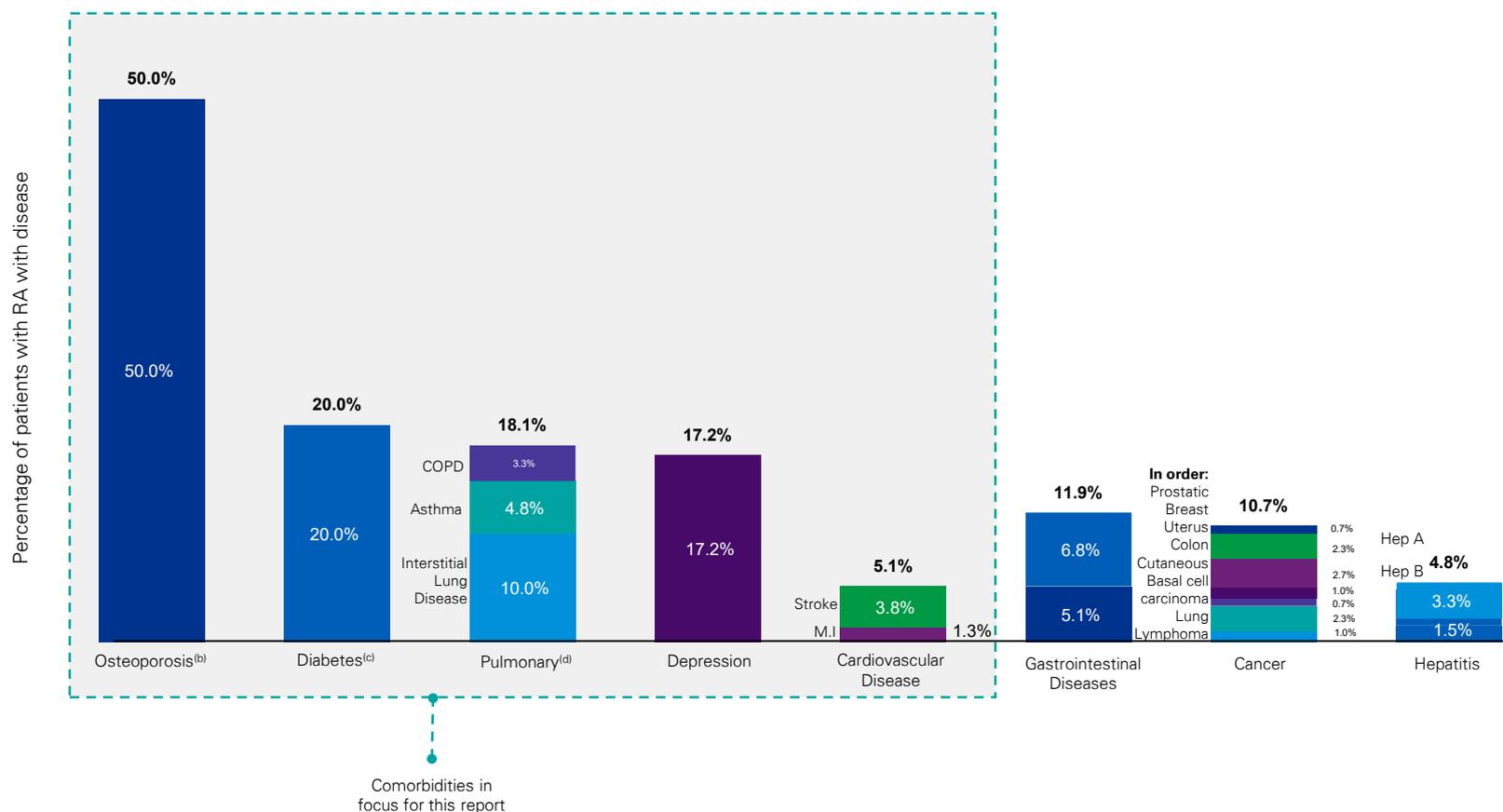
As per a Swedish study, the mean annual cost (including productivity losses) per patient with RA aged 18–64 years is €23,147<sup>(b)</sup>



The mean annual cost in patients with established RA, and mean monthly cost in newly diagnosed patients with RA, is 2-3 times higher than in the general population<sup>(b)</sup>

# Patients with RA are at higher risk of a number of comorbidities and complications

## The prevalence of comorbidities in patients with RA<sup>1(a)</sup>



### Notes:

1. Table has been adapted from prevalence data taken predominantly from 2017 COMORA study. The study was not exhaustive, with the following comorbidities missing from this dataset:
- Osteoporosis (There is a 2x increase in osteoporosis among patients with RA compared with the general population.<sup>(b)</sup> 44% of patients with RA in the COMORA study were on Vitamin D treatment and therefore had been optimally screened<sup>(a)</sup>)
  - Periodontitis (68% of patients in a small sample size)<sup>(d)</sup>
  - Uveitis
  - Infection and infectious diseases (e.g., influenza, tuberculosis etc.). Indeed, patients with RA have elevated susceptibility to serious infections due to features of the disease itself, comorbidity and immunosuppressive treatment<sup>(e)</sup>

**Sources:** (a) Dougados et al. 2014. Prevalence of comorbidities in rheumatoid arthritis and evaluation of their monitoring: results of an international, cross-sectional study (COMORA) (b) Wegierska et al. 2016. Osteoporosis diagnostics in patients with rheumatoid arthritis (c) Albrecht et al. 2018. High prevalence of diabetes in patients with rheumatoid arthritis: results from a questionnaire survey linked to claims data (d) Olson et al. 2011. Rheumatoid arthritis-interstitial lung disease-associated mortality (e) Listing et al. 2013. The risk of infections associated with rheumatoid arthritis, with its comorbidity and treatment

# Pharmacological treatments range from synthetic disease-modifying anti-rheumatic drugs (DMARDs) to biologics

		EULAR recommendations <sup>(a)</sup>		Treatment rationale	
patient with RA population	'Remission / low disease activity'	→	<b>1<sup>st</sup> line:</b> <ul style="list-style-type: none"> <li>— Steroid (oral/injection)</li> <li>— Mono or combination synthetic DMARD therapy e.g. methotrexate, sulfasalazine, leflunomide</li> </ul>	—	Oral tablet or a subcutaneous steroid injection is also used as a short-term treatment option  Methotrexate is the gold standard first line synthetic DMARD in the US and EU  All of those defined as having low disease activity will be managed by a combination of steroids and conventional synthetic DMARDs (csDMARDs)
	'Moderate disease activity'		<b>1<sup>st</sup> line:</b> <ul style="list-style-type: none"> <li>— Steroid (oral/injection)</li> <li>— Mono sDMARD therapy</li> </ul>	—	Patients diagnosed with moderate to severe RA are treated in the same way as patients with low disease activity in 1st line
	+		→	<b>2<sup>nd</sup> line:</b> <ul style="list-style-type: none"> <li>— Mono (rotation of sDMARD) or combination (addition of sDMARD) therapy</li> </ul>	—
	'High disease activity'		<b>3<sup>rd</sup> line:</b> <ul style="list-style-type: none"> <li>— Biological DMARD (bDMARD) therapy or targeted synthetic DMARD (tsDMARD)</li> </ul>	—	If second or combination sDMARDs do not achieve improvement, or prognostically unfavourable factors are present, then a bDMARD or tsDMARD should be added

Sources: (a) Smolen et al. 2017. EULAR recommendations for the management of rheumatoid arthritis with synthetic and biological disease-modifying antirheumatic drugs: 2016 update



# Treat-to-target is the leading strategy for overall management of RA - developed to achieve four overarching goals<sup>(a)(b)(c)</sup>

## Shared decision-making



Between patient and rheumatologist

### Example KPIs

% of patients who received education about self-management within one month of diagnosis

## Maximise quality of life (QoL)



Through:  
 — Control of symptoms  
 — Prevention of structural damage  
 — Normalisation of function  
 — Participation in social and work-related activities

Pain Visual Analogue Scale

## Reduce inflammation



To achieve the above goals

% of patients in remission (DAS28 < 2.6)

## Treat to optimise outcomes



— By measuring disease activity  
 — Adjusting therapy accordingly to optimise outcomes in RA

% patients who maintain remission over a year



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CONTEXT



# Treat-to-target encompasses 10 key recommendations



The 10 'treat-to-target' recommendations<sup>(a,b)</sup>

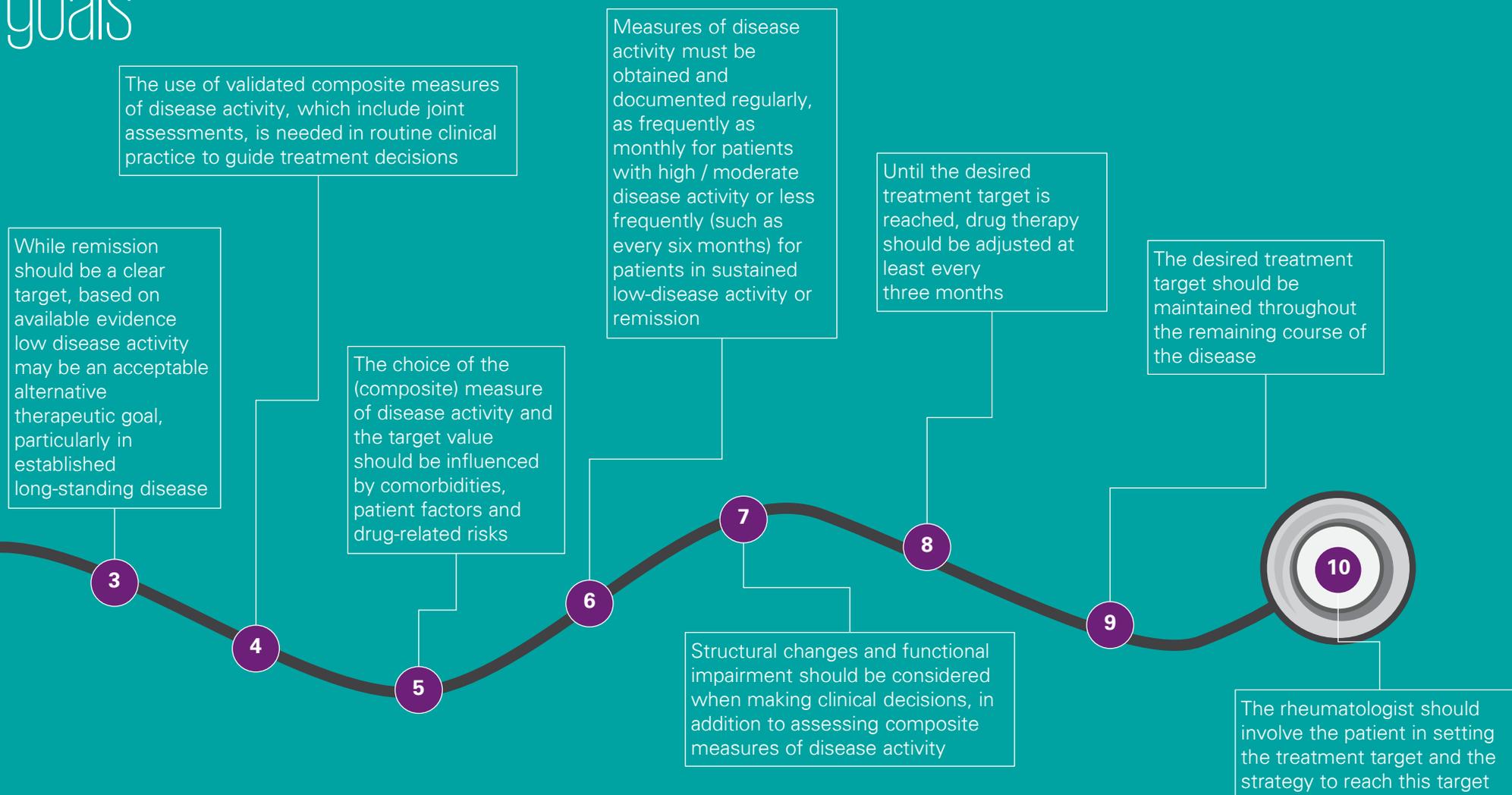
Clinical remission is defined as the absence of signs and symptoms of significant inflammatory disease activity

The primary target for treatment of RA should be a state of clinical remission

1

2

# to enable physicians and patients to meet the overarching goals



# Despite advances in treatment and published guidelines patient outcomes remain suboptimal

Outcome	Indicator	Example evidence
<b>Disease activity</b> 	Disease activity score (DAS 28) Simplified Disease Activity Index (SDAI) Clinical Disease Activity Index (CDAI)	<ul style="list-style-type: none"> <li>— In patients receiving targeted monotherapy the proportion of patients achieving DAS28 clinical remission at 24 and 264 weeks was 40.2% and 65.2%, respectively<sup>(a)</sup></li> </ul>
<b>QoL</b> 	Pain visual analogue scale (VAS) Functional Assessment of Chronic Illness Therapy (FACIT) fatigue score	<ul style="list-style-type: none"> <li>— Up to 55% of patients with RA report severe pain on VAS measurement<sup>(b)</sup></li> <li>— 52% of all patients reported VAS pain score <math>\geq 30</math>mm (DANBIO)<sup>(e)</sup></li> <li>— Patients with RA report high levels of fatigue, with the mean FACIT-Fatigue score approximately 29.5<sup>(c)</sup></li> </ul>
<b>Social/work impact</b> 	Social / work impact	<ul style="list-style-type: none"> <li>— It is estimated that within 10 years of RA onset, only 50% of patients are able to sustain their full-time job<sup>(d)</sup></li> </ul>

**Sources:** (a) Jones et al. 2017. Five-year Efficacy and Safety of Tocilizumab Monotherapy in Patients with Rheumatoid Arthritis Who Were Methotrexate- and Biologic-naive or Free of Methotrexate for 6 Months: the AMBITION Study, The Journal of Rheumatology (b) Walker et al. 2017. Disease activity dynamics in rheumatoid arthritis: patients' self-assessment of disease activity via WebApp (c) Berntzen et al. 2016. A 6-Week Progressive Training Class Improves Function and Fatigue in Rheumatoid Arthritis Patients, British Society for Rheumatology (d) World Health Organization. 2018. WHO | Chronic rheumatic conditions (e) Christensen et al. 2017. Pain and pain mechanisms in patients with inflammatory arthritis: A Danish nationwide cross-sectional DANBIO registry survey, Journal Plos

Key:  Existing guidelines published by key regulatory bodies or disease associations

 Existing recommendations published in academic literature

 No existing guidelines or guidance found at a regional or national level

 Focus areas for this report



# Lack of guidelines in the management of comorbidities in RA leads to suboptimal patient outcomes

Comorbidity	Guidance present at a regional / national level?	Evidence for Outcomes
<b>CVD</b>	 (a), (b), (c)	<ul style="list-style-type: none"> <li>— Risk of cardiovascular death is 2 times higher among patients with RA than the general population<sup>(d)</sup></li> <li>— Patients with RA are 2x as likely to experience unrecognised myocardial infarctions (MIs) and sudden deaths and 64% less likely to undergo coronary artery bypass grafting compared with non-RA subjects<sup>(e)</sup></li> </ul>
<b>Diabetes</b>	 (c)	<ul style="list-style-type: none"> <li>— Patients with RA with diabetes are 26% less likely to receive recommended screening and monitoring tests, and are therefore more likely to develop micro / macro vascular complications, than non-RA diabetes patients [19% more likely to have chronic kidney disease, 77% more likely to have lower limb ulcers, 32% more likely to have peripheral vascular disease was, as with amputations (0.9% vs 0.6%)]<sup>(f)</sup></li> </ul>
<b>Depression</b>	 (c)	<ul style="list-style-type: none"> <li>— Patients with RA with clinical depression have poor medication adherence, increased health service utilisation, pain and disability, it also reduces RA remission<sup>(g)</sup></li> <li>— Risk of death in patients with RA with clinical depression is 2.2x higher than in patients with RA without depression<sup>(h, i)</sup></li> </ul>
<b>Pulmonary</b>	 (j)	<ul style="list-style-type: none"> <li>— Approximately 7% of all deaths in RA are related to ILD<sup>(k)</sup></li> </ul>
<b>Osteoporosis</b>	 (l)	<ul style="list-style-type: none"> <li>— The rate of fracture is doubled among patients with RA<sup>(m)</sup></li> <li>— 51% of the patients taking at least 5 mg of prednisone for ≥ 3 months have either undergone bone mineral density testing or received a prescription medication<sup>(n)</sup></li> </ul>
<b>Infection and Infectious diseases</b>	 (c)	<ul style="list-style-type: none"> <li>— Patients with RA have a higher risk of severe infections, presenting with atypical symptoms and are 2x more likely to require hospitalisation<sup>(i)</sup></li> </ul>
<b>Periodontitis</b>		<ul style="list-style-type: none"> <li>— Patients with RA are at 1.13x increased risk of developing periodontitis regardless of disease activity or treatment (there is no significant change in risk after DMARD treatment), compared with the general population<sup>(h)</sup></li> </ul>
<b>Malignancy</b>		<ul style="list-style-type: none"> <li>— There is an additional cancer mortality risk from having RA, including a 40-50% increased mortality for breast and prostate cancer respectively when compared with individuals who do not have RA</li> <li>— There is also an additional morbidity risk<sup>1</sup> from having RA when compared with individuals who do not have RA<sup>(n)</sup></li> </ul>
<b>Gastrointestinal</b>		<ul style="list-style-type: none"> <li>— Patients with RA who have gastrointestinal (GI)<sup>2</sup> disorders have a 46% higher mortality rate than those without GI disorders<sup>(o)</sup></li> </ul>

**Note:** 1. Due to the disease itself, the adverse effects of cancer therapies, and the presence of other comorbid conditions. The added deleterious effect of comorbid conditions remains after adjusting for age and sex, and has been observed for many different cancer types (i). 2. Disorders of the stomach, disorders of the liver, disorders of the gall bladder, or serious disorder of the intestines longer than 3 months. 3. Only the most common comorbidities have been categorised according to guidance present at the regional / national level, resulting in Periodontitis, Malignancy and Gastrointestinal being excluded

**Sources:** (a) Agca et al. 2017. EULAR recommendations for cardiovascular disease risk management in patients with rheumatoid arthritis and other forms of inflammatory joint disorders: 2015/2016 update (b) Peters et al. 2010. EULAR evidence-based recommendations for cardiovascular risk management in patients with rheumatoid arthritis and other forms of inflammatory arthritis (c) Baillet et al. 2016. Points to consider for reporting, screening for and preventing selected comorbidities in chronic inflammatory rheumatic diseases in daily practice: a EULAR intervention; (d) Maradit-Kremers et al. 2005. Cardiovascular death in rheumatoid arthritis: a population-based study (e) Maradit-Kremers et al. 2005. Increased unrecognized coronary heart disease and sudden deaths in RA: a population-based cohort study (f) Bartels et al. 2012. Monitoring diabetes in patients with and without RA: a Medicare study (g) Fiest et al. 2017. Systematic Review and Meta-analysis of Interventions for Depression and Anxiety in Persons With RA (h) Ang et al. 2005. Comorbid depression is an independent risk factor for mortality in patients with RA (i) Sheehy et al. 2006. Depression in RA—underscoring the problem (j) Bluett et al. 2017. Practical Management of Respiratory Comorbidities in Patients with RA (k) Dixon et al. 2010. Influence of anti-TNF therapy on mortality in patients with rheumatoid arthritis-associated interstitial lung disease: results from the British Society for Rheumatology Biologics Register (l) Hoes et al. 2015. Management of osteoporosis in rheumatoid arthritis patients (m) Äyräväinen et al. 2017. Periodontitis in early and chronic rheumatoid arthritis: a prospective follow-up study in Finnish population (n) Nayak et al. 2017. Impact of RA on the Mortality of Elderly Patients Who Develop Cancer: A Population-Based Study (o) van den Hoek et al. 2016. Association of Somatic Comorbidities and Comorbid Depression With Mortality in Patients With RA: A 14-Year Prospective Cohort Study



# Objectives



# Our initiative aims to improve management of RA and associated comorbidities

To develop a set of guiding principles, supporting treat-to-target (T2T) ambitions, for the future of holistic RA and associated comorbidities care in Europe



— We want to understand what good practice care of RA and associated comorbidities - supporting T2T ambitions - looks like across the patient pathway in Europe



— We want to understand recommendations and good practices for management (prevention, detection and treatment) of associated comorbidities



— We want to support provision of leading-practise care for patients in Europe and around the world



The goal of our project is to define good practices in holistic care for RA, and to compile these into a report which may be used to support the provision of leading-practise care for patients in Europe and around the world





# Methodology



# 5-step approach

## Key steps to arrive at report findings



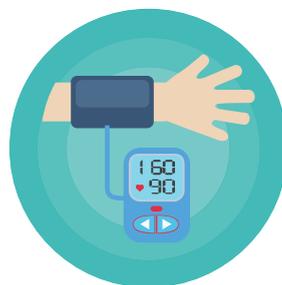
### Conduct literature review

To review key published evidence to understand the challenges and good practices in the care and management of RA and associated comorbidities



### Visit centres

To observe and document the challenges in care and examples of good practice in prominent centres across Europe



### Synthesise findings

To collate our findings from the literature review and observational centre visits



### Review with expert Steering Committee

To ensure our findings capture: the key challenges and gaps in the care of RA and associated comorbidities; and the most relevant good practices to HCPs and patients in the region



### Finalise report

To crystallise our findings into one comprehensive report to be disseminated across the region

Why?

How?

We reviewed articles from peer-reviewed journals and internationally recognised guidelines and recommendations (EULAR, ACR) for evidence-based practice of care and management

We visited 12 RA centres across the region and conducted over 100 interviews with a wide range of stakeholders. We combined semi-structured interviews with open questions to gain a complete understanding of good practice interventions in place

We synthesised findings from our interviews, developing centre-specific reports (available in appendix) and identified key themes and common interventions of good practice seen across the 12 centres visited

We submitted our centre-specific findings to each centre to verify for accuracy. We then shared all of our findings with the expert Steering Committee to review and prioritise our findings<sup>1</sup>

We have summarised our findings, identifying key themes and good practice interventions that were observed across the region, and outlining case studies of good practice, with a particular emphasis on management of comorbidities in RA

# Conducting our literature review

## Our approach



We have reviewed over 50 academic and clinical publications in addition to high-quality grey literature from a number of reputable sources



We have reviewed the major international recommendations and guidelines for all indications in the scope of this report, including EULAR, EUMUSC and local recommendations/guidelines



We have consulted numerous publications by government and private institutions detailing healthcare good practices and future plans

Our literature review formed a basis for the findings from our fieldwork to build upon. Together this has helped us to form a comprehensive view of the RA care and management landscape and offer tangible examples of how the quality of care in RA and its associated comorbidities can be improved



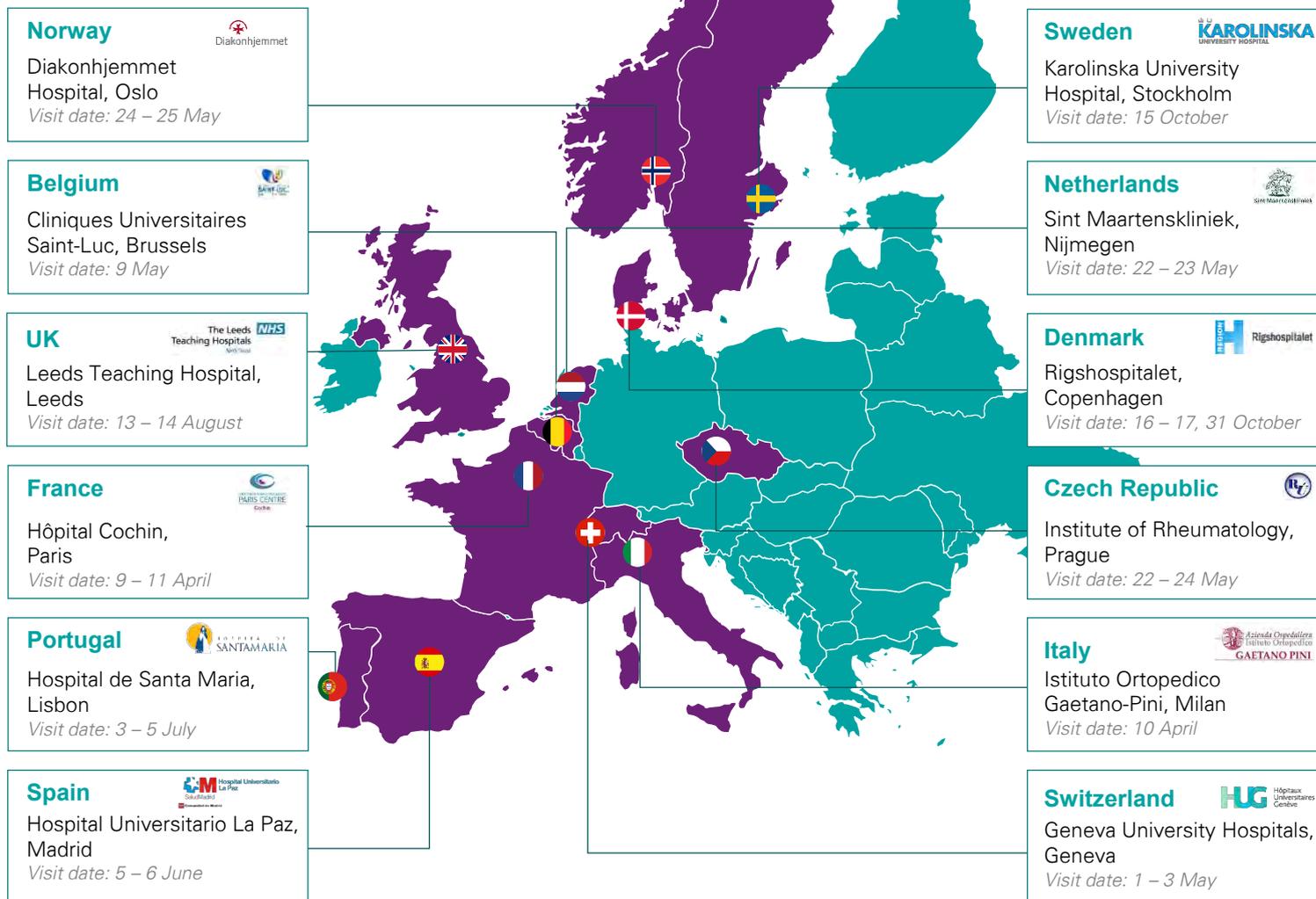
# Visiting centres

KPMG guided the selection of 12 centres to take part in the initiative and have one representative join the Steering Committee<sup>1</sup>

Centres had a track record of innovation (e.g. involvement in clinical trials and novel programmes) and improving patient care for RA and associated comorbidities

Centres were representative of the majority of national healthcare systems throughout the region, as well as being seen to operate models which were representative of the care continuum

For further information please see slides 107-108: Centre selection and Limitations to our methodology



# Visiting centres – what did we do?

## Who did we speak to?



### The key stakeholders involved in RA and comorbidity care:

#### RA

- Rheumatologist
- Rheumatology nurse
- Rheumatology research nurse
- Community rheumatologist

#### Multi-disciplinary team

- Pharmacist
- Service coordinator
- Comorbidity coordinator
- Physiotherapist
- Occupational therapist
- Podiatrist

#### Comorbidity

- Psychologist
- Diabetologist
- Cardiologist
- Pulmonologist
- Primary Care Physician (PCP)

## What did we ask them?



### Interview questions covered the following areas of the patient pathway in order to identify gaps in care:<sup>1</sup>

- Screening
- Diagnosis
- **Linkage to care / referral**
- **Clinical management**
- **Multi-disciplinary care**
- **Follow-up care**
- **Patient education/empowerment**
- Communication
- Training of HCPs
- Use of technology

## Overview of key themes:



### The discussions included:

- **Overview of centre**
  - Number of patients, services, demographics, team, funding flows, collaborations
- **Challenges** in RA and comorbidity care
- **Interventions**
  - Successful / unsuccessful attempts to overcome challenges
- **Implementation**
  - Practical steps to replicate (who / what / how / when)
  - Requirements (time, funding, resources)
- **Measurements of benefits**
  - Outcomes
  - KPIs (how and when to capture)

# Synthesising our findings and reviewing with an expert Steering Committee



## Our approach

### 1. Synthesis

#### Centre-specific findings

- Through our visits to 12 RA centres, we identified key practices that underpin provision of high-quality care
- At each centre we visited we:
  - Walked the ‘patient journey’ to understand the different steps in care and the patient experience
  - Discussed the key challenges in RA and comorbidity care
  - Identified specific good-practice ‘interventions’ that improve the quality of care, including the benefits and tips for implementation
  - Noted how benefits of interventions were being measured
- Following each visit, we shared our findings with the centre, to review and approve for accuracy

#### Good practice interventions

- We synthesised our findings, identifying distinct good practice interventions, that may have been implemented in varying ways by different centres, but were at the core trying to achieve the same objectives
- We conducted an additional literature review to support our observed good practice interventions with further evidence

### 2. Review

#### Steering Committee

We engaged a Steering Committee of 18 members including rheumatologists representing the centres visited, four comorbidity specialists with differing areas of expertise, a patient representative and a rheumatology nurse representative

Their role was to:

- Provide direction on the overall project scope, approach and outputs
- Review, challenge and prioritise our findings
- Guide future dissemination and implementation of good practice
- Assure the quality of the report outputs regarding their specific centres

#### Steering Committee meetings

We convened three separate Steering Committee meetings over the course of the project

The aim of these Steering Committee meetings were to:

- Review, challenge and refine our findings
- Reach consensus on good practice care for RA and associated comorbidities





# Findings

**a) Key profiles of patients with RA across the care continuum**



# Using KPMG research, the Steering Committee identified the stages of RA disease progression in three patient profiles

## Patient profile

## Description

### Patients with suspected RA



These patients who have not yet been given a diagnosis but may have interacted with primary care or had a first contact with a rheumatologist, who may suspect RA (inflammatory manifestations not diagnosed)

### Patients recently diagnosed with RA



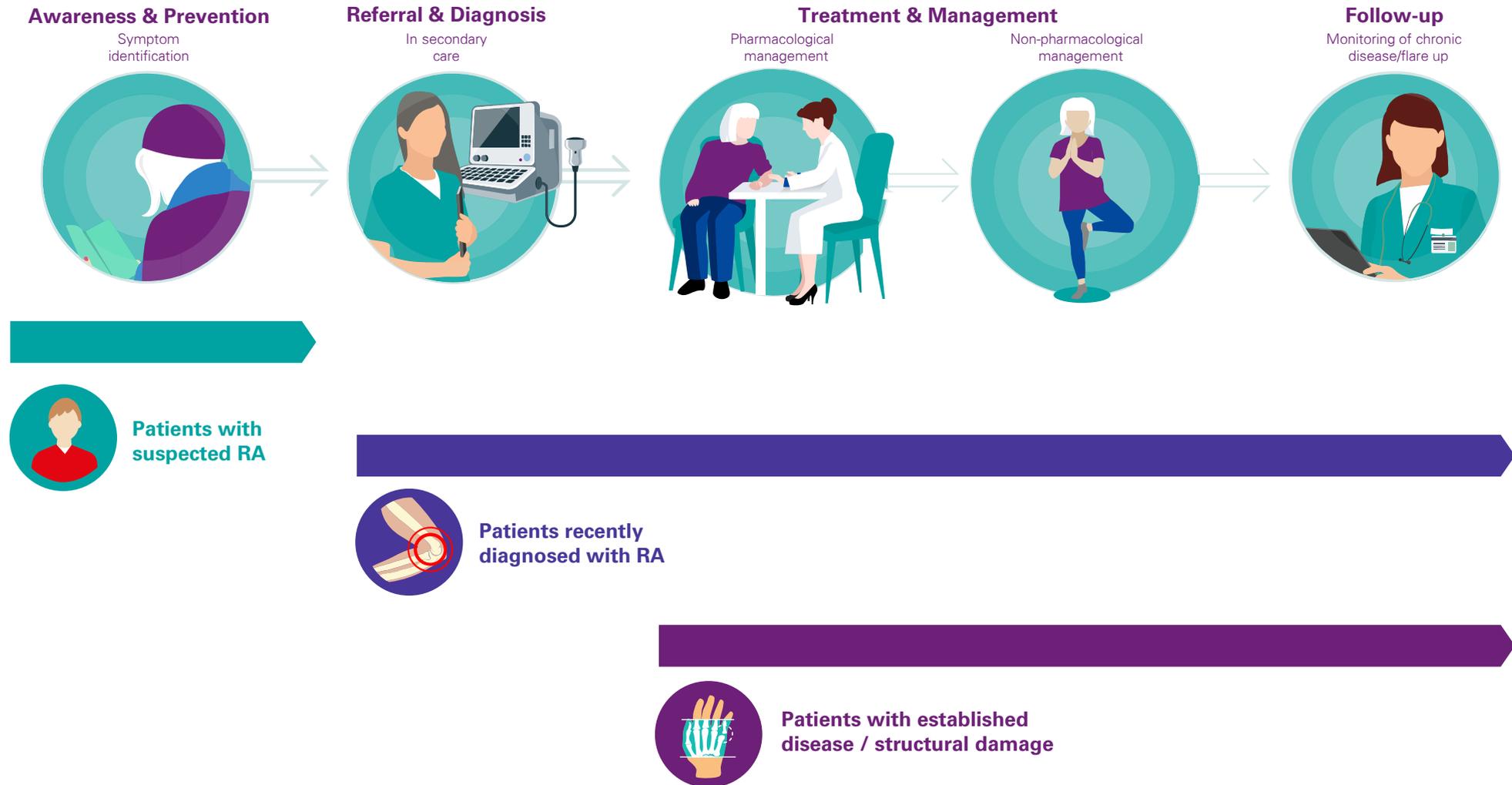
Patients have been given a diagnosis of RA, and usually have been started on treatment with regular follow-up

### Patients with established disease / structural damage



Patients have had a diagnosis of RA for a number of years or may have presented late (most likely from less developed healthcare economies). At this stage treatments have become progressively less effective at reducing inflammation and preventing further joint damage

# The three patient profiles each cover different parts of the care pathway



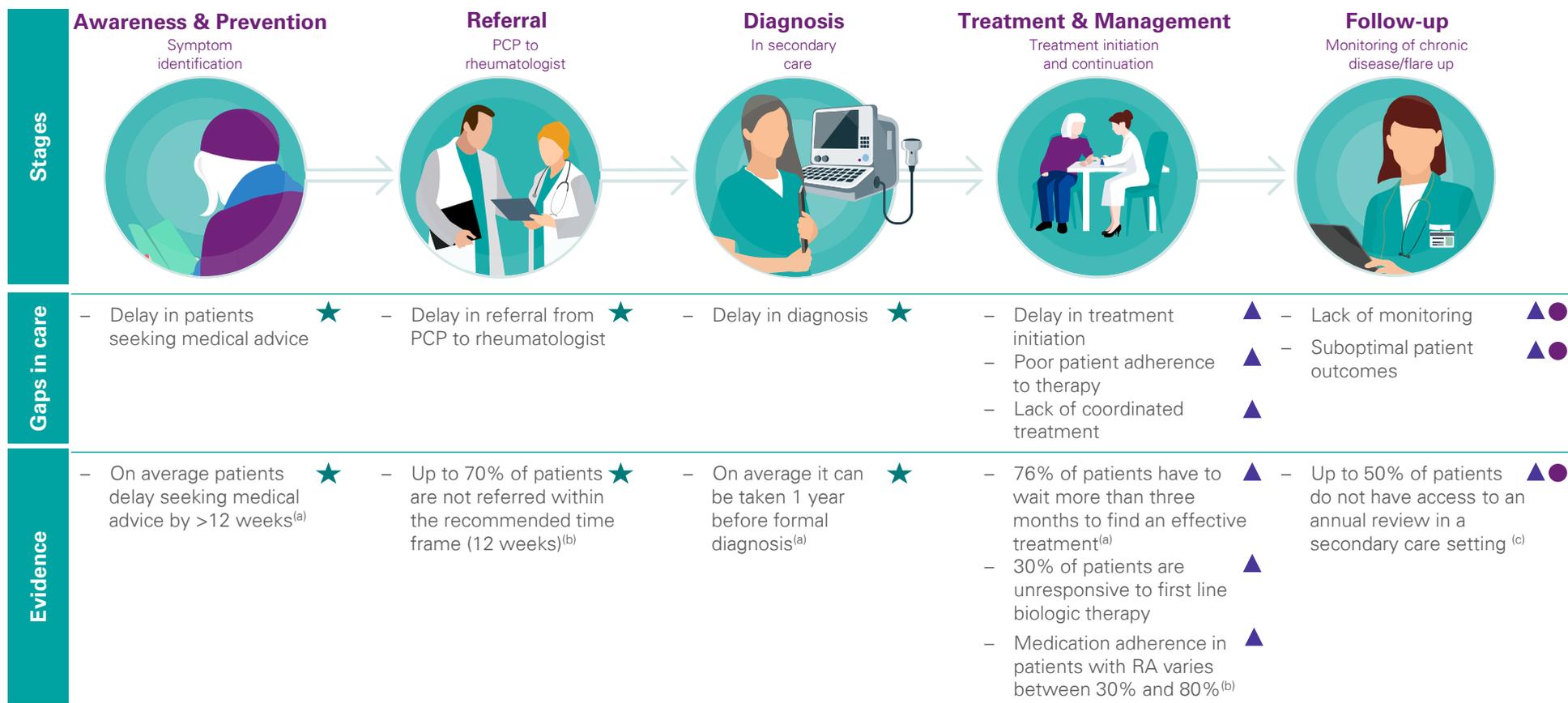


# Findings

## b) Challenges in RA care and associated comorbidities



# We found a number of gaps in care that exist across the patient pathway

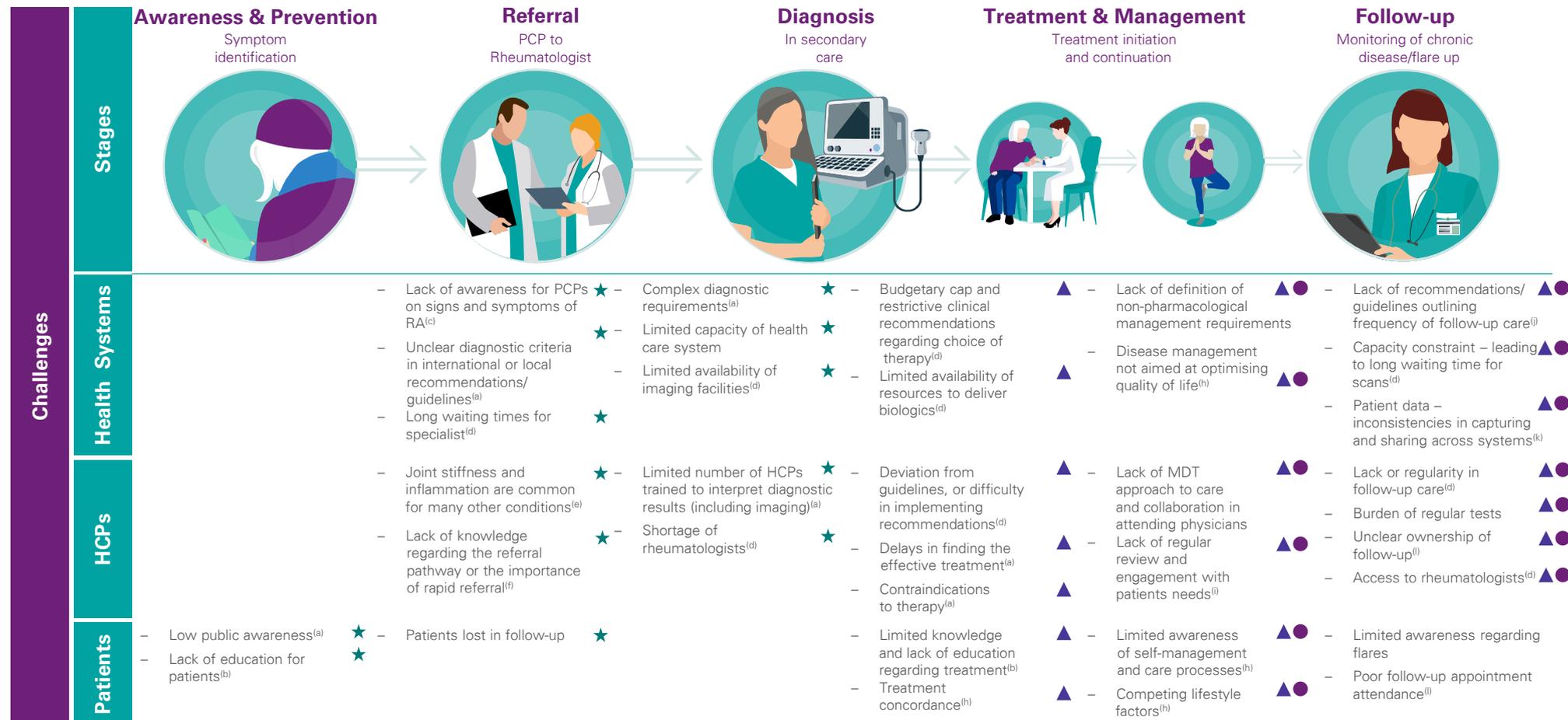


★ Patients with suspected RA  
▲ Patients recently diagnosed with RA  
● Patients with established disease / structural damage

**Notes:** These gaps were identified and verified through the literature review, site visits and expert Steering Committee

**Sources:** (a) National Rheumatoid Arthritis Society, 2013. Breaking Down Barriers: Rheumatoid Arthritis and Public Awareness (b) National Rheumatoid Arthritis Society, 2018. Keep taking the pills – the critical importance of adherence in the management of rheumatoid arthritis (c) Hider et al. 2016. What does a primary care annual review for RA include? A national PCP survey. *Clinical Rheumatology*

# There are a number of drivers of these gaps in RA care at the health system, HCP and patient levels



**Notes:** These gaps were identified and verified through the literature review, site visits and expert Steering Committee

**Sources:** (a) National Rheumatoid Arthritis Society (NRAS), 2013. Breaking Down Barriers: Rheumatoid Arthritis and Public Awareness (b) British Society for Rheumatology (BSR) & National Rheumatoid Arthritis Society (NRAS), 2016. Rheumatology in Wales, The State of Play (c) UK Parliament, 2010. Early identification and diagnosis of rheumatoid arthritis (d) i3 innovus, 2009. A survey of Barriers to Treatment Access in Rheumatoid Arthritis (e) Santos-Moreno et al. 2014. Rheumatoid arthritis misdiagnosis and osteoarthritis as most frequent cause for diagnosis mistake (f) Garneau et al. 2011. Primary care physicians' perspectives towards managing rheumatoid arthritis: room for improvement (g) Vermeer et al. 2012. Adherence to a treat-to-target strategy in early rheumatoid arthritis: results of the DREAM remission induction cohort (h) Marengo et al. 2015. Improving treatment adherence in patients with rheumatoid arthritis; what are the options; (i) National Rheumatoid Arthritis Society (NRAS), 2012. The impact of Rheumatoid arthritis comorbidities (j) Baecklund et al, 2011. Guidelines for the pharmaceutical management of rheumatoid arthritis. Swedish Society of Rheumatology (k) National Audit Office, 2009. Patient Groups on RA in the NHS; (l) Pope et al. 2013. Treating to Target in Established Active Rheumatoid Arthritis Patient Receiving a Tumour Necrosis Factor Inhibitor: Results From a Real-World Cluster-Randomised Adalimumab Trial (m) Bartlett et al. 2015. Feasibility and Domain validation of RA Flare Core Domain Set: A Report of the OMERACT 2014 RA Flare Group Plenary

- ★ Patients with suspected RA
- ▲ Patients recently diagnosed with RA
- Patients with established disease / structural damage

# Gaps in care of RA associated comorbidities are also driven by a number of challenges

Challenges	Stages				
	Screening Symptom identification	Referral Rheumatologist to comorbidity HCP	Diagnosis In secondary care	Treatment & Management Initiation, implementation and continuation	Follow-up Monitoring of comorbidity
Gaps in Care	<ul style="list-style-type: none"> <li>Lack of screening for comorbidity risk factors ▲</li> </ul>	<ul style="list-style-type: none"> <li>Delay in referral ▲</li> </ul>	<ul style="list-style-type: none"> <li>Delay in diagnosis ▲</li> </ul>	<ul style="list-style-type: none"> <li>Inadequate management of comorbidities ▲●</li> </ul>	<ul style="list-style-type: none"> <li>Suboptimal patient outcomes ▲●</li> </ul>
Healthcare Systems	<ul style="list-style-type: none"> <li>Limited screening pathways and frameworks in place to detect comorbidities amongst patients with RA<sup>(a)</sup> ▲</li> <li>Lack of comorbidity-specific recommendations (often vague when present e.g. EULAR recommendations/ guidelines)<sup>(b)</sup> ▲●</li> </ul>	<ul style="list-style-type: none"> <li>Inadequate communication between departments ▲</li> <li>Inefficient / absent sharing of records between attending physicians ▲</li> </ul>	<ul style="list-style-type: none"> <li>Limited diagnostic tests available</li> <li>Varied waiting times for investigation results ▲</li> </ul>	<ul style="list-style-type: none"> <li>Lack of clear recommendations on the management of comorbidities ▲●</li> <li>Goals for the management of RA and comorbidities are misaligned / discordant ▲●</li> <li>Inadequate communication across MDT<sup>(a)</sup></li> </ul>	<ul style="list-style-type: none"> <li>Fragmented systems for cross-specialty care and follow-up ▲●</li> <li>Issues with patient data inconsistencies in capturing and sharing across different systems<sup>(f)</sup> ▲●</li> </ul>
HCPs	<ul style="list-style-type: none"> <li>Low HCP awareness of RA-associated comorbidities ▲●</li> <li>Most rheumatologists do not systematically screen for comorbidities<sup>(c)</sup> ▲</li> </ul>	<ul style="list-style-type: none"> <li>Lack of education of HCPs on referral pathways if they are present<sup>(d)</sup> ▲</li> </ul>	<ul style="list-style-type: none"> <li>Diagnosis of comorbidities is more difficult due to atypical symptoms and disease presentation<sup>(e)</sup> ▲</li> <li>Symptoms of RA/RA treatment can mask comorbidity signs and symptoms<sup>(f)</sup> ▲</li> <li>Comorbidities are often underdiagnosed<sup>(g)</sup> and more likely to be diagnosed when severe<sup>(e)</sup> ▲</li> </ul>	<ul style="list-style-type: none"> <li>Patients with RA who have comorbidities do not always receive the recommended comorbidity treatment<sup>(a)</sup> ▲●</li> <li>RA pharmacotherapy can increase the risk of developing comorbidities ▲</li> <li>Limited recording of drug-drug interactions<sup>(h)</sup> ▲●</li> </ul>	<ul style="list-style-type: none"> <li>Lack of regularity in follow-up care ▲●</li> <li>Burden of regular tests ▲●</li> <li>Unclear ownership of follow-up ▲●</li> </ul>
Patients	<ul style="list-style-type: none"> <li>Lack of education for patients on symptoms and opportunities for presentation ▲●</li> </ul>	<ul style="list-style-type: none"> <li>Patient drop out rate i.e. loss to follow-up ▲</li> <li>Logistical and ambulatory difficulty can negatively impact outpatient attendance<sup>(a)</sup> ▲●</li> </ul>		<ul style="list-style-type: none"> <li>Lack of education for patients on comorbidity treatment and management ▲</li> <li>Lack of patient autonomy / incorporation of patient voice ▲●</li> </ul>	<ul style="list-style-type: none"> <li>Poor follow-up appointment attendance<sup>(a)(i)</sup> ●</li> <li>Increased morbidity and mortality is seen in patients with complex therapeutic needs<sup>(d)</sup> ●</li> </ul>

**Notes:** These gaps were identified and verified through the literature review, site visits and expert Steering Committee

**Sources:** (a) Bartels et al. 2012. Monitoring diabetes in patients with and without RA: a Medicare study (b) Peters et al. 2010. EULAR evidence-based recommendations for cardiovascular risk management in patients with rheumatoid arthritis and other forms of inflammatory arthritis (c) Dixon et al. 2010. Influence of anti-TNF therapy on mortality in patients with RA-associated interstitial lung disease: results from the British Society for Rheumatology Biologics Register (d) Selmi et al. 2011. Liver involvement in subjects with rheumatic disease (e) Doran et al. 2002. Frequency of infection in patients with RA compared with controls: A population-based study (f) Nakajima et al. 2015. Presence of comorbidity affects both treatment strategies and outcomes in disease activity, physical function, and quality of life in patients with rheumatoid arthritis (g) Margaretten et al. 2011. Depression in patients with RA: description, causes and mechanisms (h) Sheehy et al. 2006. Depression in rheumatoid arthritis—underscoring the problem (i) Fiest et al 2017. Systematic Review and Meta-analysis of Interventions for Depression and Anxiety in Persons With RA

- ★ Patients with suspected RA
- ▲ Patients recently diagnosed with RA
- Patients with established disease / structural damage



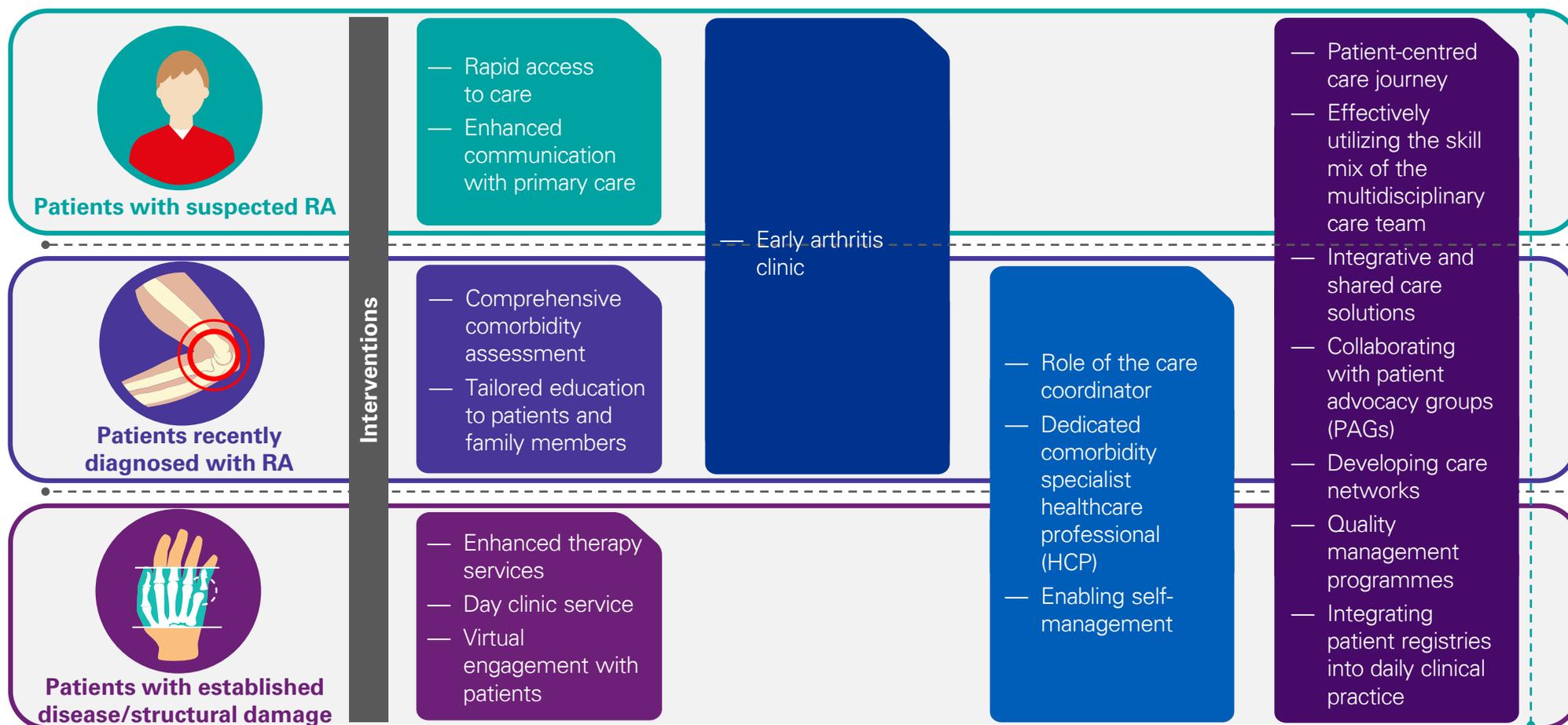
# Findings

## c) Good practice interventions

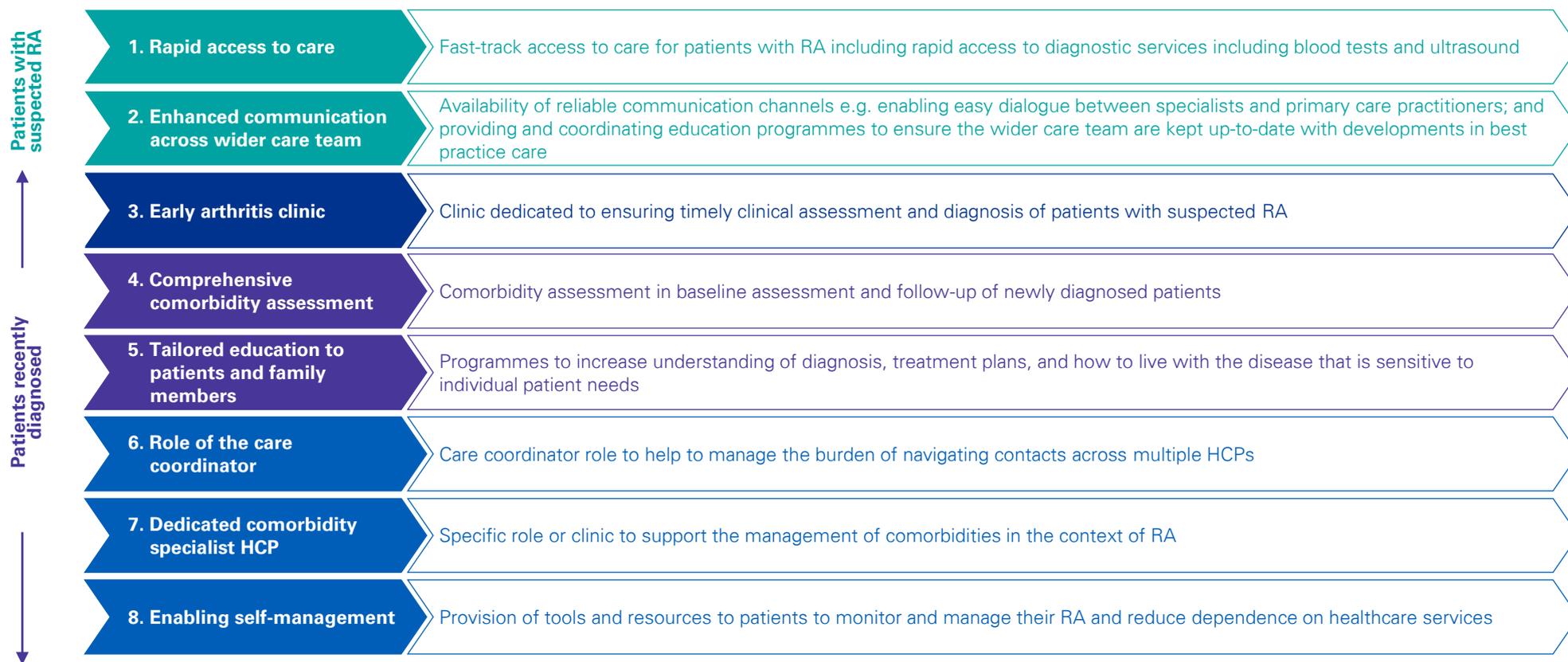


# The Steering Committee identified a number of good practice interventions - meeting the needs of the patient profiles

The interventions were informed and documented in case studies as part of KPMG centre visits. Based on the case studies, the Steering Committee identified 18 distinct good practice interventions, each of which varied in terms of which patient group's or groups' needs they addressed



# Definitions of good practice interventions in care of RA and associated comorbidities



**Key:**

Undiagnosed patients

Undiagnosed + recently diagnosed

Patients recently diagnosed with RA

Recently diagnosed + established disease

# Definitions of good practice interventions in care of RA and associated comorbidities (cont.)



**Note:** These identified good practice interventions should not be viewed as isolated activities, as synergies that exist between them can be leveraged to generate a robust platform for a disease management model for RA in Europe.

## What is the challenge?

- Patients with suspected RA need to be seen rapidly to ensure disease progression and joint damage are effectively prevented and managed<sup>(a)</sup>. Delays in diagnosis and referral from primary care mean patients can arrive at secondary centres with irreversible damage to their joints and other organs<sup>(b)</sup>. It is vital that these patients are triaged rapidly into care and start treatment straight away<sup>(c)</sup>
- There are often long waiting times for patients, leading to late diagnosis and therefore unnecessary disease progression<sup>(d,e)</sup>. Ensuring patients are seen in a timely manner for diagnostic procedures can help alleviate this challenge<sup>(f)</sup>



# Rapid access to care

## Fast-track access to care for patients with RA including rapid access to diagnostic services including blood tests and ultrasound



Patients with suspected RA



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FINDINGS  
INTERVENTIONS (RA)

### What is the intervention?



#### Which staff members are involved?

- Rheumatologists
- Trainee rheumatologists
- Rheumatology nurse

#### What is offered as part of the intervention?

- Ultrasound-guided diagnosis
- Ultrasound-guided procedures
- Online referral systems
  - Patients can enroll themselves
  - Primary care physicians (PCPs) can refer to hospital specialists directly
  - Referral to comorbidity specialist services
- Triage
  - Referred patients are initially assessed via a triaging step to determine either likelihood of inflammatory arthritis and the severity / stage of disease
  - Depending on the outcome of triage, they are rapidly assessed in the Early Arthritis Clinic

### What is the goal of the intervention?



#### What are the objectives?

- Reduce time to diagnosis
- Effectively and efficiently triage patients depending on the need for rapid diagnosis and treatment
- Ensure new patients are seen as rapidly as possible (typically within 72h)
- Provide rapid access to the investigations and procedures required to make a diagnosis of RA
- Filter less severe patients to a general follow up appointment within an appropriate timeframe

#### How were they achieved?

- Rapid assessments and investigations run by a rheumatology nurse prior to consultation
- Triage
  - Rapid assessment conducted by an experienced rheumatologist
- Triage protocols created to categorise level of suspicion of inflammatory arthritis
- Initial assessments for less complicated cases are taken by trainee rheumatologists or rheumatology nurse (both still supervised by a more senior rheumatologists)

**Sources:** (a) Smolen et al. 2016. EULAR recommendations for the management of rheumatoid arthritis with synthetic and biological disease-modifying antirheumatic drugs: 2016 update (b) Villeneuve et al. 2012, A systematic literature review of strategies promoting early referral and reducing delays in the diagnosis and management of inflammatory arthritis (c) Aletaha et al. 2010. 2010 Rheumatoid Arthritis Classification Criteria (d) i3 innovus, 2009. A survey of Barriers to Treatment Access in Rheumatoid Arthritis (e) National Rheumatoid Arthritis Society, 2018. Keep taking the pills – the critical importance of adherence in the management of rheumatoid arthritis (f) Puchner et al. 2016, Implementation of rapid access clinic linked with better access to rheumatology assessment (g) KPMG interviews

# Rapid access to care (cont.)



Patients with suspected  
RA



CONTENTS



FINDINGS  
INTERVENTIONS (RA)

## What are the potential outcomes?



### Patients

- Patients who have a suspected inflammatory arthritis diagnosis are seen in a timely manner and have prioritised access to the correct treatment
- Shorter wait times
- Better experience of care through reduction in inappropriate referrals and therefore reduction in unnecessary outpatient visits
- Patients may directly access their chosen physician through either the hospital's online platform and e-mail

### HCPs

- Two-way communication system between rheumatologist and primary care helps PCPs to be supported in assessing the risk of RA, and prevent inappropriate referrals
- Feedback on referrals helps to train referring PCPs, leading to higher quality referrals
- Rheumatology medical team support each other with sharing responsibilities (e.g. initial assessment is taken by a trainee rheumatologist or rheumatology nurse) which also helps to upskill other HCP involved in RA care

### Healthcare system

- Better integration of care and patient flow
- Patients get treated correctly and in a timely manner reducing burden on the healthcare system of care of established disease

## Relevant case studies



- **Rapid access to early care**, Cliniques Universitaires Saint-Luc,
- **Joint rheuma-respiratory clinic**, Hospital de Santa Maria
- **Online direct communication system**, Hospital Universitario La Paz
- **Rapid access clinics**, Institute of Rheumatology
- **Joint rheuma-obstetrics clinic**, Hospital de Santa Maria
- **Use of ultrasound**, Diakonhjemmet Hospital Leeds Teaching Hospitals, Rigshospitalet



## Patient story<sup>1</sup>:

Maria, a 40 year old busy journalist, has been experiencing increasing early morning joint stiffness, swelling and pain in her hands for the past three months and is finding it increasingly difficult to type. Upon visiting her GP she is referred for a same-day review at the local hospital rheumatology department, which hosts rapid access rheumatology clinics two times a week. On arrival to the rapid access clinic, the attending rheumatology nurse gathers her baseline observations and blood investigations (including ESR and ACPA). A rheumatologist then conducts a 5 minute triage assessment, which indicates that Maria has a high level of suspicion for RA. Following this assessment, Maria is invited to attend Early Arthritis Clinic within 72 hours for an initial appointment to review blood test results and conduct a further, more thorough assessment. Following this a management plan can be formulated and ongoing referral can be made to the appropriate clinic (early arthritis / seronegative inflammatory arthropathy / non-inflammatory arthropathy) dependent on the diagnosis. Her GP will continue to be updated of all secondary/tertiary care activities in relation to this referral



**Note:** 1 This patient story including patient name is fictive  
**Sources:** (a) KPMG interviews with HCPs treating RA and associated comorbidities



Patients with suspected  
RA



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FINDINGS  
INTERVENTIONS (RA)

# Enhanced communication across wider care team

## What is the challenge?

- Often patients are not transitioned between different parts of the healthcare system in a timely manner<sup>(a)</sup>
- This can be due to a number of factors including lack of awareness of referral pathways and systems, low communication between specialists and PCPs, and sharing of up-to-date patient information<sup>(b)</sup>



**Availability of reliable communication channels e.g. enabling easy dialogue between specialists and primary care practitioners; and providing and coordinating education programmes to ensure the wider care team are kept up-to-date with developments in best practice care**

What is the intervention?



### Which staff members are involved?

- All physicians involved in care, predominantly within the breakpoints of referral between primary and secondary / tertiary care

### What is offered as part of the intervention?

- A hotline for PCPs to access specialist rheumatological advice
- Linked information systems to ensure that patient information for consultations is shared in a timely manner between HCPs
- Links between secondary care HCPs and primary care network to share feedback on the quality of referrals
- Education sessions to inform PCPs about e.g. new developments within the field, how to improve detection of RA, and how to write effective referral letters

What is the goal of the intervention?



### What are the objectives?

- Improve communication between attending physicians across the whole patient pathway
- A coordinated effort is required by the rheumatology and primary care community to effectively address delays in care<sup>(c)</sup>

### How were they achieved?

- Online forms to ensure PCPs have direct access to hospital teams. The form allows for comprehensive and systematic documentation of patients' symptoms
- Dedicated role for a HCP to liaise with the PCP to ensure they are aware of how to effectively detect suspected patients with RA, and write referral letters
- Provision of training sessions to update PCPs and rheumatology nurses on developments in the field

**Sources:** (a) Garneau et al. 2011. Primary care physicians' perspectives towards managing rheumatoid arthritis: room for improvement (b) i3 innovus, 2009. A survey of Barriers to Treatment Access in Rheumatoid Arthritis (c) Villeneuve et al. 2012, A systematic literature review of strategies promoting early referral and reducing delays in the diagnosis and management of inflammatory arthritis

# Enhanced communication across wider care team (cont.)

## What are the potential outcomes?



### Patients

- More timely diagnosis and access to treatment as PCPs have greater awareness for indicators of RA
- Reduction in unnecessary visits to specialists

### HCPs

- Decreased misdiagnoses from the PCPs
- Improved education and increased awareness in PCP community for RA and associated comorbidities
- Improved communication between primary and secondary care
- Improvement in the quality of referral letters, containing relevant information required for diagnosis of patient.
- PCPs gain accreditation credits for attending specialist courses for RA and can learn more about potential comorbid disorders

### Healthcare system

- Better integration and fluidity of patients, who get treated correctly and in a timely manner reducing burden on the healthcare system of flares and emergency appointments
- Reduction in inappropriate referrals and therefore reduction in healthcare demand pressures

## Relevant case studies



- **Hospital and City Rheumatology Network**, RHEVER, Hôpital Cochin
- **Dedicated primary care coordinator**, Diakonhjemmet Hospital
- **Direct communication system**, Hospital Universitario La Paz



**Note:** 1 This patient story including patient name is fictive  
**Sources:** (a) KPMG interviews with HCPs treating RA and associated comorbidities  
 (b) Schulpen et al. 2003. Joint consultation of general practitioner and rheumatologist: does it matter? Ann Rheum Dis



Patients with suspected RA



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FINDINGS  
INTERVENTIONS (RA)

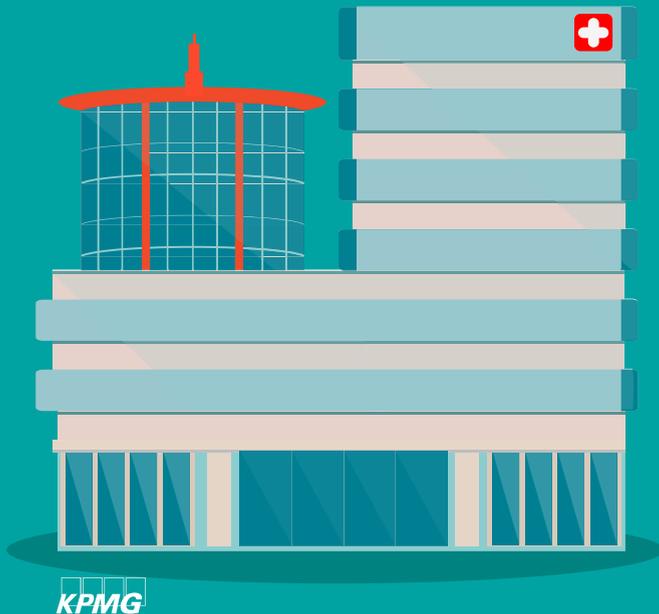


## Patient story<sup>1</sup>:

Lucas was diagnosed with RA 5 years ago. He is an active 70 year old retiree with many social commitments, however has recently had a flare after many years of remission. Following discharge from a recent hospital admission for his flare, he will require more frequent outpatient review and is now receiving community physiotherapy. He was particularly impressed with the level of care received in hospital, commenting that the rheumatologists, rheumatology nurses, physiotherapists and occupational therapists all seemed to work 'in tandem'. He finds that this continues in the community, when attending his multiple appointments; all the HCPs have access to his medical record and are able to communicate with one another electronically. This communication system was put in place following suggestion from the rheumatology-GP network which exists in his region to increase communication between primary and secondary care physicians and increase RA awareness among GPs. Lucas has noticed himself that his symptoms are better managed by his GP since this system has been introduced

## What is the challenge?

- Current treatments are more effective in reducing inflammation when given early on in the disease process<sup>(a)</sup>
- Early treatment delays overall disease progression and therefore prevents the accumulation of damage that causes irreversible joint deformation<sup>(b)</sup>



# Early arthritis clinic

## Clinic dedicated to ensuring timely clinical assessment and diagnosis of patients with suspected RA

### What is the intervention?



#### Definition

- Provision of a clinic dedicated to ensuring timely clinical assessment and diagnosis of patients with suspected RA

#### Which staff members are involved?

- Rheumatologists
- Rheumatology nurses

#### What is offered as part of the intervention?

- Provision of a clinic dedicated to ensuring timely clinical assessment and diagnosis of patients with suspected RA, including initial triage, to which patients can be referred by PCPs and other specialists

**Sources:** (a) Smolen et al. 2016. EULAR recommendations for the management of rheumatoid arthritis with synthetic and biological disease-modifying antirheumatic drugs: 2016 update (b) Villeneuve et al. 2012. A systematic literature review of strategies promoting early referral and reducing delays in the diagnosis and management of inflammatory arthritis (c) KPMG interviews

### What is the goal of the intervention?



#### What are the objectives?

- Identify and treat RA as early in the disease course as possible

#### How are they achieved?

- Early arthritis (EA) clinic provides rapid access to diagnostics including blood tests and imaging through the use of a clear process for referral, through to management and follow-up
- Referrals to EA clinic are screened via a suspected arthritis / triage clinic or referred directly by other rheumatologists. In some settings, patients can self-refer
- Patients referred to EA clinic are seen within a defined timeframe (e.g. one week) of referral
- In suspected arthritis / triage clinic, a rapid clinical assessment is made on the likelihood of inflammatory arthritis by an experienced rheumatologist
- Ultrasound of the joint(s) may be performed by a specialist in the clinic on the day - where indicated and a rheumatologist trained in ultrasound is available
- Once diagnosed, the patient is treated rapidly - target is the same day
- More frequent follow-up in the early phase (first 3-6 months) as response to disease-modifying treatments are evaluated, and treatment regimens may be changed
- Then less frequent review for up to 2 years before referral on to a general rheumatology clinic



# Early arthritis clinic (cont.)

## What are the potential outcomes?



### Patients

- Patients are rapidly put onto Treat-to-Target (T2T) pathway – target of 6 weeks from community to treatment
- Early diagnosis and treatment is the key factor for: ensuring maximum response to disease-modifying treatment; delaying disease progression; and maintaining quality of life / independence over the medium / long term
- Streamlined patient journey, contributing to improved patient experience

### HCPs

- Non-inflammatory cases are separated from those requiring immediate care, meaning HCP resources are focused on severe cases

## Relevant case studies



- **Early arthritis clinic**, Institute of Rheumatology, Hospital de Santa Maria, Cliniques Universitaires Saint-Luc, Sint Maartenskliniek, Diakonhjemmet Hospital, Leeds Teaching Hospitals, Karolinska University Hospital, Hospital Universitario La Paz, Rigshospitalet



Patients recently diagnosed with RA



Patients with suspected RA



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FINDINGS  
INTERVENTIONS (RA)

Sources: (a) KPMG interviews with HCPs treating RA and associated comorbidities

56 | Improving Quality of Care in RA

## What is the challenge?

- Certain patients with RA are at increased risk of morbidity and mortality due to existence of comorbidities such as cardiovascular disease, depression, osteoporosis, interstitial lung disease and diabetes<sup>(a, b, c, d)</sup>
- Systems for cross-specialty care and follow-up can be fragmented<sup>(a)</sup>



# Comprehensive comorbidity assessment

## Comorbidity assessment in baseline assessment and follow-up of newly diagnosed patients

### What is the intervention?



- Incorporating comorbidity assessment in baseline assessment and ongoing monitoring of chronic patients

### Which staff members are involved?

- Rheumatologists
- Comorbidity specialists

### What is offered as part of the intervention?

- Regular (usually 6-monthly) full comorbidity assessment as a standalone service or in conjunction with RA appointments

### What is the goal of the intervention?



### What are the objectives?

- Manage RA comorbidities

### How were they achieved?

- A programme coordinator provides dates and times for all relevant tests and appointments and keeps track of all patients on a database
- The coordinator requests the nursing staff send across to patients an invitation letter for an appointment, information leaflet, and a comorbidity screening questionnaire
- Assessment includes measurement and collection of a suite of measures for comorbidities by a rheumatology nurse, via history, examination, blood tests and other investigations
- The patients are given their own log to record their blood results and this is reviewed together with the rheumatologist / comorbidity specialist at the next appointment



Patients recently diagnosed with RA



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FINDINGS INTERVENTIONS (RA)

# Comprehensive comorbidity assessment (cont.)

What are the potential outcomes?



## Patients and HCPs

- Greater coverage of disease indicator and risk factor measurements taken in comorbidity patients
- Increased awareness amongst HCPs across the team (secretaries, rheumatology nurses, physicians, PCPs). This helps to remind them that there is a heightened risk of certain comorbidities and that the ill effects can be reduced through effective monitoring
- Rheumatologists can focus on the consultation with all test results required to ensure best care and correct and timely prescriptions are given. RA and comorbidity therapies may therefore be adjusted (tapered or intensified) more frequently and more aptly

## Healthcare system

- Reduced patient mortality due to comorbidity complications in patients with RA (e.g. CVD, ILD)

Relevant case studies



## COMorbidities EDUcation in Rheumatoid Arthritis, COMEDRA, Hôpital Cochin

**Joint rheuma-respiratory clinic**, Hospital de Santa Maria

**Dedicated psychologist**, Hospital de Santa Maria

**Joint rheuma-obstetrics clinic**, Hospital de Santa Maria

**Preventive cardio-rheuma clinic**, Diakonhjemmet Hospital

**Systematic inflammatory osteoporosis screening**, Hospital Universitario La Paz

**Joint comorbidity services**, Leeds Teaching

## Patient story<sup>1</sup>:

Anna has recently been diagnosed with RA and has had diabetes for almost 10 years, currently treated with oral hypoglycaemics. Her rheumatologist is aware that having co-existing diabetes and RA places her at increased risk of developing cardiovascular disease (CVD). Due to this, Anna is flagged as needing an annual comprehensive comorbidity assessment with regards to her diabetes and screening for CVD. On baseline assessment within the department, Anna is given a comorbidity status/screening questionnaire to fill in and the following investigations are conducted: HbA1c, random fasting glucose, lipid profile and blood pressure. These indicators are measured and recorded at each RA consultation, enabling a trend to be established and monitored, not only by the rheumatology team but also by Anna's diabetologist and GP. Having this done each time has also highlighted the increased risk to Anna of developing CVD and she decided to quit smoking in order to improve measurement readings.

**Note:** 1 This patient story including patient name is fictive

**Sources:** (a) KPMG interviews with HCPs treating RA and associated comorbidities

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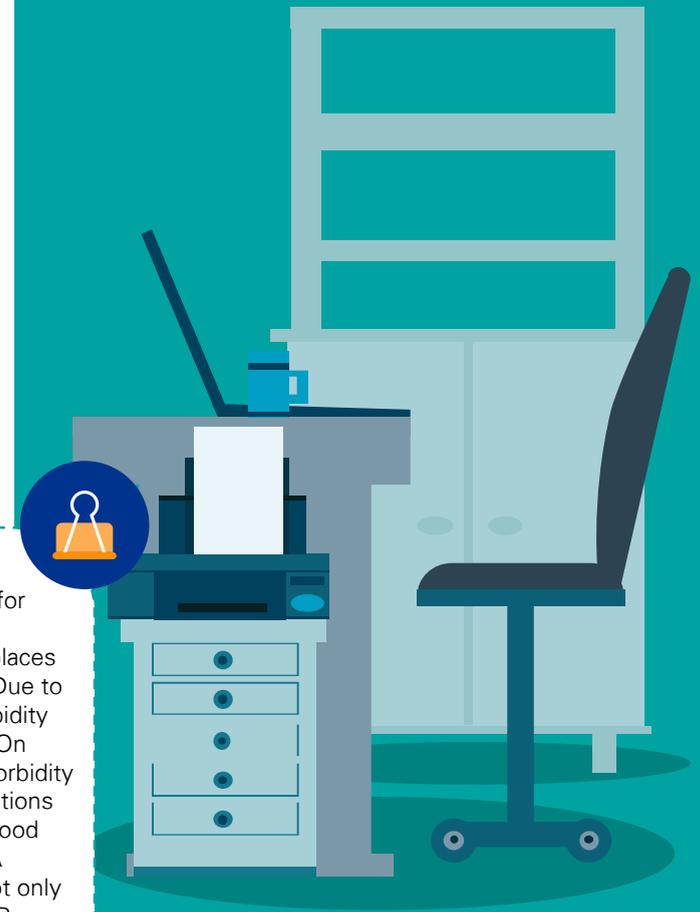
Patients recently diagnosed with RA



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FINDINGS  
INTERVENTIONS (RA)



## What is the challenge?

- There are few readily available avenues for patients to access services aimed at improving patient empowerment and self-management<sup>(a,b)</sup>



# Tailored education to patients and family members

**Programmes to increase understanding of diagnosis, treatment plans, and how to live with the disease that is sensitive to individual patient needs**

What is the intervention?



### Which staff members are involved?

- Rheumatologists
- Rheumatology nurses; or
- Other HCPs with a focus on patient education

### What is offered as part of the intervention?

- A programme to increase understanding of diagnosis and treatment plans. Varied communication methods (e.g. one-on-one, group sessions, literature) can all be utilised for coordinated and structured patient engagement

What is the goal of the intervention?



### What are the objectives?

- Help patients with RA and those around them to maintain or acquire the skills they need to better care for themselves
- Support patients to maintain independence and ability to do activities of day-to-day living
- Support patient to better understand the nature of their disease

### How were they achieved?

- Education is given soon after the diagnosis is confirmed
- It is delivered primarily via face-to-face consultation with the patient either by a rheumatologist or a rheumatology nurse
- Caregivers, friends and family members can also attend education sessions



Patients recently diagnosed with RA



CONTENTS



FINDINGS INTERVENTIONS (RA)

# Tailored education to patients and family members (cont.)

## What are the potential outcomes?



### Patients

- A research programme conducted at one of the centres (Hopital Cochin), showed that tailored education improves patient satisfaction and outcomes

### Caregivers

- Caregivers have a forum to discuss concerns and learn how best to manage and overcome challenges

### HCPs

- Rheumatology nurses can be seen as being better placed as they have more time and knowledge of improving self-management through education and support of patients with RA. This allows rheumatologists the time to focus on pharmacological management
- Education should be the main goal of the treatment, health care team and patients in order to help better management of RA

## Relevant case studies



- **Education Programme for Patients and caregivers: ETP**, Hôpital Cochin
- **ETP in the community setting (Private Practice)**, Hôpital Cochin
- **Rheumatology nurse-led education**, Hôpitaux Universitaires de Genève
- **Role of the rheumatology nurse**, Cliniques Universitaires Saint-Luc
- **Learning and coping centre**, Diakonhjemmet Hospital
- **Continuous education and behavioural change training**, Sint Maartenskliniek

## Patient story<sup>1</sup>:



Sandra, a 35 year old teacher has recently been diagnosed with RA. Her husband is keen to know more about the disease and how he can support her. Sandra wants to provide him with this information but is taking a lot of information in herself. At her first rheumatology nurse consultation, the nurse informs her that the centre actually run education sessions for patients as well as their family members every other month and that there is a choice to attend separate or combined sessions. Sandra is pleased to hear this and she and her husband attend the next combined session. Following this, she continues to attend patient sessions, feeling empowered regarding knowledge of her RA and also reassured that her husband understands the disease and has access to an educational support network.



Patients recently diagnosed with RA



CONTENTS



FINDINGS INTERVENTIONS (RA)

**Note:** 1 This patient story including patient name is fictive

**Sources:** (a) KPMG interviews with HCPs treating RA and associated comorbidities

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## What is the challenge?

- Care provided by multiple professionals from different disciplines and / or working for different providers can be fragmented leading to poor patient care and / or duplication of care; and lead to worse health outcomes<sup>(a,b)</sup>
- Physicians and other healthcare practitioners can find it difficult to find the time to play a care coordinator role in the context of their jobs<sup>(a,c)</sup>



# Role of the care coordinator

## Care coordinator role to help to manage the burden of navigating contacts across multiple HCPs

What is the intervention?



### Which staff members are involved?

- Rheumatology nurses
- Other HCPs who can also play care coordinator roles e.g. therapists, medical secretaries

### What is offered as part of the intervention?

- Establishing a care coordinator role to provide a single point of contact to the patient, negating the burden of navigating multiple HCPs

What is the goal of the intervention?



### What are the objectives?

- Provide a single point of contact for the patient to navigate multiple touchpoints with HCPs over the course of their care

### How were they achieved?

- Deployment of a HCP with knowledge of RA and the pathway as the care coordinator
- The care coordinator is available during work hours as the first point of contact for queries from existing patients either by e-mail or by phone
- The coordinator will ensure any contacts with members of the team involved in care are managed on behalf of the patient, beginning from the patient's first appointment – to effectively provide a single point of contact / access
- Patient education can be an important part of the care coordinator's role. The care coordinator is on hand for advice as required, e.g. when the patient has been recently diagnosed – and would like more comprehensive advice and coaching about managing their RA

**Sources:** (a) i3 innovus, 2009. A survey of Barriers to Treatment Access in Rheumatoid Arthritis (b) Dixon et al. 2010. Influence of anti-TNF therapy on mortality in patients with rheumatoid arthritis-associated interstitial lung disease: results from the British Society for Rheumatology Biologics Register (c) Pope et al. 2013. Treating to Target in Established Active Rheumatoid Arthritis Patient Receiving a Tumour Necrosis Factor Inhibitor: Results From a Real-World Cluster-Randomised Adalimumab Trial (m) Bartlett et al. 2015. Feasibility and Domain validation of RA Flare Core Domain Set: A Report of the OMERACT 2014 RA Flare Group Plenary (d) KPMG interviews



# Role of the care coordinator (cont.)



## What are the potential outcomes?



### Patients

- Greater understanding of the disease and care leading to greater patient satisfaction
- Improved patient experience through less of a burden in navigating a complex pathway
- Enhanced confidence and convenience for the patient in being able to contact one person to ask questions or to raise concerns with

### HCPs

- Patient load should be spread across the whole team. The role of the care coordinator can be beneficial in alleviating time of treating physicians to address their patients' medical issues

## Relevant case studies



- **Role of the rheumatology nurse,** Cliniques Universitaires Saint-Luc
- **Expanded role of the Clinical Nurse Specialist (CNS),** Leeds Teaching Hospitals

## Patient story<sup>1</sup>:



Jonathan, a 55 year old male has recently been diagnosed with RA and has multiple upcoming appointments with the rheumatology team and therapies services, as well as with his cardiologist – all within the same week. He will require transport for the visits but isn't sure how to go about making arrangements. He calls the RA care coordinator during the week and has a 15 minute phone conversation addressing his query. She is able to inform him that there is a hospital transportation service and also provides assistance with booking, including to the cardiology appointment. Following the conversation, she assures Jonathan that he is free to call again if he has any queries, as well as email out of hours. Jonathan is relieved and can move on with his day knowing his care is well looked after.



**Note:** 1 This patient story including patient name is fictive

**Sources:** (a) KPMG interviews with HCPs treating RA and associated comorbidities

## What is the challenge?

- There is increased prevalence of some associated diseases in RA including cardiovascular disease; interstitial lung disease; osteoporosis; depression; diabetes<sup>(a,b,c,d,e)</sup>
- There is a risk that these comorbid diseases are not given appropriate focus and attention because rheumatologists are not specialists in these areas<sup>(f)</sup>



# Dedicated comorbidity specialist HCP

## Specific role or clinic to support the management of comorbidities in the context of RA

What is the intervention?



### Which staff members are involved?

- Rheumatologists
- Comorbidity specialists e.g. cardiologists, respiratory physicians, diabetologists, psychologists

### What is offered as part of the intervention?

- Deployment of an in-house comorbidity specialist e.g. a cardiologist dedicated to the cardiological manifestations of rheumatological disorders

What is the goal of the intervention?



### What are the objectives?

- Provide dedicated expertise in comorbidity care

### How were they achieved?

- Integration of a dedicated non-rheumatological specialist in an RA comorbidity
- High-risk patients are detected in the inpatient health record system
- Patients requiring assessment for a comorbidity assessment or established comorbidity-related issue are referred to the relevant comorbidity specialist e.g. to cardio-rheuma clinic
- Patients have longer consultations (up to 60 minutes) to conduct a more comprehensive history and examination, and spend more time communicating and explaining treatment to patients
- The consultation may be coordinated with related appointments for e.g. rheumatological RA consultation; blood tests; imaging and other investigations

**Sources:** (a) Dougados et al. 2014. Prevalence of comorbidities in rheumatoid arthritis and evaluation of their monitoring: results of an international, cross-sectional study (COMORA) (b) Wegierska et al. 2016. Osteoporosis diagnostics in patients with rheumatoid arthritis (c) Albrecht et al. 2018. High prevalence of diabetes in patients with rheumatoid arthritis: results from a questionnaire survey linked to claims data (d) Äyräväinen et al. 2017. Periodontitis in early and chronic rheumatoid arthritis: a prospective follow-up study in Finnish population (e) Olson et al. 2011. Rheumatoid arthritis-interstitial lung disease-associated mortality (f) National Rheumatoid Arthritis Society 2012. The Impact of Rheumatoid Arthritis on Comorbidities



# Dedicated comorbidity specialist HCP (cont.)

## What are the potential outcomes?



### Patients

- Earlier detection and screening of comorbid disease in RA leading to increased prevention
- Greater focus on comorbidities and involvement of specialist comorbidity expertise leading to more effective decisions and better patient outcomes

### HCPs

- Greater awareness amongst rheumatology HCPs of comorbidities and their interaction with joint-related issues in RA

## Relevant case studies



- **Dedicated comorbidity care services,** Institute of Rheumatology
- **Preventive cardio-rheuma clinic,** Diakonhjemmet Hospital
- **Combined clinic for comorbid ILD,** Hospital Universitario La Paz
- **Joint rheuma-respiratory clinic,** Hospital de Santa Maria
- **Dedicated rheuma-psychologist,** Hospital de Santa Maria
- **Joint comorbidity services,** Leeds Teaching Hospitals



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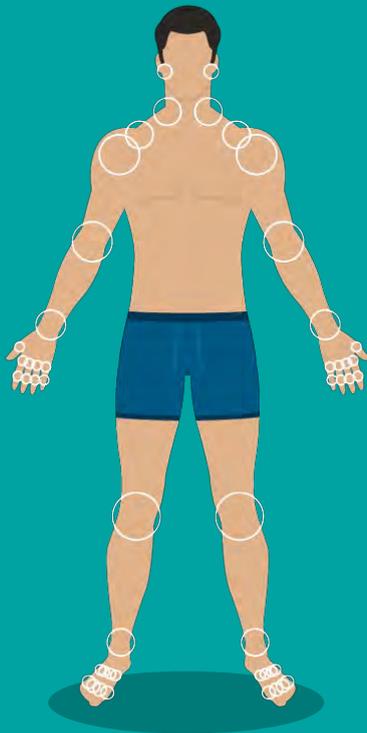
FINDINGS  
INTERVENTIONS (RA)

Sources: (a) KPMG interviews with HCPs treating RA and associated comorbidities

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## What is the challenge?

- Patients do not have long enough consultation sessions with rheumatologists and rheumatology nurses and other HCPs to fully educate themselves about the impact of the disease and how to manage it<sup>(a)</sup>
- On average, fewer than 20% of patients have a personalised care plan with embedded self-management support<sup>(b)</sup>



# Enabling self-management

## Provision of tools and resources to patients to monitor and manage their RA and reduce dependence on healthcare services

What is the intervention?



### Which staff members are involved?

- Any member of the multidisciplinary care team

### What is offered as part of the intervention?

- Providing support and guidance to self-monitor and manage disease activity and symptoms, enabling them to feel more motivated and in control of their RA

What is the goal of the intervention?



### What are the objectives?

- Provide patients with the tools and resources required to manage their RA
- Maximise the role the patient plays in achieving the best possible clinical outcomes for their care
- Reduce reliance on healthcare services in the non-pharmacological management of RA

### How were they achieved?

Two models to comprehensively address this need:

- Provision of an accredited educational programme for patients and caregivers. The programme provides education on
  - The nature of the disease including basic scientific context (rheumatologist)
  - Treatment steps in RA (pharmacist)
  - Healthcare contacts e.g. investigations, emergencies (rheumatology nurse)
  - Day-to-day life with RA including fatigue, pain, intimacy, living with a partner, carrying out activities of daily living (rheumatology nurse, occupational therapist)
  - Relationship between mind and body (psychologist)
  - Nutritional aspects of living with RA

**Sources:** (a) i3 innovus, 2009. A survey of Barriers to Treatment Access in Rheumatoid Arthritis (b) British Society for Rheumatology (BSR) & National Rheumatoid Arthritis Society (NRAS), 2017. Rheumatology in Wales, The State of Play



# Enabling self-management (cont.)

## What is the goal of the intervention? (cont.)



- Provision of a 'learning and coping' centre. The centre:
  - Provides courses and sessions for patients and caregivers on understanding and managing their RA
  - Training is provided by a multi-disciplinary team including rheumatologists, rheumatology nurses, physiotherapists, psychologists, social workers, 'expert' patients
  - Training is delivered by various methods including: pedagogy, question and answer sessions, exercises and workshops

## Relevant case studies



- **Personalised patient care**, Cliniques Universitaires Saint-Luc
- **Learning and coping centre**, Diakonhjemmet Hospital
- **Education Programme for Patients and Carers: ETP**, Hôpital Cochin

## What are the potential outcomes?



### Patients

- Improved patient concordance to medication and treatment plans
- Greater motivation of patients to participate in the management of their RA
- Improved patient satisfaction

### HCPs

- Increasing patients ownership of the disease helps the individual reach their treatment goals faster, and enables their treating HCPs to better assist the patient to achieve them



FINDINGS  
INTERVENTIONS (RA)

## Patient story<sup>1</sup>:



Caroline, a 40 year old female would like to take a more active role in managing her RA but is unsure as to how to do this. She mentions this to her rheumatologist who informs her that the centre offers training and coping mechanisms from all members of the multidisciplinary team. Over the next weeks, Caroline attends sessions from an expert patient and the team psychologist, where she learns skills such as mindfulness, receives tips and suggestions on lifestyle issues such as diet, exercise and pacing herself as well as psychological techniques for self-empowerment. Caroline especially likes that there are multiple sessions on offer which can be attended as and when desired, according to her schedule and educational needs.

## What is the challenge?

- Rheumatoid Arthritis (RA) can have a major impact on the ability of patients to live their day-to-day lives<sup>(a,b)</sup>
- Patients can find it difficult to perform activities of day-to-day living including household and work-related tasks<sup>(a,b)</sup>
- Patients also achieve better health and quality-of-life outcomes when they are able to self-manage their RA<sup>(c,d)</sup>



# Enhanced therapy services



Patients with established disease/structural damage



CONTENTS



FINDINGS INTERVENTIONS (RA)

## Additional care centred around non-physician-led management including care led by therapists to promote rehabilitation and reablement

What is the intervention?



### Which staff members are involved?

- Physiotherapist
- Occupational therapist
- Podiatrist

### What is offered as part of the intervention?

- Therapy services have a key role in supporting patients to lessen and manage the impact of RA on their independence and day-to-day life
- Therapy services can support patients and their attending health professionals to prevent disability, improve function, manage pain, lessen mood disturbance and improve overall fitness and wellbeing

What is the goal of the intervention?



### What are the objectives?

- Support to maintain / regain independence
- Maintain overall wellbeing

#### Physiotherapy

- Improve pain
- Prevent deformity
- Regain / maintain strength

What is the goal of the intervention? (cont.)



### What are the objectives?

#### Occupational therapy

- Help provide exercises that help patients to overcome potential physical constraints in the performance of day-to-day tasks

#### Podiatry

- Maintain / improve foot function and mobility

### How were they achieved?

#### Physiotherapy

- Train patients in exercises and activity types to alleviate pain, improve strength and prevent muscle contractures
- Provide alternative therapies e.g. paraffin wax therapy; hydrotherapy, acupuncture

#### Occupational therapy

- Supply / recommend aids for specific day-to-day situations e.g. home kitchen, workplace, stairs

#### Podiatry

- Prescribing specialist orthoses for the feet
- Advising on appropriate footwear
- Advising on joint protection, managing chronically inflamed joints, beneficial exercises / activities

**Sources:** (a) Ahlstrand et al. 2015. Pain and difficulties performing valued life activities in women and men with rheumatoid arthritis (b) Katz et al. 2015. Subclinical Disability in Valued Life Activities Among Individuals With Rheumatoid Arthritis (c) National Rheumatoid Arthritis Society (NRAS), 2018. The role of a Physiotherapist (d) British Society for Rheumatology (BSR) & National Rheumatoid Arthritis Society (NRAS), 2017. Rheumatology in Wales, The State of Play

# Enhanced therapy services (cont.)

## What are the potential outcomes?



### Patients

- Improved quality of life
- Achieving patient goals around their day-to-day life: e.g. improved patient mobility, ability to stay in work
- Prevention of disability
- Prevention of further damage e.g. deformity / contracture
- Less time-pressured environment to ask questions / learn from specialists about managing RA

### HCPs

- Provision of additional education and guidance from other HCPs (e.g. physiotherapist, occupational therapists, psychologists etc.) regarding the benefits of increased movement, physical exercise schedules and sleep routines helps the patient to maintain independence
- Greater sensitivity to flare-ups / new patient medical issues – through greater and more sustained contact with HCPs
- More holistic approach to care through collaboration of multiple disciplines

**Note:** 1 This patient story including patient name is fictive

**Sources:** (a) KPMG interviews with HCPs treating RA and associated comorbidities

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## Relevant case studies



- **Rehabilitation centre**, Cliniques Universitaires Saint-Luc
- **Education Programme for Patients and Carers:** ETP, Hôpital Cochin
- **National Unit for Rehabilitation for Rheumatic Patients with Special Needs (NBRR)**, Diakonhjemmet Hospital
- **Role of physiotherapist**, Institute of Rheumatology
- **Therapies services**, Leeds Teaching Hospitals
- **Access to holistic care** Rigshospitalet
- **Sleep outpatient clinic** Rigshospitalet

## Patient story<sup>1</sup>:

Stephen is a 55 year old builder who was diagnosed with RA 3 years ago. He has been having increasing joint pain in his hands over the past month and has also developed palmar contractures, making it difficult for him to perform some activities such as lifting at work. He has been tried on multiple analgesics with no relief. His rheumatologist decides to refer him to therapy services to undergo some exercises and activities which may help. In these weekly sessions, Stephen's functional status is assessed and a four-week action plan is made together with the physiotherapists and occupational therapists. Stephen especially found paraffin wax treatment useful for pain relief and increasing range of movement in his hands. He also received useful advice and home exercises to help manage his chronic joint inflammation. He is also able to reach out to the physiotherapists and occupational therapists for ongoing advice now that he has made contact with them which he finds reassuring.



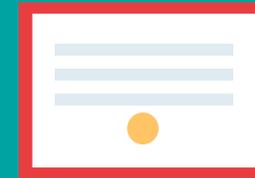
Patients with established disease/structural damage



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FINDINGS INTERVENTIONS (RA)



## What is the challenge?

- Patients with chronic RA often have multiple appointments relating their RA e.g. consultations, procedures, investigations
- A lack of coordination of these appointments can effectively diminish access for some patients, especially those who have issues affecting their ability to travel, or prefer to avoid seeking medical care for their RA as far as possible<sup>(b)(c)(d)</sup>

# Day clinic service

**The coordination of services enabling provision of stacked outpatient appointments across specialities and disciplines over one day or session**



Patients with established disease/structural damage



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FINDINGS INTERVENTIONS (RA)

What is the intervention?



### Which staff members are involved?

- Rheumatologists
- Rheumatology nurses
- Day-hospital coordinator
- Comorbidity specialists

### What is offered as part of the intervention?

- Coordination of appointments with different parts of the multi-disciplinary team so that appointments are organised on the same day

What is the goal of the intervention?



### What are the objectives?

- Improve accessibility to care
- Reduce non-attendances

### How were they achieved?

- Coordination of appointments with different parts of the multi-disciplinary team so that appointments were organised on the same day

What are the potential outcomes?



### Patients

- Improved access leading to more timely care and improved patient health outcomes
- Improved patient experience

Relevant case studies



- **Smart clinic design and one-stop shop to streamline care** Sint Maartenskliniek
- **Use of ultrasound in pain management**, Diakonhjemmet Hospital
- **Combined clinic for comorbid ILD**, Hospital Universitario La Paz
- **Investigations and procedures unit**, Hospital de Santa Maria
- **Systematic assessment and data collection**, Hospital de Santa Maria

**Sources:** (a) KPMG interviews with HCPs treating RA and associated comorbidities  
(b) Laires et al. 2013, Patient's access to healthcare and treatment in rheumatoid arthritis: the views of stakeholders in Portugal; (c) Flurey et al. 2014, It's like a juggling act: rheumatoid arthritis patient perspectives on daily life and flare while on current treatment regimes (d) i3 innovus, 2009. A survey of Barriers to Treatment Access in Rheumatoid Arthritis

## What is the challenge?

- Patients may not receive all the information and support they need during one-off consultations with physicians and HCPs
- Patients who are more proactive in managing their disease may experience better outcomes and better satisfaction from their care<sup>(b)(c)(d)(e)</sup>



# Virtual engagement with patients

**Digital enablement of autonomy, self-management and empowerment by providing a channel of direct communication with attending physicians in addition to online access to education around the disease, networks and peer support**

## What is the intervention?



### Which staff members are involved?

- Any members of the multidisciplinary team who are able to engage virtually with patients

### What is offered as part of the intervention?

- Digital enablement of autonomy, self-management and empowerment

## What is the goal of the intervention?



### What are the objectives?

- Provide channels for patients to share and exchange information, support and relevant resources in managing RA care
- Provide opportunities for patients to reach HCPs and share input on how care may be delivered to better meet their needs

### How were they achieved?

- This intervention was delivered by patient associations
- An online platform or forum that facilitates peer-to-peer interaction to share education around the disease, provide and receive support
- Development of a network of people who can identify with each others' problems
- A direct channel of communication with attending physicians and other HCPs providing care in RA
- Provision of a forum for patients to provide feedback on services, or engage in the development of improvements to services

**Sources:** (a) KPMG interviews with HCPs treating RA and associated comorbidities (b) Katic et al. 2016, Methotrexate Adherence in an Online Network of Patients with Rheumatoid Arthritis (c) Zangi et al. 2015, EULAR recommendations for patient education for people with inflammatory arthritis (d) Gossec et al. 2017. An e-health interactive self-assessment website (Sanoia) in rheumatoid arthritis (e) van Uden-Kraan, 2011, Determinants of Engagement in Face-to-Face and Online Patient Support Groups



Patients with established disease/structural damage



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FINDINGS  
INTERVENTIONS (RA)

# Virtual engagement with patients (cont.)

What are the potential outcomes?



## Patients

Improved clinical outcomes through:

- Improved patient concordance
- Greater engagement with lifestyle management e.g. via reduction of lifestyle-related CVD risk factors

Improved experience of care through:

- Better informed patients accessing care with greater confidence and a better sense of control over their care
- Improvements in the way services are designed based on patient feedback
- Greater awareness amongst engaging physicians on the impact of their care on the day-to-day lives of patients
- Patients who are engaged with improving the services they access also gain the feeling they are contributing to improving the healthcare of patients within their community

Relevant case studies



- **Collaboration with Revma Liga**, Institute of Rheumatology

## Patient story<sup>1</sup>:



Leila is a 34 year old who has recently been diagnosed with RA. She has already been provided with the care coordinator's email address for general queries but would specifically like to keep up to date with the management of her disease as well as stay informed on the services and networks available at the rheumatology centre. She is pleased to discover that on their website, there are patient-only forums, chaired by expert patients to provide support, as well as service feedback platforms for patients. Leila fed back on the lengthy waiting times with appointments and has noticed by her next visit, that this had been addressed as she experienced a smoother process from presentation to being seen by a HCP as she received an initial review with the rheumatology nurse.

**Note:** 1 This patient story including patient name is fictive

**Sources:** (a) KPMG interviews with HCPs treating RA and associated comorbidities

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Patients with established disease/structural damage



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FINDINGS  
INTERVENTIONS (RA)



## What is the challenge?

- The delivery of cutting-edge research presents opportunities for systematic collection of data on whole populations of patients with RA<sup>(b)(c)(d)(e)</sup>
- It can often be difficult to locate and extract clinical and other forms of data relating to patients because they are often captured on multiple different platforms and databases



# Integrating patient registries into daily clinical practice

**Employment of evidence-based practice, informed by clinical research and supported by systematic capture and monitoring of data, in order to improve the quality of clinical care delivery and promote evolution of care models**

What is the intervention?



**Which staff members are involved?**

- Rheumatologists
- Other HCPs who are active in research
- Rheumatology nurses
- Therapists
- Any other members of the multidisciplinary care team

**What is offered as part of the intervention?**

- Employing evidence-based practice, informed by clinical research and systematic capture and monitoring of data, in order to improve the quality of clinical care delivery, and promote evolution of care models

**Sources:** (a) KPMG interviews with HCPs treating RA and associated comorbidities (b) Hetland, 2011, DANBIO—powerful research database and electronic patient record (c) Eriksson et al. 2014, The Swedish Rheumatology Quality Register: optimisation of rheumatic disease assessments using register-enriched data (d) Canhao et al. 2011, Reuma.pt - the rheumatic diseases portuguese register (e) Haugeberg et al. 2015, Ten years of change in clinical disease status and treatment in rheumatoid arthritis: results based on standardized monitoring of patients in an ordinary outpatient clinic in southern Norway

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All patients



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FINDINGS  
INTERVENTIONS (RA)

What is the goal of the intervention?



**What are the objectives?**

- Register, monitor and assess all patients involved in research (e.g. on biological agents)
- Ensure effective monitoring of treatment indication, efficacy and safety for the individual patient
- Provide a comprehensive interrogable database on a whole population of patients with RA

**How were they achieved?**

- Integration of the clinical record with a patient registry, ensuring data capture into the patient registry for all patients under the care of the centre
- Capture of key clinical data points and measures e.g. (swollen joints, CRP) and composite scores (VAS/DAS; SDAI; CDAI; HAQ)
- Mandatory capture of data points that can be less reliably collected e.g. on comorbidity risk
- Data visualisations to show trends and potential triggers for action
- Links to other data domains e.g. the local biobank, with user-friendly database of projects and samples
- Linkage of the electronic patient record to enable access to primary care practitioners across the region / country

# Integrating patient registries into daily clinical practice (cont.)

## What are the potential outcomes?



### Patients

- Systematic clinical data capture:
  - Ensures potentially critical clinical information is not missed at the individual patient level
  - Enables the development of a rich and comprehensive collection of data that can help power breakthroughs in research
- Linkage of data across the region / country helps improve the coordination of care and to reduce likelihood of duplication of care

### HCPs

- A systematic and comprehensive data capture tool relieves the burden on physicians to input data and helps them focus their attention in their consultations on the key clinical issues
- Data visualisation techniques help physicians spot trends that would trigger a decision to take action

**Note:** 1 This patient story including patient name is fictive

**Sources:** (a) KPMG interviews with HCPs treating RA and associated comorbidities

## Relevant case studies



- **Patient registry**, Institute of Rheumatology
- **Swiss Clinical Quality Management in Rheumatic Diseases (SCQM)**, Hôpitaux Universitaires de Genève
- **Biobank**, Hôpitaux Universitaires de Genève
- **Emphasis on research to support clinical practice**, Hospital de Santa Maria
- **Swedish Rheumatology Quality Registry (SRQ)**, Karolinska University Hospital
- **DANBIO registry**, Rigshospitalet

## Patient story<sup>1</sup>:



Rheumatology centre 'RC' has multiple research programmes they are involved in, with the aim of improving care outcomes for patients with RA. Matilda was diagnosed with RA 5 years ago and since her first visit at the centre has had her details captured onto their patient registry. One of the rheumatologists in the team is conducting a study that can only include patients who are ACPA antibody positive. Matilda matches the inclusion criteria and it was very smooth for the rheumatologist to identify and contact her, gauging her interest in participating in the study. It has been two months since Matilda is in the study and she is happy to help the RA community and have greater contact with the RA team.

At RC, almost all patients with RA are enrolled in at least one research study, requiring varying degrees of HCP-patient interaction and monitoring. Capturing patient data for each programme can be time consuming and the department has worked out they could save up to 15 hours of HCP time a week by linking patient records to research databases. Centralising the research databases and records has allowed for greater visibility of data enabling more patients to be identified as eligible candidates for additional research programmes.



All patients



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FINDINGS  
INTERVENTIONS (RA)

## What is the challenge?

- Patient experience of care is not always positive enough to achieve good outcomes from the care delivered
- If patient satisfaction is not a focus of care delivery, there can be a negative impact on the patient's engagement with care<sup>(b),(c)</sup>



# Patient-centred care journey

All patients



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FINDINGS  
INTERVENTIONS (RA)

## Curation of care processes and physical environment that enables the patient to feel empowered and supported during their journey through care

### What is the intervention?



#### Which staff members are involved?

- Rheumatologists
- Rheumatology nurses
- Hospital administrators
- Comorbidity specialists
- Therapists

#### What is offered as part of the intervention?

- Curation of a physical environment that helps the patient feel empowered and catered to for the duration of their journey through care and experience of service
- Having defined and actionable outcome measures focused on measuring patient experience and satisfaction

### What is the goal of the intervention?



#### What are the objectives?

- Give the feeling to the patient that they are well informed and in control of their care
- Create an environment that is more conducive to healing and recovery and facilitates good access to care
- Improve patients' satisfaction with their care

### What is the goal of the intervention? (cont.)



#### How were they achieved?

- Excellent communication between centre staff and patients including:
  - Clear sign-posting on what will happen at each stage of the pathway
- Providing care in a clinic layout to facilitate access including:
  - 'One-stop shop' patient journey so patients avoid unnecessary repeat trips to the centre
  - Streamlined patient journey specifically designed to avoid delays in waiting to see HCPs and have their investigations
  - Short walking distances
  - Easy access from transport
- Providing care in an environment that was more patient-friendly e.g.:
  - Calm and tranquil with limited noise disturbances
  - More aesthetically pleasing
  - Felt more open with more sunlight
- Focusing delivery and design of care services through the use of clearly defined patient experience and satisfaction measures

# Patient-centred care journey (cont.)

## What are the potential outcomes?



- Patient can feel more active participants in their care through better communication from HCPs
- Patients can avoid unnecessary repeat visits to the centres through a streamlined patient journey – minimising: travel costs; disruption to daily life; and time spent travelling to and from appointments
- Patients can avoid added psychological stress of finding their way around a new and daunting hospital. Patients can also feel calm in their surroundings at a time when they may face a life-changing new diagnosis
- Positive patient experience also makes adherence to clinical treatment / management plans more likely

## Relevant case studies



- **Smart clinic design and one-stop shop to streamline care**, Sint Maartenskliniek
- **Personalised patient care**, Cliniques Universitaires Saint-Luc

## Patient story<sup>1</sup>:



Helen felt that each time she visited her rheumatology centre, the surroundings felt very clinical and daunting. She particularly did not like the fact that the walls looked old, or that she had to walk through many stairs, which was often tiring. She shared this as feedback via the form available in the waiting room and is glad to see that after 6 months at the next visit, the environment is more welcoming and it is a less stressful encounter for her to attend her appointments. A large portion of the renovation budget was dedicated to curating a patient-friendly environment; from the creation of open spaces and the use of indoor plants, to clear, colour-coded signage and in-built mobility modifications. Results from patient-satisfaction surveys, including Helen's, showed that patients appreciate and are aware of these efforts and felt 'at home' during their inpatient and outpatient visits.

**Note:** 1 This patient story including patient name is fictive

**Sources:** (a) KPMG interviews with HCPs treating RA and associated comorbidities

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FINDINGS  
INTERVENTIONS (IRA)

## What is the challenge?

- With improving rates of detection, there are ever increasing numbers of patients with RA for attending rheumatologists to manage
- Rheumatologists do not feel that they have enough time to adequately examine patients and to find the best treatment, leading to delays in treatment
- Elevating the role of auxiliary staff such as nurses, care coordinators, and administrative team members can play a significant role in helping to alleviate some of this burden on rheumatologists<sup>(b)(c)</sup>



# Effectively utilizing the skill mix of the multidisciplinary care team

## Enablement of non-physician HCPs to taking on greater responsibility in the assessment and management of patients

All patients



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FINDINGS INTERVENTIONS (RA)

What is the intervention?



### Which staff members are involved?

- Rheumatology nurses
- Care coordinators
- Medical secretaries
- Therapists

### What is offered as part of the intervention?

- Support for rheumatologists during outpatients clinics such as:
  - Education of patients
  - Training of other nurses to become specialised in this field
  - Care coordinator (UCL)

What is the goal of the intervention?



### What are the objectives?

- Sharing responsibilities across the wider rheumatology team with trainees and rheumatology nurses playing a more senior role in helping in the initial assessment of patients prior to their appointment, ensuring all clinical and composite measures are on the EHR prior to the patients consultation

What is the goal of the intervention? (cont.)



### How were they achieved?

- Hotline
  - Direct line for patients to call to get support and constant access to care (during working hours)
- Assessment
  - Rheumatology nurses can conduct a full assessment of the patient (including joint assessment; bone densitometry; DAS and other composite measures
  - Blood samples and lipid and cholesterol levels
  - Inputting this information into the electronic health system which then can be read during the rheumatologists consultation
- Training of auxiliary staff to be able to perform initial assessments
  - Composite score
  - Clinical measures
- Development of educational support materials:
  - to maintain continuity and ‘one voice’ approach to patient education
  - Online portals and videos to help empower
- Active participation in disseminating learnings to wider community

**Sources:** (a) KPMG interviews with HCPs treating RA and associated comorbidities (b) van Eijk-Hustings et al. 2014. Dissemination and evaluation of the European League Against Rheumatism recommendations for the role of the nurse in the management of chronic inflammatory arthritis: results of a multinational survey among nurses, rheumatologists and patients (c) Lion & Schirmer, 2018. Nurses' roles in the management of chronic inflammatory arthritis: a systematic review

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# Effectively utilizing the skill mix of the multidisciplinary care team (cont.)

## What are the potential outcomes?



### Patients

- Increased availability and access to patient education and consultations with physicians, through hotlines and online referral form
- Easy access to medication for holistic medical management available during their clinic visit

### HCPs

- Strong multidisciplinary approach to care with a collaborative approach between levels of attending physicians
- Non-physician HCPs appreciate the close collaboration between team members and being able to work closely with the rheumatologists which means they can learn consistently and have greater responsibility within the team
- High-quality pharmacological treatment due to close collaboration between pharmacist and prescriber
- Increased patient adherence due to frequent patient education touchpoints with all HCPs and ongoing monitoring and surveillance of efficacy

## What are the potential outcomes? (cont.)



### Healthcare system

- Increased efficiency through reduced costs for the same output or greater output at the same cost – because roles and responsibilities previously taken on by more expensive professional resource are now provided by lower cost HCPs

## Relevant case studies



- **Role of the pharmacist**, Sint Maartenskliniek
- **Role of the rheumatology nurse**, Diakonhjemmet Hospital, Cliniques Universitaires Saint-Luc
- **Expanded role of the Clinical Nurse Specialist**, Leeds Teaching Hospitals



All patients



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FINDINGS  
INTERVENTIONS (RA)



## Patient story<sup>1</sup>:

A rheumatology centre has recently trained the rheumatology care coordinator to be able to carry out very brief rheumatology assessments prior to triage at the rapid access clinic, as well as over the phone for flare queries. Alice, a 45 year old patient with RA, is concerned she is experiencing a flare. She calls the new coordinator hotline and is pleased that they can quickly access her records and disease activity scores and provide advice. With this information, they advise that she comes into the centre for further rheumatological assessment. Alice is relieved that she is able to access someone from the team in the absence of availability of the medical staff who is able to direct patients to the relevant HCPs and streamline their access to care. In the past, she found that she would often have to wait hours or days to speak to a HCP from the department, which left her feeling unattended to. In the month following initiation of this service, rates of patients being seen in the wrong settings have fallen. Rheumatologists and rheumatology nurses have noted a more manageable case load in their flare and routine review clinics.

**Note:** 1 This patient story including patient name is fictive

**Sources:** (a) KPMG interviews with HCPs treating RA and associated comorbidities

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## What is the challenge?

- Patients with RA often have concurrent associated problems (comorbidities) secondary to their RA, requiring input from non-rheumatological physicians
- Different professionals working with the same patient on separate problems (e.g. comorbidities) may be missing opportunities to enhance patient care through shared decision-making<sup>(b)(c)(d)</sup>



# Integrative and shared care solutions

## Ensuring regular communication between all attending physicians and other HCPs as part of a holistic and integrated approach to care

What is the intervention?



### Which staff members are involved?

- Rheumatologists
- Rheumatology nurses
- Hospital administrators
- Comorbidity specialists
- Therapy services

### What is offered as part of the intervention?

- Ensuring regular team meetings between all the attending physicians as part of a holistic and integrated approach to care: improving the effectiveness and efficiency of clinical decision-making.
- Enhancing communication between different specialty HCPs to ensure provision of regular reviews, referral and treatment of patients with associated comorbidities

What is the goal of the intervention?



### What are the objectives?

- Make better decisions on care of the patient that:
  - Address the needs of the whole patient e.g. what is the patient trying to achieve from their treatment / management of their RA?
  - Manage the often competing priorities in the management of RA e.g. targeting inflammation of the joints with a treatment that may also exacerbate comorbid lung disease
  - Resolve complex combinations of rheumatological, non-rheumatological (e.g. cardiology, respiratory, diabetic) and non-pharmacological issues that can occur together and require professional input from various disciplines

All patients



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FINDINGS INTERVENTIONS (RA)

**Sources:** (a) KPMG interviews with HCPs treating RA and associated comorbidities (b) Borgermans et al. 2017. How to Improve Integrated Care for People with Chronic Conditions: Key Findings from EU FP-7 Project INTEGRATE and Beyond (c) Lion & Schirmer, 2018. Nurses' roles in the management of chronic inflammatory arthritis: a systematic review (d) Stoffer, Smolen et al. 2014. Development of patient-centred standards of care for rheumatoid arthritis in Europe: the eumusc.net project

# Integrative and shared care solutions (cont.)

What is the goal of the intervention? (cont.)



## How were they achieved?

- Operation of a joint clinic with a non-rheumatological specialty, e.g. cardiology, respiratory, obstetrics
- Regular (i.e. monthly) multi-disciplinary team meetings with participation from other specialities and other members of the wider care team (e.g. pharmacy, therapies) to discuss complex cases
- Availability of urgent review by other specialty physicians either directly in clinic or for admitted inpatients
- In some cases, we saw physicians from other specialties maintain a specific focus on comorbidity in RA

Relevant case studies



- **Combined clinic for comorbid ILD**, Hospital Universitario La Paz
- **Joint rheuma-respiratory clinic**, Hospital de Santa Maria
- **Dedicated psychologist**, Hospital de Santa Maria
- **Dedicated comorbidity care services**, Revmatologický ústav
- **COMorbidities EDucation in Rheumatoid Arthritis – COMEDRA**, Hôpital Cochin
- **Joint comorbidity services**, Leeds Teaching Hospitals

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What are the potential outcomes?



## Patients

- More comprehensive assessments of patients' health needs
- More timely diagnostic and treatment-related decisions for patients with comorbidities that reduce the number of visits a patient needs to make
- Improved quality of decision-making in more complex cases requiring multiple HCP input

## HCPs

- More efficient decision-making processes that save valuable patient-facing time
- Enhanced awareness of comorbidities and non-pharmacological issues relating to RA
- Improved culture of knowledge-sharing and continual learning between different specialties and disciplines



All patients



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FINDINGS INTERVENTIONS (RA)

## Patient story<sup>1</sup>:



Christina is a 50 year old female with both RA and recently diagnosed hyperlipidemia, detected on routine screening by the rheumatologist. The rheumatologist would like some guidance on how to proceed with management of Christina's high cholesterol and understands that referring back to the GP may result in a delay in initiation of treatment and decides to seek cardiologist input in the joint comorbidity clinic. A thorough joint assessment is conducted by the cardiologist and rheumatologist and a joint management plan is formulated. As a result, it is decided that preventative medication can safely be started, according to current guidance confirmed by the cardiologist.

**Note:** 1 This patient story including patient name is fictive

**Sources:** (a) KPMG interviews with HCPs treating RA and associated comorbidities

## What is the challenge?

- Other patients are a huge untapped resource of knowledge and practical information and advice about RA<sup>(b)(c)(d)</sup>
- Patients often do not know others with whom they can share and discuss their experiences of rheumatoid



# Collaborating with patient advocacy groups (PAGs)

## Increasing communication with local and regional patient advocacy groups through working group sessions, conference attendance, newsletters and patient liaisons

What is the intervention?



### Which patients is it aimed at?

- All patients involved in the hospital care setting

### Which staff members are involved?

- Any member of the multidisciplinary care team

### What is offered as part of the intervention?

- Increasing communication with local and regional patient advocacy groups through working group sessions, conference attendance, newsletters and patient liaisons

What is the goal of the intervention?



### What are the objectives?

- Improve engagement of patients with their care by
- Encouraging patients to self-manage their RA
  - Supporting patient advocacy groups in their aims to educate, empower patients and improve their quality of life

### How were they achieved?

- In one centre, a group of patient treated there came together to found a PAG, which then grew to several chapters across the country
- Awareness campaigns on a national and local level
- Collaborations with PAGs to facilitate, host or run interventions such as:
  - Weekly patient activity groups including physical exercise, and other
  - National ‘challenges’ that improve engagement and quality of life
  - Intensive rehabilitation courses

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FINDINGS  
INTERVENTIONS (RA)

# Collaborating with patient advocacy groups (PAGs) (cont.)

## What are the potential outcomes?



### Patients

- Improved satisfaction with care
- Improved quality of life

### HCPs

- Effective 'outsourcing' of support to other patients, who have greater practical knowledge of living day-to-day with RA
- Improved engagement of patients leading to improved adherence to treatment plans

## Relevant case studies



- **Collaboration with Revma Liga**, Revmatologický ústav
- **Patient Council**, Karolinska University Hospital

## Patient story<sup>1</sup>:

A rheumatology centre have worked informally with a PAG for a number of years, directing patients to them upon diagnosis and notifying their patient base of their events. Joanna, a patient with RA at the centre, has become increasingly involved with PAG events over the years, becoming an expert patient educator herself. Due to the success of the relationship and good feedback from Joanna and other patients, the centre has decided to host some of the PAG's working group sessions at the centre and distribute their newsletter to its patients during inpatient and outpatient sessions. With this relationship, the PAG has noticed greater levels of participation in PAG activities such as other patients willing to become educators, attend conferences and act in liaison roles. Equally, the rheumatology team have noticed greater levels of patient self-management and adherence to treatment as a result of the collaboration, compared to other centres where such a presence isn't seen.

**Note:** 1 This patient story including patient name is fictive

**Sources:** (a) KPMG interviews with HCPs treating RA and associated comorbidities



All patients



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INTERVENTIONS (RA)



## What is the challenge?

- There can be significant variation in RA care between different specialists
- Care can be duplicated between different care providers or practitioners who are unable to access each other's patient data<sup>(b,c)</sup>
- Patients can also 'fall between cracks' in care from different providers who may not coordinate care or share information on their patients



# Developing care networks

## Developing networks with community-based RA services to maintain high-quality 'joined-up' care past the point of discharge

### What is the intervention?



### Which patients is it aimed at?

- All patients involved in the hospital care setting who are seen in the community

### Which staff members are involved?

- Rheumatologists
- Rheumatology nurses
- Therapists
- Hospital administrators

### What is offered as part of the intervention?

- Developing networks with RA community services to maintain high-quality 'joined-up' care past the point of discharge
- Collaboration between centres providing RA care

### What is the goal of the intervention?



### What are the objectives?

- Spread the knowledge of best practice care between medical peers
- Provide more standardised care to a patient population across providers / rheumatologists

**Sources:** (a) KPMG interviews with HCPs treating RA and associated comorbidities (b) Brown et al. 2016, The effectiveness of clinical networks in improving quality of care and patient outcomes: a systematic review of quantitative and qualitative studies (c) Zink et al. 2001. The national database of the German Collaborative Arthritis Centres: Structure, aims, and patients

All patients



### What is the goal of the intervention? (cont.)



### How were they achieved?

- Maintaining strong working relationships across a network e.g. by:
  - Establishing a centre liaison officer to facilitate standardisation of best practice protocols and processes
  - Ensuring frequent communication and regular touchpoints between a hub site and its satellite centres
  - Engaging all staff before implementing transformation interventions and gathering feedback on adapting and optimising protocol
- Staff-sharing can help develop deeper links e.g. by:
  - Creating joint posts across providers that split time between sites e.g. 50% at each site
  - Hub site specialists providing regular outreach clinics to satellite sites
- Shared information systems across providers and practitioners including:
  - Linked electronic health record
  - Standardised pro formas e.g. patient assessments
  - Standardised reporting on the quality of care



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# Developing care networks (cont.)

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INTERVENTIONS (RA)

## What are the potential outcomes?



### Patients

- Reduction in unwarranted variation in care through standardisation of best practices
- Greater access to specialist care locally

### HCPs

- Education and development opportunities for both experienced and less experienced staff through collaboration and staff-sharing
- Access to greater advice and support resources from stronger connections with other healthcare practitioners across the network

## Relevant case studies



- **Hospital and City Rheumatology Network**, Hôpital Cochin
- **Satellite Clinics**, Sint Maartenskliniek
- **Systematic assessment and data collection**, Hospital de Santa Maria

## Patient story<sup>1</sup>:



Mustafa was diagnosed with RA 1 year ago and has been in remission for 6 months. This has meant the majority of his care is now given in the community, from his GP. He recently had a flare and upon admission to hospital, was pleased to find that all his GP records were accessible and compatible with the record keeping standards in the rheumatology centre.

In his region, a rheumatology care network has been in place for the past year. It was devised in recognition of the fact that a patient with RA, such as Mustafa, may be seen across all care settings, necessitating the need to coordinate care and standardise care. It consists of all GP practices and rheumatology departments in the secondary and tertiary care setting within the region.

In order to support the network, a pool of resources (e.g. assessment proformas, educational materials, and staff in split-location posts) are used to provide patients with a uniform standard of care. GPs have reported having greater visibility and involvement in the care of their patients with RA and rheumatologists report improved disease outcomes for patients, due to access to a spectrum of healthcare services.



**Note:** 1 This patient story including patient name is fictive; **Sources:** (a) KPMG interviews with HCPs treating RA and associated comorbidities

## What is the challenge?

- Improving quality of care can be complex and therefore difficult to measure, analyse and improve
- A systematic approach is needed to deliver successful and sustainable improvements in the quality of care<sup>(b)(c)(d)</sup>



# Quality management programmes

## A coordinated approach and a robust system for measuring, tracking and improving the quality of care

What is the intervention?



### Which patients is it aimed at?

- All patients involved in the hospital care setting

### Which staff members are involved?

- Any member of the multidisciplinary care team

### What is offered as part of the intervention?

- A coordinated approach and a robust system for measuring, tracking and improving the quality of care

What is the goal of the intervention?



### What are the objectives?

- To establish a systematic approach to delivering quality improvement
- To develop an information infrastructure that can enable measuring, collation and reporting of quality of care metrics

**Sources:** (a) KPMG interviews with HCPs treating RA and associated comorbidities (b) HQIP Case Study, 2012. Development of quality commissioning metrics to improve the quality of rheumatoid arthritis care through routine implementation of best clinical practice (c) Haugeberg et al. 2015, Ten years of change in clinical disease status and treatment in rheumatoid arthritis: results based on standardized monitoring of patients in an ordinary outpatient clinic in southern Norway (d) Marshall & Mountford, 2013, Developing a science of improvement



All patients



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INTERVENTIONS (RA)

What is the goal of the intervention?  
(cont.)



### How were they achieved?

- Establishing clear goals and standards of care to improve the quality of RA care and associated comorbidities
  - Domains include timeliness of care; accessibility; efficacy, safety; cost-effectiveness; patient-centred care; and transparency
  - Medical, administrative and financial goals were aligned
- Defining protocol performance indicators
  - Must be measurable in a reliable way
  - Informed by diagnostic and treatment protocol
  - Including patient outcomes by physician
- Information infrastructure
  - e.g. a data warehouse used to link data across clinical, prescribing, operational and financial data
- Reporting
  - Robust reporting framework that provides accessible and timely information on the quality of care
- Quality improvement
  - A consistent approach to monitoring, processing and analysing data relating to the quality of care to generate new insights
  - A robust change management approach that leads to improvements in care

# Quality management programmes (cont.)

What are the potential outcomes?



## For Patients

- Continuous improvement in the quality of care leading to better health outcomes

## HCPs

- Clear information on the performance of their service and even their individual practice against established process and outcome indicators
- A consistent and reproducible approach to address challenges in delivering quality patient care
- The basis for delivering evidence-based decision-making as part of standard care

Relevant case studies



- **Measuring tracking and improving for better care**, Sint Maartenskliniek



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INTERVENTIONS (RA)

Sources: (a) KPMG interviews with HCPs treating RA and associated comorbidities

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# Findings

## d) Good practice interventions specific to comorbidities



# We found examples of good practice that directly meet recommendations/ guidelines on comorbidity care

Comorbidity	Recommendations / guidelines sources	Case studies targeting specific comorbidity	Case studies addressing all comorbidities
 <b>CVD</b>	(2016) Update EULAR recommendations for CVD risk management <sup>(a)</sup> (2010) EULAR recommendations for CVD risk management <sup>(b)</sup> (2016) EULAR Points to consider for reporting, preventing selected comorbidities <sup>(c)</sup>	<b>Preventive cardio-rheuma clinic,</b> Diakonhjemmet Hospital	<b>COMorbidities Education in Rheumatoid Arthritis – COMEDRA,</b> Hôpital Cochin  <b>Joint comorbidity services,</b> Leeds Teaching Hospitals  <b>Dedicated comorbidity care services,</b> Institute of Rheumatology  <b>Education Programme for Patients and caregivers:</b> ETP, Hôpital Cochin  <b>Comorbidity research programme,</b> Karolinska University Hospital  <b>Role of the pharmacist,</b> Sint Maartenskliniek  <b>Comorbidities monitoring on SQM,</b> Geneva University Hospitals
 <b>Diabetes</b>	(General comorbidity guidance)) (2016) EULAR Points to consider for reporting, preventing selected comorbidities <sup>(c)</sup>	<b>Dedicated primary care coordinator,</b> Diakonhjemmet Hospital	
 <b>Depression</b>	(2016) EULAR Points to consider for reporting, preventing selected comorbidities <sup>(c)</sup>	<b>Dedicated psychologist,</b> Hospital de Santa Maria <b>Sleep outpatient clinic</b> Rigshospitalet <b>Learning and coping centre,</b> Diakonhjemmet Hospital	

# We found examples of good practice that directly meet recommendations/ guidelines on comorbidity care (cont.)

Comorbidity	Recommendations/ guidelines sources	Case studies targeting specific comorbidity	Case studies addressing all comorbidities
 <b>Osteoporosis</b>	(2015) Management of Osteoporosis in Rheumatoid Arthritis Patients <sup>(a)</sup>	<b>Osteoporosis specialism in core rheumatology team</b> , Hôpital Cochin <b>Dedicated comorbidity care services</b> , Institute of Rheumatology <b>Investigations and procedures unit</b> , Hospital de Santa Maria <b>Systematic inflammatory osteoporosis screening</b> , Hospital Universitario La Paz	See previous page
 <b>Pulmonary</b>	(2017) Practical Management of Respiratory Comorbidities in Patients with Rheumatoid Arthritis <sup>(b)</sup>	<b>Joint rheuma-respiratory clinic</b> , Leeds Teaching Hospitals Hospital de Santa Maria <b>Combined clinic for comorbid ILD</b> , Hospital Universitario La Paz	

# Cardiovascular disease in RA



## Our approach

Through:

1. Literature review
2. Fieldwork at centre visits
3. Steering Committee review with RA specialists and comorbidity experts

we have identified key considerations for the management of cardiovascular diseases in RA



## Patients with RA are at increased risk of cardiovascular disease<sup>(a)</sup>

### 1. Literature review findings

- For patients with RA, prevalence of cardiovascular disease is 5 – 12.9%<sup>(a)</sup>
- There has been a comparable decline in CVD in the general population as well as in patients with RA during the last 3 decades. Although patients with RA still have an increased risk of CVD compared to the general population, it is comparable to the risk which CVD patients have with diabetes<sup>(b)</sup>
- The risk of developing a CVD in patients with RA is present across all ages<sup>(c)</sup> and it appears to be higher for males compared to females.<sup>(d)</sup>
- Patients with RA have more often unrecognized myocardial infarction (MI) and silent angina pectoris<sup>(e)</sup> and nearly twice as high 30-day mortality after the first MI<sup>(c)</sup> compared to non-RA individuals
- Although in general, CVD mortality in RA might not be higher than in the general population<sup>(f)</sup>, it appears that CVD morbidity is still 40% higher in RA patients compared to the general population<sup>(g)</sup>
- Apart from age, lipids are the most important risk factor for developing CVD in the general population. However in patients with RA, disease activity and seropositivity account for the same magnitude of risk for future CVD as lipids<sup>(d)</sup>

### Published guidance :

- (2019) European Society of Cardiology & European Atherosclerosis Society guidelines for the management of dyslipidaemias: lipid modification to reduce cardiovascular risk<sup>(h)</sup>
- (2016) Updated EULAR recommendations for CVD risk management<sup>(i)</sup>
- (2010) EULAR recommendations for CVD risk management<sup>(i)</sup>
- (2016) EULAR Points to consider for reporting, preventing selected comorbidities<sup>(k)</sup>
- 2016 ESC guidelines for CVD prevention<sup>(l)</sup>
  - Recognise RA as a risk factor for CVD
  - Recognise carotid plaques as a very high risk factor
  - Documented CVD on imaging includes atherosclerotic plaques on coronary angiography and carotid ultrasound and is to be regarded as a very high risk factor for CVD. Thus there is an indication for secondary prevention with statin and LDL-goal < 1.8 mmol/L

**Sources:** (a) van Halm et al. 2009. Rheumatoid arthritis versus diabetes as a risk factor for cardiovascular disease: a cross-sectional study, the CARRE Investigation (b) Lindhardsen J et al Ann Rheum Dis 2011;70:929-34; (c) Solomon DH Ann Rheum Dis 2006;65:1608-12; (d) Crowson CS et al. Ann Rheum Dis. 2018;77(1):48-54; (e) Maradit-Kremers H et al Arthritis Rheum. 2005;52(2):402-11; (f) Kerola A et al Clin & Exp Rheum 2015;33:391; (g) Holmquist M et al Ann Rheum Dis 2017;76:1642-47; (h) Mach et al. Eur Heart J. 2019. Guidelines for the management of dyslipidaemias: lipid modification to reduce cardiovascular risk (i) Agca et al. 2017. EULAR recommendations for cardiovascular disease risk management in patients with rheumatoid arthritis and other forms of inflammatory joint disorders: 2015/2016 update (j) Peters et al. 2010. EULAR evidence-based recommendations for cardiovascular risk management in patients with rheumatoid arthritis and other forms of inflammatory arthritis; (k) Baillet et al. 2016. Points to consider for reporting, screening for and preventing selected comorbidities in chronic inflammatory rheumatic diseases in daily practice: a EULAR intervention; (l) Piepoli MF et al. Eur Heart J. 2016;37(29):2315-2381



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## 2. Fieldwork findings

### Guidance covered by our case studies highlights the importance of:

#### Risk assessment

- Control of disease activity
- Cholesterol / lipid and blood pressure control
- NSAID / steroid use (intermittently at lowest effective dose)
- Lifestyle and smoking cessation advice
- Screening
- Periodic follow-up (five years for low risk patients, but annually if on secondary CVD preventative medication) <sup>(a)</sup>
- Start lipid lowering treatment and anti hypertensive medication (these are effective medications and recommended goal attainment can be achieved in 80-90% of patients in approximately three consultations <sup>(b,c,d)</sup>)
- Side effects are few and on the same level as in the general population

This can be achieved through programmes to prevent and screen for cardiovascular risk in patients with RA.

#### Case study<sup>1</sup>

**Preventive cardio-rheuma clinic**, Diakonhjemmet Hospital

## 3. Steering Committee recommendation

### Key elements to consider for improvement of the quality of care of cardiovascular disease in patients with RA:

- Organisation and responsibility of CVRM (cardiovascular risk management) at a centre
  - Set up of Preventive Cardio-Rheuma clinics
  - Having a cardiologist working inside a rheumatology outpatient clinic
  - Having a cardiologist working alongside the department of rheumatology
  - Having CVD risk evaluation performed by the rheumatologist in an outpatient setting
- Screening of cardiovascular risk factors
  - Ultrasound carotid arteries have been shown to reclassify 30-60% of patients from low to moderate risk of future CVD up to high risk of CVD<sup>(f)</sup>
- Communication about CVRM between medical professionals
- Availability of data regarding CVRM
- Education of patients and a broad spectrum of health personnel about the high CVD risk in RA patients

**Notes:** 1. Please note case study(ies) are those we identified which were specific just to this comorbidity. Case studies addressing all comorbidities can be found on page 87; 2. This patient story including patient name is fictive

**Sources:** (a) Mach et al. Eur Heart J. 2019. Guidelines for the management of dyslipidaemias: lipid modification to reduce cardiovascular risk; (b) Rollefstad S et al Ann Rheum Dis. 2013;72(12):1968-74; (c) Rollefstad S et al. Ann Rheum Dis. 2015;74(8):1544-50; (d) Rollefstad, S et al. Ann Rheum Dis, 2017;76; supplement 2), 802; (e) Semb AG et al. Arthritis Rheum. 2012;64(9):2836-46; (f) Semb AG et al. Exploring cardiovascular disease risk evaluation in patients with inflammatory joint diseases, Int J Cariol. 2016 15;223:331-336.

### Patient story<sup>2</sup>:



Sam, a 60 year old male, suffering from RA since the last 18 years presented with a CVD risk evaluation at the Diakonhjemmet Hospital. He had no symptoms of CVD, especially no chest pain/angina pectoris.

Upon evaluation it was observed he had high blood pressure and grade 2 hypertension. He did not have symptoms of coronary artery disease as if ex angina pectoris. Ultrasound of carotid arteries revealed bilateral plaques, which elicited doctors to go for an CT coronary angiograph and selective coronary angiography which revealed serious 3 vessel disease with both a proximal left anterior descending coronary artery (LAD) stenosis, peripheral occlusion of LAD, stenosis of left obtuse marginal branch (LOM) and right coronary artery (RCA) and a stenosis of RCA with peripheral occlusion.

Four days later, he underwent coronary artery bypass grafting (CABG). He has been followed regularly at the Preventive Cardio-Rheuma clinic post operatively.

# Diabetes in RA



## Our approach

Through:

1. Literature review
2. Fieldwork at centre visits
3. Steering Committee review with RA specialists and comorbidity experts

we have identified key considerations for the management of diabetes in RA

## Patients with RA have an approximately 50% increased risk of diabetes<sup>(a)</sup>

### 1. Literature review findings

- For patients with RA, incidence of diabetes is 8.6 per 1000 people<sup>(a)</sup> and prevalence is 20%<sup>(b)</sup>
- The prevalence of diabetes in patients with RA is high and is associated with known sociodemographic factors
- The Centre for Disease Control (US-based organisation) estimates that >26% of adults over 65 have diabetes and note that diabetes is a key mortality predictor in patients with RA<sup>(c)</sup>
- The inflammation of RA may increase the risk of developing type 2 diabetes
- Corticosteroids used to treat RA may also increase type 2 diabetes risk by increasing blood-sugar level
- Despite these impressive numbers, current standard of care guidelines for diabetes and RA do not account specifically for this comorbidity

#### Published guidance :

- (General comorbidity guidance) (2019) Points to consider for reporting, screening for and preventing selected comorbidities in chronic inflammatory rheumatic diseases in daily practice: a EULAR initiative<sup>(c)</sup>

### 2. Fieldwork findings

#### Guidance covered by our case studies highlights the importance of:

- Screening and detection
- Periodic follow-up
- This can be achieved by coordination of chronic disease management for both RA and diabetes in conjunction with one another.

#### Case study<sup>1</sup>

**Dedicated primary care coordinator**, Diakonhjemmet Hospital

### 3. Steering Committee recommendation

#### Key elements to consider for improvement of the quality of care of diabetes in patients with RA:

- Effective treatment of RA with novel targeted therapies may improve glycaemic control (reduce HbA1c<sup>2</sup> levels) in patients with diabetes and RA<sup>(d)</sup>

**Notes:** 1. Please note case study(ies) are those we identified which were specific just to this comorbidity. Case studies addressing all comorbidities can be found on p. 87  
**Sources:** (a) Solomon DH, et al. Risk of diabetes among patients with rheumatoid arthritis, psoriatic arthritis and psoriasis. *Ann Rheum Dis*. 2010;69(12):2114–2117. doi:10.1136/ard.2009.125476; (b) Albrecht K, et al. High prevalence of diabetes in patients with rheumatoid arthritis: results from a questionnaire survey linked to claims data. *Rheumatology (Oxford)* 2018;57(2):329-336. doi: 10.1093/rheumatology/kex414; (c) Baillet A, et al. Points to consider for reporting, screening for and preventing selected comorbidities in chronic inflammatory rheumatic diseases in daily practice: a EULAR initiative. *Ann Rheum Dis* 2019;0:1-9. doi: 10.1136/annrheumdis-2016-209233; (d) Otsuka Y, et al. Effects of tumor necrosis factor inhibitors and tocilizumab on the glycosylated hemoglobin levels in patients with rheumatoid arthritis: an observational study. *PLoS ONE*. 2018;13(4). doi: 10.1371/journal.pone.0196368

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# Depression in RA



## Our approach

Through:

1. Literature review
2. Fieldwork at centre visits
3. Steering Committee review with RA specialists and comorbidity experts

we have identified key considerations for the management of depression in RA

## Patients with RA have a 2-fold increased risk of depression<sup>(a)</sup>

### 1. Literature review findings

- For patients with RA, lifetime prevalence of depression is 16.8%<sup>(b)</sup>
- Patients with RA who are depressed are likely to have poorer medication adherence, increased health service utilisation, more severe pain and disability, and reduced RA remission<sup>(b)</sup>

#### Published guidance :

- (2016) EULAR Points to consider for reporting, preventing selected comorbidities<sup>(c)</sup>

### 2. Fieldwork findings

#### Guidance covered by our case studies highlights the importance of:

- Screening and detection
- Periodic follow-up
- Targeted depression history
- Sleep hygiene
- Watchful watching for 2 weeks (critical timeframe for proactively checking patient)
- Exercise
- Guided self-help (cognitive-behavioral principles)

This can be achieved by having dedicated psychological and / or psychiatric services as well as focusing on socioeconomic impacts of depression e.g. sleep disturbance and empowering patients to cope with depression.

#### Case studies<sup>1</sup>

**Dedicated psychologist**, Hospital de Santa Maria

**Sleep outpatient clinic** Rigshospitalet

**Learning and coping centre**, Diakonhjemmet Hospital

### 3. Steering Committee recommendation

#### Key elements to consider for improvement of the quality of care of depression in patients with RA:

##### Prevention

- Pay attention to individual maintaining factors: inflammation, sleep, physical activity, poor (cognitive, behavioral, emotional) coping, obesity, co-morbidities
- Encourage a healthy lifestyle: sleep hygiene and day-night rhythms, physical activity, doing pleasant things, social contacts, living a valued life

##### Treatment of moderate to severe depression

- If guided self-help and exercise fail: evidence-based cognitive, behavioral, cognitive-behavioral or interpersonal psychotherapy (combined with anti-depressants if needed)

# Osteoporosis in RA



## Our approach

Through:

1. Literature review
2. Fieldwork at centre visits
3. Steering Committee review with RA specialists and comorbidity experts

we have identified key considerations for the management of osteoporosis in RA



## Patients with RA have a high risk of fracture secondary to osteoporosis which increases morbidity and mortality<sup>(a)</sup>

### 1. Literature review findings

- For patients with RA, incidence of osteoporosis is 33%<sup>(b)</sup> and prevalence is 50%<sup>(c)</sup>
- The course of osteoporosis is closely connected with the activity of the underlying disease and other risk factors<sup>(d)</sup>
- Development of osteoporosis in patients with RA leads to further decline of the quality of life, and can increase the costs of treatment and rehabilitation<sup>(e)</sup>
- There is strong association between osteoporosis and glucocorticoids, which appear to reduce both the bone mineral density and increase the risk of fractures<sup>(f)</sup>
- The frequency of occurrence of femoral neck fractures and vertebral compression fractures in patients with RA is twice as high as in healthy persons of the same age<sup>(e)</sup>
- The risk of osteoporotic fractures is closely associated with the disease duration as well as with other factors such as low body mass index, difficulties with movement GC therapy and sarcopenia<sup>(g)(h)</sup>
- Provision of a Vitamin D supplement can be used to treat patients with active RA, as an inexpensive, potentially safe and beneficial therapy<sup>(i)</sup>

### Published guidance :

- (2015) Management of Osteoporosis in Rheumatoid Arthritis Patients<sup>(j)</sup>

Sources: (a) Mirza F, et al. Secondary osteoporosis: Pathophysiology and management. *Eur J Endocrinol.* 2015;173(3):R131–R151. doi: 10.1530/EJE-15-0118; (b) Jin S, et al. Incidence of fractures among patients with rheumatoid arthritis: a systematic review and meta-analysis. *Osteoporos Int.* 2018;29(6):1263-1275. doi: 10.1007/s00198-018-4473-1; (c) Hafez EA et al, Bone Mineral Density Changes in Patients with Recent-Onset Rheumatoid Arthritis. *Clin Med Insights Arthritis Musculoskelet Disord.* 2011;4:87–94. doi: 10.4137/CMAMD.S7773; (d) Leszczyński P, et al. Osteoporoza u chorych na reumatoidalne zapalenie stawów – realny problem czy fikcja? Ocena występowania złamań trzonów kręgowych u kobiet z reumatoidalnym zapaleniem stawów w wieku do 50 lat. *Reumatologia* 7. 2007;45:362-368; (e) Wegierska M, et al. Osteoporosis diagnostics in patients with rheumatoid arthritis. *Reumatologia.* 2016;54(1):29-34. doi: 10.5114/reum.2016.58759; (f) Laan RF, et al. Low-dose prednisone induces rapid reversible axial bone loss in patients with rheumatoid arthritis: a randomized controlled trial. *Ann Intern Med.* 1993;119(10):963-8; (g) Colon CJP, et al. Muscle and bone mass loss in the elderly population: Advances in diagnosis and treatment. *J Biomed (Syd).* 2018;3:40–49. doi: 10.7150/jbm.23390; (h) Glucocorticoid-Induced osteoporosis and osteonecrosis. *Endocrinol Metab Clin North Am.* 2012;41(3):595–611. doi: 10.1016/j.ecl.2012.04.004; (i) Hajjaj-Hassouni N, et al. Evaluation of Vitamin D Status in Rheumatoid Arthritis and Its Association with Disease Activity across 15 Countries: "The COMORA Study". *Int J Rheumatol.* 2017. doi: 10.1155/2017/5491676; (j) Hoes JN, et al. management of osteoporosis in rheumatoid arthritis patients. *Expert Opin Pharmacother.* 2015;16(4):559-71. doi: 10.1517/14656566.2015.997709



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FINDINGS  
COMORB.

## 2. Fieldwork findings<sup>(a)</sup>

### Guidance covered by our case studies highlights the importance of:

- Fracture risk assessment
- Imaging (DXA) as appropriate
- Control of disease activity
- Calcium & Vitamin D supplementation
- Pharmacotherapy

This can be achieved by having osteoporosis specialism within the core rheumatology team, provision of specialist diagnostic and care services and screening for osteoporosis

### Case studies<sup>1</sup>

**Osteoporosis specialism in core rheumatology team**, Hôpital Cochin

**Dedicated comorbidity care services**, Institute of Rheumatology

**Investigations and procedures unit**, Hospital de Santa Maria

**Systematic inflammatory osteoporosis screening**, Hospital Universitario La Paz

## 3. Steering Committee recommendation<sup>(b)</sup>

### Key elements to consider for improvement of the quality of care of osteoporosis in patients with RA:

- The Steering Committee recommended the use of the 2015 Management of Osteoporosis in Rheumatoid Arthritis Patients guidelines for treating osteoporosis in patients with RA
- Emphasis was given towards incorporating objective measures (e.g. Bone Mineral Density tests, DXA) into the patient pathway in order to improve the diagnosis and management of osteoporosis in patients with RA

**Notes:** 1. Please note case study(/ies) are those we identified which were specific just to this comorbidity. Case studies addressing all comorbidities can be found on p. 87

**Sources** (a) KPMG interviews with HCPs treating RA and associated comorbidities (b) KPMG Steering Committee advice



# Pulmonary diseases in RA



## Our approach

Through...

1. Literature review
2. Fieldwork at centre visits
3. Steering Committee review with RA specialists and comorbidity experts

...we have identified key considerations for the management of pulmonary diseases in RA

## Patients with RA have an increased risk of interstitial lung disease (ILD)<sup>(a)</sup>

### 1. Literature review findings

- For patients with RA, incidence of ILD is 7.7%<sup>(a)</sup> and prevalence is up to 60%<sup>(b)</sup>
- Compared to the general population, patients with RA have an adjusted lifetime hazard ratio for ILD of 8.96 (a 7% increased risk)<sup>(a)</sup>
- An ILD diagnosis may precede the onset of RA<sup>(c)</sup>
- There is currently a lack of effective RA-ILD treatment options, with limited information available from clinical trials or prospective cohort studies regarding the efficacy of these therapies (e.g. immunosuppressive or biological therapy)<sup>(d)</sup>

### Published guidance :

- (2017) Practical Management of Respiratory Comorbidities in Patients with Rheumatoid Arthritis<sup>(e)</sup>

### Why do patients with RA develop pulmonary diseases?

- Due to underlying disease
- Due to therapy
- As a consequence of smoking
- Due to infections

#### Types of ILD:

- Diffuse alveolar damage (DAD)
- Nonspecific interstitial pneumonia (NSIP)
- Organizing pneumonia (OP)
- Usual interstitial pneumonia (UIP)

#### Other Manifestations:

- Airways disease
- Bronchiectasis
- Bronchiolitis (follicular/constrictive)
- Emphysema
- Pleural effusion
- Pulmonary hypertension
- Rheumatic nodules
- Upper airways obstruction

Sources: (a) Bongartz, Nannini, Medina-Velasquez et al. 2010. Incidence and mortality of interstitial lung disease in rheumatoid arthritis: a population-based study; (b) Iqbal K, Kelly C. Treatment of rheumatoid arthritis-associated interstitial lung disease: a perspective review. *Ther Adv Musculoskelet Dis.* 2015;7(6):247–267. doi:10.1177/1759720X15612250; (c) Solomon JJ, Brown KK. Rheumatoid arthritis-associated interstitial lung disease. *Open Access Rheumatol.* 2012;4:21–31. Published 2012 Mar 5. doi:10.2147/OARRR.S14723; (d) Olivas-Flores EM, Bonilla-Lara D, Gamez-Nava JI, Rocha-Muñoz AD, Gonzalez-Lopez L. Interstitial lung disease in rheumatoid arthritis: Current concepts in pathogenesis, diagnosis and therapeutics. *World J Rheumatol* 2015; 5(1): 1-22; (e) Bluett L, et al. Practical Management of Respiratory Comorbidities in Patients with Rheumatoid Arthritis. *Rheumatol Ther.* 2017 Dec;4(2):309-332. doi: 10.1007/s40744-017-0071-5

## 2. Fieldwork findings<sup>(a)</sup>

### Guidance covered by our case studies highlights the importance of :

- Screening and detection
- For diagnostic work-up
- Chest x-ray
- Chest auscultation
  - Respiratory symptoms (dyspnoea, cough, fatigue) or crackle
  - Spirometry (FEV<sub>1</sub>, FVC, TLC, DLCO)
  - 6 minute walking test with oxygen saturation measurement
  - Lung biopsy: not as common as in non-connective disorder-ILD
  - Multidisciplinary conferences (representatives from respiratory medicine, radiology, pathology, rheumatology, physiology)
- Periodic follow-up / outpatient clinic
- Management of adverse respiratory events
  - Lung rehabilitation – education for patients and relatives, physical training – with oxygen if needed, ADL, nutrition, psychosocial support
  - Evaluate with PROMS
- Smoking cessation advice

This can be achieved through collaboration between rheumatologists and pulmonologists.

### Case studies<sup>1</sup>

**Joint rheuma-respiratory clinic**, Leeds Teaching Hospitals, Hospital de Santa Maria

**Combined clinic for comorbid ILD**, Hospital Universitario La Paz

## 3. Steering Committee recommendation<sup>(b)</sup>

### Key elements to consider for improving the quality of care of pulmonary diseases in patients with RA :

- The expert panel emphasized the importance of collaborations between rheumatologists and pulmonologists
- ILD should be diagnosed in multidisciplinary discussions where the presence of rheumatologists is encouraged. These conferences can also enable pulmonologists to consider the possibility of an underlying systemic disease including RA in patients with ILD
- Comorbidity assessments may lead to reduced patient mortality due to comorbidity complications in patients with RA (e.g. ILD)



# Infections and vaccination

Patients with autoimmune inflammatory rheumatic diseases (AIIRD) such as RA are at an increased risk of infection due to their underlying autoimmune disease, comorbidities and prescribed immunosuppressive therapies (commonly applied at early disease stages with the aim of achieving remission). Vaccinations therefore play a crucial role in preventing serious infections in patients with AIIRD.<sup>(a)(b)</sup>

**Table 1:** Vaccines recommended for use in AIIRD patients before and after initiating immunosuppressive therapy<sup>(c)</sup>

	Killed vaccines			Recombinant vaccine	Live attenuated vaccine
	Pneumococcal	Influenza (intramuscular)	Hepatitis B	Human Papiloma	Herpes Zoster
<i>Before initiating therapy</i>					
DMARD monotherapy	✓	✓	✓	✓	✓
Combination DMARDs	✓	✓	✓	✓	✓
TNFi biologics	✓	✓	✓	✓	✓ (PICO J.1)
Non-TNF biologics	✓	✓	✓	✓	✓ (PICO J.1)
<i>While already taking therapy</i>					
DMARD monotherapy	✓	✓	✓	✓	✓
Combination DMARDs	✓	✓	✓	✓	✓
TNFi biologics	✓	✓	✓ (PICO J.4, J.5)	✓	Not recommended (PICO J.2, J.3)
Non-TNF biologics	✓	✓	✓ (PICO J.4, J.5)	✓	Not recommended (PICO J.2, J.3)



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# Appendix



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# Additional notes on methodology

# Glossary

ACPA: Anti-Citrullinated Protein/Peptide Antibody	EULAR: European League Against Rheumatism	PICO: Patient, Intervention, Comparator, Outcome
ACR: American College of Rheumatology	EUMUSC: the European musculoskeletal conditions surveillance and information network	PPA: Professional Practice Assessments
ADL: Activities of Daily Living	FACIT: Functional Assessment of Chronic Illness Therapy	PPM: Patient Pathway Manager
AIIRD: Autoimmune Inflammatory Rheumatic Diseases	FVC: Forced Vital Capacity	PRO: Patient Reported Outcomes
BMD: Bone Mineral Density	GC: Glucocorticoid	PROMs: Patient Reported Outcome Measures
BP: Blood Pressure	GI: Gastrointestinal	PT: Physiotherapy
CAGB: Coronary Artery Bypass Grafting	GSG: Global Steering Group	QoC: Quality of Care
CBT: Cognitive Behavioural Therapy	HAQ: Health Assessment Questionnaire	RA: Rheumatoid Arthritis
CDAI: Clinical Disease Activity Index	HCP: Healthcare Professional	RCA: Right Coronary Artery
CME: Continuing Medical Education	HTA: Health Technology Assessment	Regeneron: Regeneron Pharmaceuticals, Inc.
CNS: Clinical Nurse Specialist	IA: Intra-Articular	RWG: Regional Working Group
CoE: Centre of Excellence	IJD: Inflammatory Joint Disease	SCQM: Swiss Clinical Quality Management
COMEDRA: COMorbidities EDucation in Rheumatoid Arthritis	ILD: Interstitial Lung Disease	SDAI: Simplified Disease Activity Index
CRO: Contract Research Organisation	KPI: Key Performance Indicator	SME: Small Medium Enterprise
CRP: C-Reactive Protein	KPMG: KPMG LLP	SRQ: Swedish Rheumatology Quality
CTD: Connective Tissue Diseases	LAD: Left Anterior Descending	T2T: Treat-to-Target
CVD: Cardiovascular Disease	LOM: Left Obtuse Marginal	TLC: Total Lung Capacity
CVRM: Cardiovascular Risk Management	MDT: Multidisciplinary Team	TNF: Tumor Necrosis Factor
DAD: Diffuse Alveolar Damage	MIs: Myocardial infarctions	UIP: Usual Interstitial Pneumonia
DALYs: Disease Adjusted Life Years	NBRR: Nasjonal Behandlingstjeneste for Revmatologisk Rehabilitering (National Unit of Rehabilitation for Rheumatic Patients with Special Needs)	VAS: Visual Analogue Scale
DAS: Disease Activity Score	NHS: National Health Service	
DAS28: Disease Activity Score (based on 28 joints)	NKRR: Nasjonal Kompetansetjeneste for Revmatologisk Rehabilitering (National Advisory Unit on Rehabilitation in Rheumatology)	
DMARD: Disease-Modifying Anti-Rheumatic Drugs	NSAID: Nonsteroidal Anti-Inflammatory Drugs	
DRG: Diagnosis Related Group	NSIP: Nonspecific Interstitial Pneumonia	
DXA: Dual-X-ray Absorptiometry	OA: Osteoarthritis	
EA: Early Arthritis	OP: Organising Pneumonia	
EAC: Early Arthritis Clinic	OT: Occupational Therapy	
ECG: Electrocardiography	PAG: Patient Advocacy Group	
EHR: Electronic Health Records	PCP: Primary Care Professional	
EMR: Electronic Medical Records		
EPR: Enhanced Permeability and Retention		
ESR: Erythrocyte Sedimentation Rate		
ETP: Education Thérapeutique du Patient		

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APPENDIX  
METHODOLOGY

# Contributor roles and responsibilities



## KPMG

This study was solely conducted by KPMG, including the collection, study, management, analysis and interpretation of data, and the preparation of the report.



## Steering Committee

The Steering Committee of RA healthcare professionals, comorbidity specialists and patient representative was engaged to provide direction for the overall project scope, approach and outputs, review and prioritise findings, and guide the dissemination and implementation of good practice following publication of the report. All experts that were consulted were invited to join the Steering Committee.



## Sponsor

This report was commissioned and funded by Sanofi Genzyme.

Sanofi Genzyme had no role in the collection, management, analysis or interpretation of data, or preparation of the final report.

# Centre selection

## Approach

Secondary research was performed using publically available sources to identify potential centres. Recent EULAR recommendations, conference programmes, and key papers (Treatment to Target; COMORA study) were used to identify key rheumatologists and centres. The final selection aimed to include a range of health systems, resources and experience (e.g. well-established / new services).

Centres were selected based on a set of criteria which included:



### Centres

- **Geography:** 12 RA centres across Europe, each located in a different European country, were selected to represent a multinational approach to RA management
- **Focus:** The centre's experience with RA was considered. Specialised and generalist centres were selected to ensure the report would be applicable to a wide audience
- **Centre type:** The centres' models and involvement in the wider healthcare ecosystem (e.g. private versus public funding, size, partnerships within the community etc.) were assessed

# Limitations to our methodology

It was recognised that there were limitations to the study methodology and several actions were taken to mitigate these.

## Limited patient interviews:

- **Limitation:** There is an absence of patient interviews which limited the patient perspective on challenges in the patient pathways and intervention benefits (e.g. benefits of self-management)
- **Mitigation:** The role of the very experienced patient representative on the expert committee helped to overcome this by providing a collective patient perspective, on behalf of patients

## Inclusion of one centre per country:

- **Limitation:** The inclusion of one centre per country limited the findings with respect to the representativeness of the wider healthcare system in which they reside.
- **Mitigation:** When conducting research which did not solely focus on centres themselves but rather their entire ecosystems; including the various institutions they collaborate with, whether formally or informally. However, the goal of this study was rather to find centres that had developed good quality of care practices which could serve as models if implemented in other centres.

## Selection of larger teaching centres:

- **Limitation:** Larger teaching centres were selected
- **Mitigation:** To ensure smaller and less developed centres could replicate the interventions, information was gathered and documented on the interviewees' perspectives on how the interventions could be replicated

## Inclusion of co-morbidities

- **Limitation:** We have not included gaps, challenges and interventions related to all co-morbidities associated with RA
- **Mitigation:** We have prioritised the six most prevalent co-morbidities in line with guidance from our Steering committee and have incorporated findings from interviews with specialists in those comorbidities into this report



# Centre-specific reports

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# Cliniques Universitaires Saint-Luc

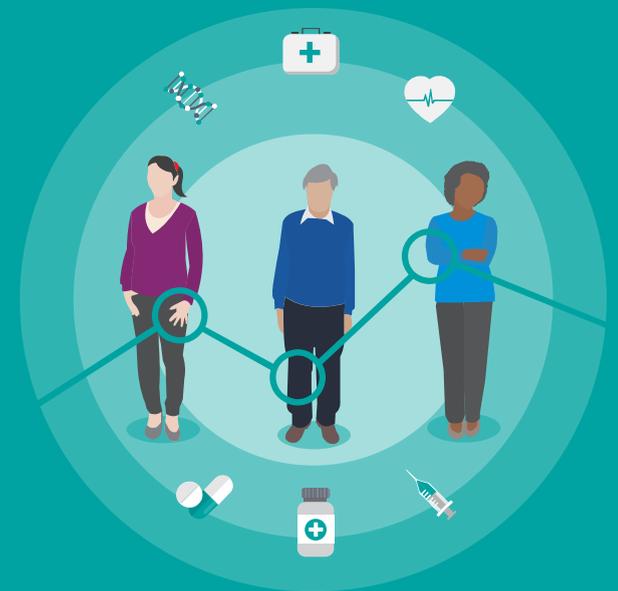
Brussels, Belgium



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APPENDIX  
CENTRE REPORTS



# Summary



## Context

- **High educational standard** with rheumatologists training for 13 years (including 3 years of internal medicine, 3 years of rheumatology training)
- **Easy access to rheumatology specialists** as patients can self-refer to specialists of their choice or via PCPs
- **Education of wider hospital teams** through hosting RA-specific educational sessions for all HCPs within the hospital
- **Personalised patient care** specifically tailored to individual patient needs
- Strong research focus within the department, running various projects assessing the impact of biomarkers, extracted from the joints and a longitudinal study called CAP48 looking at the impact of mobility on slowing disease progression



## Patients recently diagnosed with RA

- **Personalised patient care** to ensure that treatment and management of patients with RA is tailored specifically to the individual's needs through a disease-based segmentation (early, chronic, severe), demographics and motivations / attitudes
- **Rapid access to care** is enabled through a variety of protocols that help triage the patients so that they receive the right level of care as and when is required, fast-tracking those with more severe symptoms
- **Role of the rheumatology nurse** has been developed to help support patients throughout their care, acting as a bridge between the rheumatologists and patients to help them navigate their care providing education and advice for both the patients and their families
- **Rehabilitation centre** with a comprehensive offering to promote movement and exercise in patients with RA. Facilities include occupational therapy, physiotherapy and sport facilities to provide comprehensive mobility support and paratherapeutic care



## Key challenges faced in delivery of RA care

- National recommendations have led to a reduction in appointment times from ~30mins to ~15 minutes
- Restricted reimbursement for nurse-led care
- Restricted reimbursement for mental health care (for psychologist and psychiatrist) with RA
- Limited integration with other specialties
- Low PCP awareness and engagement in managing comorbidities in patients with RA

# RA Belgium healthcare system overview



## Belgium healthcare system overview:



**Public health service:** 99% of population is covered by a broad benefits package, which covers over 8,000 services. For those services that are not reimbursable additional services can be offered by the sickness fund and will need to be paid for privately by the patient (extra dental services, hospitalisation etc.). Patients are given a social security card (Carte SIS / eID) to take to the health insurance company sickness fund of their choice. There is mandatory health insurance, with six private, non-profit making national associations of sickness funds and one public. National patients are able to choose their own medical professionals and places of treatment.

## Belgium healthcare system overview (cont.):



Patients generally pay costs upfront and are reimbursed. There are 2 systems: 1 direct payment (ambulatory services) where the patient pays the full amount and is reimbursed fully or partially by the sickness fund afterwards, 2. third-party payment system (ambulatory drugs and hospitalisation) where the sickness fund pays most of the costs and the patient only the co-payment. The amount of reimbursement varies according to the treatment and your personal circumstances (i.e. usually 75% for doctors consultation or minor treatment).

- **Private insurance:** account for only a small part of non-compulsory health insurance market (5.9%)
- **Funding:** Partially funded by social security contributions (3.8% of salary, 3.55% from employers). This is based on progressive direct taxation, proportional social security contributing related to income and alternative financing related to consumption of goods and services. The rest is supplemented by government subsidies and taxes, and external sources of funding such as insurance companies and pharma sponsorship, with the remaining being paid by patient contributions and private insurance. Healthcare expenditure is 10.4% of annual GDP. 20% of total health care expenditures are paid by patients through official co-payments, supplements and non-reimbursed medical acts, drugs and series.

## Rheumatoid Arthritis in Belgium:



### Patients:

- 0.5% (80,000 – 100,000) in Belgium <sup>(d)</sup>

### Physicians:

- 200 rheumatologists in Belgium <sup>(e)</sup>

### Guidelines:

#### RA:

- EULAR/ACR <sup>(b)</sup>

### PAGs/ Medical Societies:

- Belgium Royal Society of Rheumatology <sup>(c)</sup>

## RA challenges in Belgium healthcare system :



- Reimbursement is not offered for additional roles of the rheumatology nurse. This acts as a barrier to supplementary care delivery for patients with RA
- Incorrect reporting and collation of data
- Lack of unique patient identification between all available databases, data concerning voluntary health insurance,
- Difficulties in diagnosis and treatment data in particular for comorbidities <sup>(a)</sup>

# The Rheumatology unit

Cliniques Universitaires Saint-Luc is the largest hospital in Brussels

The hospital			
<b>Type</b>	Private non-profit-making (ASBL) hospital associated with Université Catholique de Louvain <sup>(b)</sup>	<b>Locations</b>	Wolume-Saint-Lambert <sup>(b)</sup>
<b>Core services</b>	Provides specialist care and treats serious, rare and complex diseases of patients. Structured into medical departments but also multidisciplinary centres and healthcare networks, including orthopaedic, internal medicine, chest and cardiac, ENT, ophthalmic, dental, neurological, psychiatric, plastic surgery and gynaecological <sup>(b)</sup>	<b>Population served</b>	Patients across Belgium, as well as some international patients <sup>(b)</sup>
<b>Size</b>	5800 employees >1,000 beds	<b>Demographics</b>	n/a



The rheumatology unit			
<b>Services</b>	Over 15,000 consultations a year. Highly optimised methodology of assessment, treatment and management to provide individualised care. Provides treatment to patients across the patient pathway through: day clinics (for IV); early arthritis clinic; inpatient facilities (complex and / or severe cases); technical procedures (bone densitometry, capillaroscopy, ultrasound or mini - arthroscopic diagnosis); functional rehabilitation; targeted orthopaedic surgery; psychological support and socio-professional support.	<b>Collaborations</b>	Partnered with Université Catholique de Louvain <sup>(b)</sup> CAP48 – longitudinal study
<b>Funding and Resources</b>	They have benefited from numerous funding (FNRS, FRSM, Walloon Region, Marshall Plan, Eurocores, Fund for Scientific Research in Rheumatology) and the Fondation Saint-Luc	<b>Teaching/ research scope</b>	First hospital to gain the full AAHRPP* accreditation, and international recognition <sup>(b)</sup> ; Developed translational / transfer research activity which assesses the mechanism operating in pre-clinical models and applying to human pathology, including studies that assess joint biomarkers and a recent longitudinal study assessing the impact of physical therapy on disease progression – CAP48 <sup>(a)</sup> ; from 2005 – 2010 they produced 120 scientific articles & 150 clinical investigations <sup>(b)</sup>



Note: Association for the Accreditation of Human Research Protection Programs, Inc. (AAHRPP) promotes high-quality research through an accreditation process that helps organizations worldwide strengthen their human research protection programs (HRPPs).

Source: (a) KPMG interviews with HCPs treating RA and associated comorbidities ; (b) <https://www.saintluc.be/>

# The Rheumatology unit (cont.)



## Overview of services

Service Division	Day clinic	Ambulatory care	Inpatient	Physiotherapy
<b>Duration of stay</b>	~2 - 3h (this can be extended as necessary for each patient)	As long as is required for infusion process	As long as is required	For the session
<b>Hours of availability</b>	– 7:30am - 9pm	– 7:30am - 9pm	– 24/7	– 7:30am - 9pm
<b>Capacity (no. of beds/rooms)</b>	25 – 30 patients a day	– N/A	– 10 beds for RA	– N/A
<b>No. of patients seen</b>	– 1,500	– N/A	<1	1 per week
<b>Patient type catered to</b>	– Early arthritis, chronic and severe patients	– Those requiring IV drug infusions	– Sever complications, infections and medications	<ul style="list-style-type: none"> <li>– Chronic patients with RA I</li> <li>– Patients with early RA who have achieved remission (after 6 months)</li> </ul>
<b>Services offered</b>	– Consultation, radiology (ultrasound / echography)	– 2 clinics on the 4 <sup>th</sup> floor for infusions	– 24h care for treatment	<ul style="list-style-type: none"> <li>– Physiotherapy</li> <li>– Kinaesthesia</li> <li>– Sports therapy</li> <li>– Occupational therapy</li> </ul>
<b>Specific tools</b>	<ul style="list-style-type: none"> <li>– HAS-Q</li> <li>– Saint-Luc's joint assessment tool</li> <li>– FACIT</li> <li>– VAS-fatigue score</li> </ul>			<ul style="list-style-type: none"> <li>– Occupational therapy facilities (bathroom, workstation, kitchen, Wii games room, crafts room etc.)</li> <li>– Sports physio and gym machines</li> <li>– Swimming pool</li> <li>– OT training facilities</li> <li>– Psychological support and assistance</li> </ul>

# The team

## Core team profiles

- 5 professors
- 5 consultants rheumatologists
- 5-6 trainees
- 2 rheumatology nurses
- 2 service coordinators
- 1 physiotherapist
- 1 kinesiologist
- 1 psychologist
- 1 occupational therapists
- rheumatology researchers
- orthopaedic surgeons
- social care assistants

## Affiliate team profiles

- Psychiatrist
- Psychologist
- Cardiologist
- Pulmonologist
- Endocrinologist / diabetologist



## Key features of the care delivery team

- **Rheumatologist is the central point of all care**
- **Lead professors are specialised across the rheumatic diseases** (rheumatoid arthritis, psoriatic arthritis spondyloarthritis, sclerosis and chondropathies)
- **Rheumatology nurse** acts as key support for the rheumatologist; also providing education and support for the patient and their family, clinical examinations and coordination of the services within the RA centre
- **Clinical trials coordinator** who helps to coordinate and integrate data points, currently running a major longitudinal study into the benefits of non-pharmacological management and exercise
- **Research coordinator** acts as key point of contact integrating the findings from biopsies, histologies etc. into a database in order to help future prediction of the biomarkers associated with RA

## Governance and processes

### Team meetings:

- Ad hoc MDT meetings with cardiologist, pulmonologist and ophthalmologist when required
- Weekly meetings with physiotherapist/ kinaesthesiologist team

### Protocols:

- No local guidelines used
- Internal measures for evaluating patients are input into the database

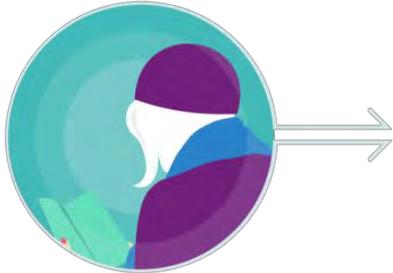
### Patient records:

- Database for Rheumatology department which includes measurement of comorbidities

# Overview of interventions in place for RA

## Awareness & Prevention

Symptom identification



## Referral & Diagnosis

In secondary care



## Treatment & Management

Pharmacological management



Non-pharmacological management



## Follow-up

Monitoring of chronic disease/flare up



Interventions

### PCP and nurse RA training

- Rheumatologists provide educational course to upskill local PCPs and hospital nurses

### Arthritis hotline

- Rheumatologists 'man' the hotline for rapid referrals

### Secretary triage

- Medical secretaries are trained to triage, identify and prioritise patients with high-risk or RA for 48h referrals

### Patient online self-referral

- Online platform and email address for patients to contact rheumatologists directly

### Comprehensive diagnostic assessment

- Assessment measures (including HAQ)
- All patients receive radiology (ultrasound) enabling diagnosis of early RA

### Biomarker study

- Ongoing study to identify biomarkers from synovial fluid that predispose patients to RA

### Tailored RA database

- Standardised data collection tailored specifically to RA

### Early arthritis clinic

- Dedicated appointment availability on Monday morning for priority patients
- Initial assessment triage by trainee, followed by rheumatologist to explain therapeutic strategy and set treatment objectives together

### Day clinic

- For consultation, infusion, monitoring and side effects

### Patient segmentation

- By disease severity (early, chronic or severe), demographic and motivation to personalise care

### Biomarker study

- Ongoing study to predict response to biologics in order to personalise treatment
- Draining of synovial fluid and injection of corticosteroids

### Educational materials

- Lead rheumatologist authored patient information, sponsored by a Patient Association Group (PAG)

### Rehabilitation centre

- Initial evaluation of individual needs to develop personalised programme
- Facilities include an: occupational therapy area for day-to-day activities; physio and moderate exercise area and sports rehabilitation and exercise facilities

### CAP48

- Longitudinal study to assess the effects of exercise and movement on RA progression

### Role of the rheumatology nurse

- Holistic management including reassurance, disease education, clinical examinations, and coordination of patients and their families through the care system

### Family education

- Family members are invited to an educational session to help support patients

### Tailored RA database

- Enables longitudinal monitoring of disease progression and patient-reported outcomes

### Patient empowerment

- HCPs encourage patients to take ownership and responsibility for their disease

### Use of ultrasound for discordant cases

- Conduct ultrasound for patients with conflicting clinical results and patient-reported outcomes

### Follow-up appointments

- Rheumatology nurse uses email and telephone to follow-up as appropriate for reminders and missed appointments

# Overview of interventions in place for RA

## Awareness & Prevention

Symptom identification



## Referral & Diagnosis

In secondary care



## Treatment & Management

Pharmacological management

Non-pharmacological management



## Follow-up

Monitoring of chronic disease/flare up



Interventions

### PCP and nurse RA training

- Rheumatologists provide educational course to upskill local PCPs and hospital nurses around comorbidities associated with RA (focus on cardiovascular and infection)

### Prevention

- Evaluate risk of cardiovascular disease (lipid profile) and infection
- Vaccinations given by rheumatologists most importantly for hepatitis B and pneumococcal

### Screening

- Rheumatologists and trainees evaluate for cardiovascular comorbidities, such as high blood pressure and hypercholesterolemia, on a case-by-case basis

### Referral

- Rheumatologists use their internal network to refer patients to ophthalmologists, pulmonologists and cardiologists on a case-by-case basis
- Other referrals go via the PCP through referral letters

### MDTs for severe patients

- Rheumatologists meet with specialist on an ad hoc basis to review treatments plans and assess complications

### Rheumatology nurse congress attendance

- Annual attendance to congress to update knowledge and share insights between nurses

### Smoking cessation advice

- Patients are referred to these services on a case-by-case basis at a time when they will be most receptive
- Provision of services within the hospital

### Medication reduction

- Ultimate aim of the centre lead is to reduce the number of medications patients with RA require
- Promoting lifestyle changes including weight-loss and activity

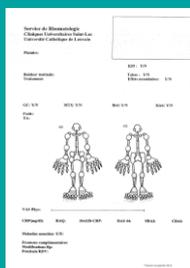
### Psychologist referrals

- Patients struggling with depression and low motivation can be referred to onsite psychologist
- These services are not reimbursed in Belgium

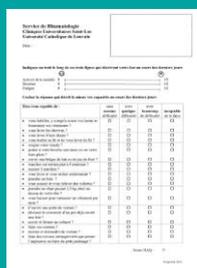
### Tailored RA database

- Screening and monitoring of comorbidities on a case-by-case basis

# These interventions have improved outcomes



Consultation record



HAS Questionnaire



How do you quantify the benefits in RA?

**Objective measures (KPIs):**

- Consultation record which assesses the:
  - Treatment, DAS 28, VAS- phys, DAS 44, SDAI CDAI; joint damage, comorbidities
- Radiological imaging: Ultrasound

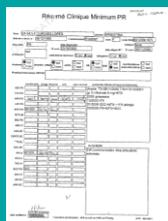
**Patient reported outcome measures (PROMs):**

- HAQ-DI questionnaire
- Pain VAS
- VAS-fatigue
- FACIT

**Centre routinely measures comorbidity outcomes by:**

**Objective measures (KPIs):**

- Centre has its own 'Treatment status summary' (Resume Clinique Minimum PR)
  - This is a method used to capture all the relevant data by recording the patient's disease status at each consultation
  - These documents are then scanned into the patient database
- Screening those patients that are at risk:
  - This is specifically tailored to the patient and not applied to all



Treatment status summary



How have these interventions improved patient outcomes?  
**RA**

- Benefit: greater patient engagement and reduced dropout rate, increased awareness of RA in the wider community
- As per the above measures outcomes have improved with the implementation of the interventions identified in this report

**“Measuring outcomes helps to focus care on the patient’s needs”**

- Rheumatologist

# How can care be improved?



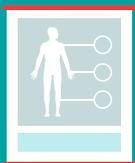
## What is next for the centre?

### Overview: Increase the number / volume of patients enrolled in appropriate rehabilitation services

- **Why?** The benefits of increasing this service for more patients will ensure that they have a better awareness, understanding and knowledge of how to practically apply the rheumatologist's advice to improve their lifestyle (weight loss and increased physical activity)
- **How?** Increase collaboration between services by having a physio / occupational therapist to participate in consultations with the rheumatologist to advise on services. Integrating a visit to the rehabilitation centre within the Day Clinic or Early Arthritis clinic. Continue to measure outcomes from the CAP48

### Overview: Further expand the role of the rheumatology nurse in RA care and comorbidities

- **Why?** Currently there are two rheumatology nurses who are dedicated to rheumatology, who's primary roles are to act as assistant to the rheumatologists but also as the main point of contact for patients, often acting as a bridge between the patients and their rheumatology specialist. This requires the role of the rheumatology nurse to cover many parts of the patient pathway, spanning across education, clinical examinations, coordination and treatment of patients; however the role is not paid in alignment to the greater skills and capabilities required
- **How?** Increasing the funding available to pay nurses effectively for their time, through lobbying the appropriate authorities or seeking funding from other sources. Develop additional nurse capabilities through providing training, both on the job but also in a classroom setting in order to free up more senior nurses to take on additional responsibilities



## What advice would you give less specialised centres?

### Overview of advice: Develop strong relationships with sport centres, physiotherapists and occupational therapists to build a network with local community

- **Why?** Sports rehabilitation facilities available for patients with RA are key in their treatment and prevention of further joint damage. The centre firmly believes in the reduction of medication and the promotion of lifestyle choices (weight loss and increased activity) to improve patient outcomes. Patients often have to travel to reach the centres, so providing access to these services at locations close to their homes could increase adherence to physical 'prescriptions'
- **How?** Create relationships with local rehabilitation physiotherapy and sport centres in order to create a network of facilities that patients can visit near their homes in order to maintain their prescribed therapies

### Overview of advice: Provision of more specialist rheumatology nurses

- **Why?** To help alleviate the burden on rheumatologists and act as a bridge between the patient and the rheumatologist providing education, management with availability to the patient as and when is needed
- **How?** Provide training for general nurses to specialise in rheumatology and therefore have more capacity and availability of nurses to fulfil each part of their role adequately. Provide opportunities for rheumatology nurses to share about their day-to-day practices and experience so that other nurses can leverage learnings for implementation within their own centre



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# Case study 1

## Personalised patient care

### Overview

- The rheumatology department provides individually tailored care and management of their patients, depending on their disease severity, demographic segmentation and motivations surrounding their disease
- Education is highly personalised for patients and is predominantly supported by the rheumatology nurse, and sometimes is supplemented by educational materials

Source: (a) KPMG interviews with HCPs treating RA and associated comorbidities



### What is the rationale?



- Understanding the patient's medical history and goals helps the HCPs to provide the best possible care for the patient
- Gaining an understanding of their motivations will help the HCP to engage better with the patient's motivations and concerns to improve outcomes and reduce joint damage

### What are the key features of the intervention?



#### Segmentation

- Patients are segmented depending on the following factors:
  - Disease severity: early arthritis, chronic and severe
  - Demographics (e.g. age and gender)
  - Motivations

#### Treatment and management

- Patient care is specifically adapted to the individuals needs this includes:
  - Therapeutic measures
  - non-pharmacological measures (e.g. occupational, physiotherapy and sports rehabilitation)
  - Level of education
    - Supplemented by rheumatology nurse sessions to ensure understanding of key protocols
  - Follow-up procedures and regularity of appointments
    - Decreased frequency for chronic patients as their disease is well-controlled

- There are a variety of additional measures that are tailored to patient's needs and motivation:
  - Involving the family in their care
  - Frequency of correspondence
  - Additional education (from the rheumatology nurse or with materials)

#### Education

- There is an information booklet written by the lead rheumatologist, which is also sponsored by a PAG (L'association Polyarthrite)
- However there is a preferred focus on face-to-face education as it can be tailored and understood more clearly
- Rheumatology nurse education is provided in order to help explain diagnosis, treatment and management to the patients and their families in a more patient-friendly manner
- There is a notice board in the day clinic waiting room with newsletters which provides information for the patients about PAG events and activities

### What are the outcomes so far?



#### Patient empowerment

- Patients are more engaged in their care which ensure greater adherence and self-management

#### Treatment outcomes

- Patients are segmented and therefore receive the right care more rapidly and through methods that suit the individual patient and ensure greater adherence to their medication, treatment and care

## Personalised patient care (cont.)

### Challenges



- Personnel capacity constraints mean that rheumatologists often have limited availability and time to spend with the patients
- There is a limited number of trained rheumatology nurses which means they do not necessarily have the capacity to provide the level of education and support required for patients
- Specialised knowledge required to fully understand the patient's needs, which requires 'on the job' experience

### Tips to replicate this intervention



- Establish clearly defined measures in order to segment patients effectively
- Ensure rheumatology nurses are available to help provide education and support for the patient and their family members
- Ensure rheumatology nurses and physicians have good levels of communication to share learnings around the patient's needs and motivations and ensure care can be tailored effectively
- Ask the patient what it is that they would like to have in terms of educational support (materials, introduction to PAGs etc.)

### Benefits



#### Benefits to patients

- Patients are more involved in their care through a specifically tailored treatment plan
- Each patient receives individualised care with a one-to-one consultation with the lead rheumatologist, supported by the rheumatology nurse, meaning they have more contact time to receive more thorough education and understanding around RA and its associated comorbidities
- The involvement of first degree relatives means there is increased awareness amongst family members of RA and its associated comorbidities and how best to help support the patients

#### Benefits to Rheumatology team

- Segmentation of patients helps to align them to the correct treatment protocols, and therefore likely to improve outcomes
- Greater understanding of the patient's motivations will mean the rheumatologist can tailor the treatment and educational approach to the individual



Understanding the patient's motivations is key to their successful treatment

– Rheumatologist



Source: (a) KPMG interviews with HCPs treating RA and associated comorbidities

# Case study 2

## Rapid access to early care

### Overview

The centre provides a variety of services to ensure that patients receive rapid access to care and the correct services required for their treatment

This is especially targeted at those patients experiencing acute and severely heightened symptoms of RA

Source: (a) KPMG interviews with HCPs treating RA and associated comorbidities



### What is the rationale?



- A key aim of RA care is to reduce disease progression by starting treatment as early as possible
- The hospital provides various services to help triage patients in order to but also to determine and prioritise those who need rapid access to care, and make sure all are diverted to the appropriate professional or team
- Once the patient enters care there are defined systems and protocols to ensure they receive the correct diagnosis, treatment and management of their disease

### What are the key features of the intervention?



#### Hotline for PCPs

- A direct telephone line to the hospital rheumatologists which PCPs can call to refer patients from primary to secondary care
- A rheumatologist constantly monitors this phone during their clinic and helps to prioritise patients for their initial assessment

#### Patient enrollment through online platforms

- These facilities are accessible through the hospital website and enable patients to take responsibility for their own care by determining which centre and physician they would prefer to see

#### Medical secretary

- The team secretary is trained and has experience in triaging patients for early RA care through a series of questions assessing history, demographics, symptoms (e.g. number of swollen joints)
- This helps to prioritise patients with severe symptoms for urgent appointments (~48h) and filter those who can attend a follow-up appointment at a later date

#### Early arthritis clinic

- This clinic has been developed for the initial assessment of patients suffering from suspected RA
- The patient is initially assessed with a standardised questionnaire by a trainee and then is sent to the radiology department in order to gain a full assessment of the joints
- They then attend their first consultation with the rheumatologist who will help to explain the therapeutic strategies available
- Together the patient and the rheumatologist set treatment objectives to ensure the patient is motivated and empowered to manage their own care

#### Day clinic

- The centre has a defined procedure for patients who are attending an outpatient appointment, which entails a consultation with a full examination and referral to the ambulatory unit for infusions for those patients on biologics
- If a patient has a complication (e.g. due to infection or associated comorbidity symptoms) they are triaged or directed to the corresponding specialist
- Additional ultrasound scans are conducted if there is discordance between clinical results and the patient-reported outcomes

#### Referral to other specialists for comorbidities

- The rheumatologists screen for comorbidities on a case-by-case basis
- It is the rheumatologist who refers the patients to the specialist as and when required (sometimes this can be referred back to the patient's PCP but is often more efficient to refer to the required physician on-call)
- There is ad hoc correspondence and meetings between the rheumatologists and required specialist for the associated comorbidity



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## Rapid access to early care (cont.)

### Benefits



#### Benefit to the patient

- Patients who are experiencing severe symptoms are seen in a timely manner and have prioritised access to the correct treatment
- Because patients in Belgium can choose which rheumatologist they would like to see, they can directly access their chosen physician through either the hospital's online platform and e-mail and do not experience long waiting times
- Chronic patients know that they can be seen quickly if symptoms worsen

#### Benefit to the community

- Patients have a shorter referral time due to relationships between PCPs and the clinic and availability of the hotline

#### Benefit to the rheumatology team

- Triage patients helps to ensure that the rheumatologist's time is used effectively and efficiently
- Initial assessment is then taken by a trainee rheumatologist or rheumatology nurse— freeing up the rheumatologist to conduct a focused medical consultation

### Challenges



#### At the level of the Healthcare System

- There are time constraints on appointments set by the TARDIS

#### At the hospital level

- Ensuring that rheumatologists have the availability and capacity to provide treatment to those triaged patients with severe symptoms within ~48h
- Ensuring there is the training and support for individuals to become medical secretaries, so that they are able to help support the triaging of patients
- Ensuring effective and efficient cohesion and integration of services for the early arthritis and day clinics

#### In a community setting

- Educating community physicians to ensure they are aware of the hospital's services dedicated to RA, such as the hotline
- Improving awareness of PCPs around the symptoms and signs of RA so that they can be referred to a specialist in a timely manner

### What are the outcomes so far?



- Reduced burden for rheumatologists as the patient is effectively triaged before their appointment
- Patient-reported outcomes

Source: (a) KPMG interviews with HCPs treating RA and associated comorbidities



# Case study 3

## Role of the rheumatology nurse

### Overview

The rheumatology nurse plays a significant role at Saint Luc, acting as an assistant to the rheumatologist

The rheumatology nurse is also the main point of contact for patients, acting as a bridge between the rheumatologist and the patient

They help to coordinate care and educate the patient and their families about RA and associated comorbidities, the available treatments, and the potential impact of these on their day-to-day lives

Source: (a) KPMG interviews with HCPs treating RA and associated comorbidities



### What is the rationale?



- Rheumatoid arthritis is a chronic disease and therefore it is important to have an available point-of-contact for patients, whom they can trust and rely on over the course of their treatment
- The rheumatology nurse is available for patients if they require additional support between consultations, as the rheumatologist is often very busy with the large number of patients visiting the hospital
- The rheumatology nurse helps to coordinate the patient's care throughout including follow-up
- The rheumatology nurse helps to provide additional education to the patients and their families around the complexity of the disease and the associated comorbidities

### What are the key features?



### Training

- The hospital's rheumatology professors initiated a year-long program to help educate other physicians in the hospital about RA
- The rheumatology nurses initially received their training through attendance over the year, and once they demonstrated a heightened interest, were selected to continue training as part of the rheumatology team
- Rheumatology nurses attend an annual conference on RA where they can meet with other nurses who hold a similar role within other centres in Belgium
- Rheumatology nurses also have the opportunity to attend additional courses on health education for chronic patients

### Day-to-day

- The rheumatology nurse supports the rheumatologist, spending 3 days in the clinic assisting consultations of patients and 2 days in the office answering the phone and coordinating the patients' care
- The rheumatology nurse is always available during work hours for the patient, by e-mail and by phone
- The rheumatology nurse helps to coordinate the care of misdiagnosed patients and their referral to the clinic

### Education of patients

- Often the patient may leave their consultation with limited understanding of the disease and what is required of them to effectively self-manage, e.g. due to a reticence to ask questions of the doctor. The rheumatology nurse therefore helps to provide education about RA for patients and their family members and its effective treatment (e.g. medication, adherence, physical rehabilitation, how to maintain a good quality of life and the potential for developing associated comorbidities)
- Any gaps in the patient's knowledge will be fed back by the rheumatology nurse to the rheumatologist so they are aware of the patient's needs and concerns

### Care coordination

- The rheumatology nurse helps to coordinate the patient's care from initial consultation through to chronic management and follow-up along the course of the disease
- The rheumatology nurse will call or e-mail patients to remind them of follow-up appointments and also to check how they are coping with new treatments

### Clinical examinations

- Once a week the rheumatology nurse is able to practice clinically, where she can conduct physical examinations, such as initial assessment measures (e.g. swollen joint counts, HAQ); steroid injections and taking biopsies for the hospitals research studies



## Role of the rheumatology nurse (cont.)

### What are the outcomes so far?



Greater involvement and motivation of patients which can increase their adherence to treatment and attendance to follow-up consultations

Families can have more of an understanding of the disease so can be more involved in and support in the patients

### Benefits



#### Benefit to the patient

- Greater patient satisfaction and awareness
- Patients are empowered to take ownership of their care and manage their symptoms. They better understand their disease and know they can make use of the nurse's support
- Chronic patients tend to build a strong relationship with the nurses who they rely on for advice and reassurance

#### Benefit to the Rheumatology team

- This role greatly alleviates the burden on rheumatologists by ensuring the rheumatologist has the information required prior to the patient consultation, and helps the patient to be well informed before they attend the consultation

### Challenges



The availability of rheumatologists to help provide education, training and opportunity for nurses to become specialists

Currently there is no reimbursement for these nurse roles by the government, meaning there is less incentive for the nurses to gain additional training and skills

There is limited time for nurses on the job to balance all the requirements - including coordinating other colleagues involved in the care of patients with RA

### Going forward



- Create an established network of nurses in order to share learnings
- Provide the opportunities for nurses to present at conferences to share ideas and advocate the role of the rheumatology nurse in RA care
- Provision of more training at both a hospital and national level
- Apply for more government funding for rheumatology nurse roles



Our job is to help reassure patients and act as a bridge between the rheumatologist and them to help them better understand their disease

- Rheumatology nurse



The goal is to put their care in their hands - we want to empower them to monitor their own disease

- Nurse



Source: (a) KPMG interviews with HCPs treating RA and associated comorbidities

# Case study 4

## Rehabilitation centre

### Overview

The hospital has a great focus on the benefits of exercise and movement in helping treat RA and associated comorbidities

A recently opened centre within the hospital provides a range of facilities to help patients from across all areas of the hospital increase mobility and help rehabilitation of day-to-day activities

Source: (a) KPMG interviews with HCPs treating RA and associated comorbidities



### What is the rationale?



- Research evidence supports the prescription of physical activity in helping reduce the progression of joint damage in RA and other associated symptoms
- This also has a great impact for reducing the causal factors and symptoms of RA-associated comorbidities, such as cardiovascular disease
- Rheumatologists within the centre are focused on reducing the amount of medication their patients are taking, preferring instead to promote lifestyle changes such as weight loss and increased exercise

### What are the key features?



#### Personnel

- 1 specialist physiotherapist who conducts all the sessions with patients with RA
- 1 coordinator who liaises with the rheumatologists once a month to discuss severe cases

#### Procedure

- Patients can only be admitted after 6 months once they have achieved clinical remission
- The patient's motivation is evaluated in order to effectively tailor their care, to ensure they maintain and adhere to their treatment
- Set the goals of what the patient would like to improve throughout therapy
- Patients can start by visiting the centre 2-3 times a week and then more infrequently, as and when they feel necessary

- The patient is trained to practise a variety of activities with the aim of reducing the impact of their symptoms, and can receive prescriptions to take to local physiotherapists
- Follow-up tends to be reduced to 2-3 times a year as patients become more independent in managing their physical movements and inspections of their own joints

#### Education & research

- An e-learning platform is available for HCPs and patients so they can learn exercises remotely
- CAP48 is an ongoing longitudinal study that is running to assess the benefits of physio and increased movement on RA progression

### What are the activities undertaken?



#### Assessment

- Patients are assessed with measures such as the Canadian occupational performance measure, S36, Fatigue index (VAS-fatigue and FACIT score)

#### Physiotherapy

- Rheumatologists within the centre are wanting to reduce the amount of medication that their patients are taking and instead promote lifestyle changes such as weight loss and increased exercise

#### Occupational therapy

- Support to better perform activities of daily life through virtual training rooms including a bathroom, a creative room (to enable people to re learn their trades e.g. carpentry); a kitchen; a room for playing video games, and a back-to-work desk space.
- Patients are also taught to use different adapted tools to enable them to manage better at home, at work, and other common living environments



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## Rehabilitation centre (cont.)

### What are the activities undertaken?



#### Sports therapy

- This area includes an entire fully functioning gym rehabilitation centre, with many machines and a swimming pool
- Alongside this are private booths where up to 5 sports physios can treat patients

### What are the outcomes so far?



- Better patient mobility from practising prescribed exercises
- Increased patient satisfaction and quality of life
- CAP48 outcomes data is being collected and will be processed in 2023

### Benefits



#### Benefit to the patient

- Ease of access - with facilities in hospital
- Holistic care offering – with benefits of reducing and preventing onset of associated comorbidities

#### Benefit to the Rheumatology team

- Provides more integrated care
- Helps to alleviate symptoms and delay progression of the disease and associated comorbidities
- Follows the rheumatologist's focus of reducing patient's medication

### Challenges



Patients providing their time and willingness to co-operate with the service. The centre may be far for many patients to travel, especially those patients who have been referred by their local centre

Ensuring the patients stay motivated throughout and maintain exercises without instruction

Integrating psychological and psychiatric care when patients are unwell with depression. This is difficult as it is not reimbursed in RA and therefore requires additional funding

Because there is currently a long waiting list for patients due to capacity, only the most motivated candidates are selected to participate

There is only one rheumatology patient per week, they need to optimise this by integrating the care into their day-centre

### Tips to replicate this intervention



- Build relationships with local physiotherapy, occupational therapy and sport centres so that patients can receive treatment in the hospital but maintain this through accessing care as part of a hospital-provided network

CAP 48 2018-2023		
CONTRATTO	DESCRIZIONE	VALORE IN EURO
1	1	1
2	2	2
3	3	3
4	4	4
5	5	5
6	6	6
7	7	7
8	8	8
9	9	9
10	10	10



We want to help enable patients to have a better quality of life in their day-to-day life

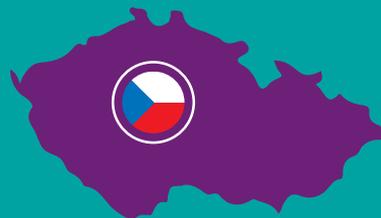
- Physiotherapist





# Institute of Rheumatology

Prague, Czech Republic



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# Summary



## Context

- **Patient-friendly centre design** with a focus on ensuring a welcoming and comfortable patient experience. It has a spacious design with multiple dedicated rooms
- **Hospital-based rheumatologists have a direct influence on generalist care** through educational conferences with primary care coordinators (PCPs) and the development and dissemination of national referral guidelines
- **Personalised patient care** through accessibility to HCPs via telephone and email for medical advice
- **Strong research focus** within the centre, supported by the use of the national patient registry for patients with RA on biologics (ATTRA)
- **Strong links with patient advocacy group (PAG)** Revma Liga (The Czech League against Rheumatism) which was founded by patients treated at the centre



## Key strengths in the delivery of RA care

- **Collaboration with comorbidity specialists** who provide once-weekly reviews of inpatients. The centre collaborates with a cardiologist, a neurologist and an orthopaedist who provide comorbidity care in these specialty areas and are able to provide ad hoc advice in-between reviews
- **High level of education of HCPs at the centre**, with a large proportion of HCPs including physiotherapists, educated to PhD level. Staff have demonstrated dedication to RA care and research through the attainment of various relevant qualifications
- **Specialised physiotherapists** who are trained to deliver RA-specific physiotherapy.
- **Physiotherapist-led holistic care** which is unique to the centre in the Czech Republic. Physiotherapists take a leading role in providing psychosocial support and education in addition to conventional physical therapy. They also coordinate physical therapy services by acting as a referral point between rheumatologists and occupational therapy services

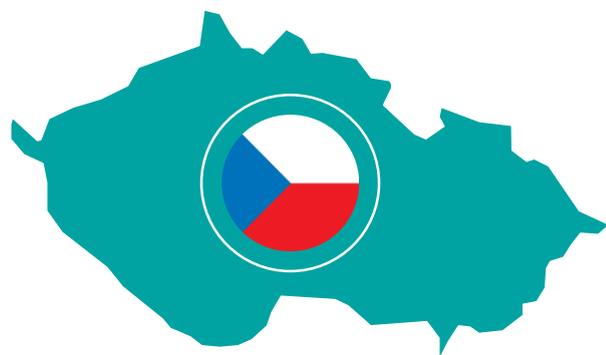


## Key challenges faced in delivery of RA care

- There is an **uneven distribution of rheumatologists** throughout the Czech Republic, with there being fewer in more rural areas. This makes access to care more difficult and adds to the caseload of the centre, which serves as a reference centre for the country
- The **current reimbursement system** in the Czech Republic doesn't take into account the case-mix seen at the centre. This has led to a national funding deficit, making service delivery and provision of high-quality care challenging across specialised centres
- There is a **lack of disease awareness** and enforcement of referral protocols amongst PCPs

Sources: (a) KPMG interviews with HCPs treating RA and associated comorbidities

# RA Czech healthcare system overview



## RA challenges in the Czech healthcare system<sup>(a)</sup>

- Variation in the allocation of resources and consumption of health services in different regions. This has been counteracted by user fees for doctor consultations, hospital stays and use of ambulatory services outside regular office hours and prescription drugs
- Underdevelopment of use of information and communications technology and lack of process for using health technology assessment of treatment and procedures

## Czech healthcare system overview:



### The health service:

- Hospitals are mainly publicly owned with different legal forms. Pharmacies and diagnostic laboratories as well as almost 90% of outpatient facilities are private. Some outpatient specialists are employed by hospitals to provide ambulatory care in polyclinics. Emergency care services are publicly owned

### Funding:

- The Czech Republic has a system of statutory health insurance (SHI) based on compulsory membership of a health insurance fund, of which there were seven in 2014. The funds are quasi-public, self-governing bodies that act as payers and purchasers of care
- This core health legislation of the Czech Republic was adopted in the 1990s and has changed only marginally since then
- SHI is based on universal coverage and is a basic universal benefit package provided as benefits-in-kind (paid by third party) for all insured individuals
- It is financed through mandatory, wage-based SHI contributions administered by the health insurance funds (74%). Other sources are general taxation and out-of-pocket payments. Membership of one of the seven health insurance firms is compulsory. These are quasi-public self-governing bodies that act as payers and purchasers of healthcare<sup>(a)</sup>

## Rheumatoid Arthritis in the Czech Republic:



### Patients:

- Prevalence: 610 out of every 100,000 adults<sup>(b)</sup>
- Up to 2.5 times more prevalent in women than men

### Physicians:

- 350 rheumatologists in Czech Republic<sup>(c)</sup> and 25 biologic therapy centres
- Most rheumatologists are internists
- Rheumatologists work in 2 settings: hospital-based; private practice

### Guidelines:

#### RA:

- Recommendations for treatment of RA; include recommendation for treatment with DMARD & biologicals- working on new guidelines<sup>(d)</sup>
- Recommendations for safety aspects with the use of DMARDs, non-steroidals and around operation<sup>(d)</sup>
- EULAR/ACR<sup>(e)</sup>
- Czech Rheumatological Society<sup>(f)</sup>

#### Comorbidities:

- Not available

#### PAGs / Medical societies:

- Czech Rheumatological Society<sup>(f)</sup>
- Revma Liga<sup>(g)</sup>

**Sources:** (a) Rečka et al. (2015) Czech Republic: Health system review. *Health Systems in Transition*, 2015 17(1):1–165.x; (b) The Work Foundation, 'Fit For Work? Musculoskeletal Disorders and the Czech Labour Market'. Available at: [www.ihta.org/ext/files/47/Fit-for-Work-Czech-Republic-Final-Feb-2014.pdf](http://www.ihta.org/ext/files/47/Fit-for-Work-Czech-Republic-Final-Feb-2014.pdf) (c) Szekanecz et al. *Arthritis Research & Therapy* (2017) 19:196; (d) Lopez-Olivo et al. (2008). *Quality appraisal of clinical practice guidelines and consensus statements on the use of biologic agents in rheumatoid arthritis: A systematic review. Arthritis and Rheumatism*, 59(11), 1625-38. (e) Smolen et al. (2017) EULAR recommendations for the management of rheumatoid arthritis with synthetic and biological disease-modifying antirheumatic drugs: 2016 update; (f) <http://www.prolekare.cz/en/czech-rheumatology-article/2017-recommendations-of-the-czech-society-for-rheumatology-for-the-pharmacological-treatment-of-rheumatoid-arthritis-61252> (g) [www.revma.org](http://www.revma.org)

# The Rheumatology unit

The Hospital			
<b>Type</b>	<ul style="list-style-type: none"> <li>– Specialist rheumatology centre, serving as the rheumatology reference centre for the whole of the Czech Republic</li> <li>– Major academic centre, affiliated to Charles University</li> </ul>	<b>Locations</b>	Prague
<b>Core services</b>	Clinical centre, inpatient department, osteocentre, experimental rheumatology, department of clinical biochemistry and haematology, clinical immunology and flow cytometry, therapeutic rehabilitation <sup>(b)</sup>	<b>Population served</b>	Patients from all over the Czech Republic are recruited to the inpatient department on the basis of referrals from outpatient specialist doctors or specialist workplaces of other hospitals <sup>(b)</sup>
<b>Size</b>	The inpatient department has a total of 50 beds and is divided into two stations	<b>Demographics</b>	Open to all ten million Czech Republic inhabitants
The Rheumatology unit			
<b>Services</b>	<p>The centre offers a comprehensive range of treatments and interventions, including rehabilitation therapy, following acute symptoms <sup>(b)</sup></p> <p>The centre has coverage from comorbidity specialists and access to facilities in the main hospital campus in close proximity that support the diagnosis and management of comorbidities <sup>(b)</sup></p>	<b>Collaborations</b>	<ul style="list-style-type: none"> <li>– Charles University Faculty of Medicine</li> <li>– Revma Liga (patient advocacy group)</li> </ul>
<b>Funding and Resources</b>	Funding is provided by the Czech Health Authority	<b>Teaching/ research scope</b>	Research Focus: <ul style="list-style-type: none"> <li>– Molecular and cellular aspects of joint apparatus damage in RA and OA</li> <li>– Focus on the use of new biomarkers and their use in clinical practice <sup>(b)</sup></li> </ul>

Sources: (a) KPMG interviews with HCPs treating RA and associated comorbidities; (b) <http://www.revma.cz>

# The Rheumatology unit (cont.)

Overview of Services 			
Service Division	Outpatient service	Ambulatory care service	Inpatient service
Duration of stay	3 – 4 hours	3 – 4 hours	> 1 day
Hours of availability	08:00 – 17:00		24/7
Capacity (no. of beds/rooms)	6	8 rooms dedicated to the delivery of biologic infusions	50 beds
No. of patients seen	4,000 patients seen across the centre per year		
Patient type catered to	<ul style="list-style-type: none"> <li>– Patients in all stages of disease</li> <li>– Some “pre-RA” patients</li> <li>– Patients with ‘clinically suspect arthralgia’</li> </ul>	<ul style="list-style-type: none"> <li>– Patients receiving biologic therapy</li> </ul>	<ul style="list-style-type: none"> <li>– Patients with moderate-to-severe disease, refractory to treatment</li> </ul>
Services offered	<ul style="list-style-type: none"> <li>– ‘Triage’ service</li> <li>– Early arthritis clinics</li> <li>– Clinical examination including DAS 28</li> <li>– Blood tests</li> <li>– Imaging diagnostics including x-ray and ultrasonography</li> <li>– Pharmacological and non-pharmacological treatment</li> <li>– Comorbidity screening and monitoring</li> <li>– Physiotherapy and occupational therapy services;</li> <li>– Intensive rehabilitation programmes;</li> </ul>	<ul style="list-style-type: none"> <li>– Blood tests</li> <li>– Infusion therapies</li> </ul>	<ul style="list-style-type: none"> <li>– Clinical examination including DAS 28</li> <li>– Blood tests</li> <li>– Imaging diagnostics including x-ray and ultrasonography</li> <li>– Pharmacological and non-pharmacological treatment; Comorbidity specialist in-reach</li> <li>– Physiotherapy as prescribed</li> <li>– Occupational therapy services</li> </ul>

Sources: (a) KPMG interviews with HCPs treating RA and associated comorbidities

# The team

## Core team profiles

- 30 rheumatologists
- 15 rheumatology nurses
- 30 rheumatology researchers
- 3 pharmacists
- 1 service coordinator
- 20 physiotherapists
- 1 dieticians
- 1 occupational therapists

## Affiliate team profiles

- 1 cardiologist
- 1 orthopaedist
- 1 neurologist

Dedicated cardiologist, neurologist and orthopaedic surgeon who perform weekly inpatient 'review rounds'



## Key features of the care delivery team

- **Highly specialised team members**
  - Specialised rheumatology physiotherapists
  - Rheumatologists who are all educated to a high level i.e. PhD
  - Specialised rheumatology nurses
  - Occupational therapists
- **Personable with regards to patient care and access to patient advice**
  - Patients can call physicians if they have any concerns regarding their care
  - Patients can also self-refer

## Governance and processes

### Team meetings:

- Ad hoc MDT meetings with cardiologist, pulmonologist and ophthalmologist when required
- Weekly meetings with physiotherapist/ kinaesthesiologist team

### Protocols:

- No local guidelines used
- Internal measures for evaluating patients are input into the database

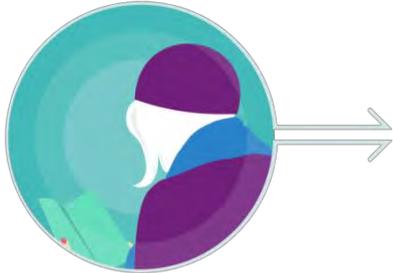
### Patient records:

- Database for Rheumatology department which includes measurement of comorbidities

# Overview of interventions in place for RA

## Awareness & Prevention

Symptom identification



## Referral & Diagnosis

In secondary care



## Treatment & Management

Pharmacological management

Non-pharmacological management



## Follow-up

Monitoring of chronic disease/flare up



Interventions

### Increasing awareness of RA among PCPs

- Hospital rheumatologists host seminars 8-10 times a year to provide professional education to PCPs
- The centre developed referral guidelines 10 years ago which have been disseminated to PCPs all over the country

### Good links with faculty and research

- The centre is linked to Charles University's Faculty of Medicine
- There are ~60 research programmes ongoing
- Being part of a research and teaching institution can be beneficial to the quality of care delivered
- One of the rheumatologists at the centre is the President of the Czech Society of Rheumatology

### Rapid access to care

- Triage by a dedicated rheumatologist to assign patients to appropriate clinic
- Early arthritis clinic with an emphasis on access to investigations leading to an early diagnosis
- Clinically suspect arthralgia clinic for referrals that are not diagnosed as RA but need further exploration for other rheumatological conditions

### Rapid access to diagnostics

- Blood tests
- X-rays
- Ultrasound
- Bone Mineral Density measurements

### Timely initiation of treatment

- 4-week target for referral to initiation of treatment (via the early arthritis clinic pathway)

### Personalised HCP-patient relationships

- Patients are able to contact HCPs, particularly rheumatologists via phone or e-mail to ask advice or discuss any concerns regarding their treatment

### Weekly MDT to discuss inpatient cases

- MDT held on inpatient ward with rheumatologists, rheumatology nurses and heads of therapy - occupational therapy (OT) and physiotherapy

### Research study focused on preventive treatment

- The centre is currently conducting a research programme focused on exploring the benefit of preventive treatment in patients with suspected RA (are anti-CCP antibody (ACCPA) positive but without symptoms)

### Specialist therapy services

- Specialised RA physiotherapist dedicated to providing RA-specific physical therapy
- Week-long intensive rehabilitation sessions are available to patients
- Weekly occupational therapy sessions are available to chronic patients. In these sessions, patients are encouraged to produce art and pottery as a means to improve dexterity, relieving pain, improving range of movement and muscle strength

### Patient education

- Patient education is delivered by all HCPs in all settings; from rheumatology consultations to physiotherapy sessions
- Leaflets, websites and verbal educational support provided

### Good relationships with Patient Advocacy Groups (PAGs) and clinical societies

- Revma Liga, the largest PAG for patients with RA, was founded by patients treated at the centre
- The team collaborate with the PAG on research, education and patient activity interventions

### Structured follow-up

- From first presentation, patients with confirmed RA are followed up at 1, 3, 6, 9 and 12 months respectively and then either every 3 or 6 months, depending on disease activity

### Comprehensive outpatient assessment

- Same day blood test results
- Measures of disease activity; DAS 28
- Comorbidities
- Side effects of medication
- Physiotherapy session

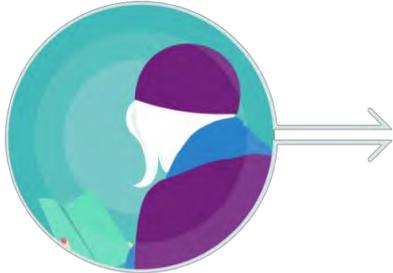
### Standardised nationwide patient registry

- ATTRA Biologics registry capturing the following data:
  - Diagnosis
  - Biologic treatment, including adverse effects
  - Baseline comorbidity history
  - Measures of disease activity; DAS 28
  - Psychosocial measures; HAQ, SF36

# Overview of interventions in place for RA comorbidities

## Awareness & Prevention

Symptom identification



### Screening for comorbidities

- Baseline comorbidity data, including risk factors are captured at initial assessment

### Education on osteoporosis risk

- Patients screened for osteoporosis are given information on their risk of developing the condition in addition to their bone mineral density (BMD) score

## Referral & Diagnosis

In secondary care



### Referral letter to PCP / Specialty physician

- If a comorbidity is diagnosed, the patient is referred back to their PCP or to the relevant specialty via the patient report generated from their visit

### Dedicated department for osteoporosis detection

- The osteocentre conducts Bone Mineral Density (BMD) and other tests to assess rate of bone loss / formation, and other key indicators in osteoporosis.

## Treatment & Management

### Pharmacological management



### Treatment advice

- E.g. rheumatologists will sometimes advise at-risk patients to get vaccinated by the PCP or at a vaccination centre

### Access to novel comorbidity treatments

- The osteocentre offers bone anabolic therapy for osteoporosis

### Weekly in-reach review from other specialties

- Comorbidity care is integrated into inpatient care through weekly comorbidity ward rounds for cardiology, orthopaedics and neurology

### PCP as central point of care

- If comorbidities are detected, a referral is made back to the PCP to either manage or refer onwards to the relevant specialty physician

### Non-pharmacological management



### Psychosomatic support

- Physiotherapist often explores psychosomatic issues with patients and addresses psychiatric issues e.g. depression

### Occupational therapy (ergotherapy)

- Occupational therapy sessions are provided where patients have the opportunity to create objects as a way to improve function, especially in the hands. This service anecdotally has some beneficial psychological effects for patients

## Follow-up

Monitoring of chronic disease/flare up



### Comprehensive outpatient assessment

- Comorbidity monitoring
- Same day blood test results
- Side effects of medication

### Standardised nationwide patient registry

- The ATTRA Biologics registry also captures comorbidity data which can be tracked and monitored

Sources: (a) KPMG interviews with HCPs treating RA and associated comorbidities

# These interventions have improved outcomes



## How do you quantify the benefits in RA care?

### Objective measures (KPIs)

Percentage of patients referred early who go on to be diagnosed with RA (following the introduction of the early arthritis clinic ~40% of those who are referred early are found to have confirmed RA, as opposed to less than 20% before the clinic was established)

Waiting times from referral to treatment (almost all patients with RA are treated within the target time of 4 weeks)

### PROMs:

(Captured in ATTRA registry) EQ5D, HAQ

Centre routinely measures comorbidity outcomes by:

### Objective measures:

- Prevalence of comorbidities among patients with RA



## How have these interventions improved patient outcomes?

### RA

Benefit: Early diagnosis and treatment leading to delayed disease progression and

Quantitative output: Time from referral to diagnosis  $\leq$  4 weeks

### Comorbidities

Benefit: Regular inpatient review of comorbidities

Quantitative output: Reduced rate of complications from comorbidities

**“Every one of us taking care of patients with RA must have a basic interest in comorbidities.**

**You can’t serve as a general physician without an interest”**

- Rheumatologist

Sources: (a) KPMG interviews with HCPs treating RA and associated comorbidities

# How can care be improved?



## What is next for the centre?

**Overview:** *Collaboration on e-health project based in Copenhagen*

### — Why?

- To enable self-monitoring of disease activity as a way to overcome the barrier of self-presentation, reduce the frequency of required visits and enable quicker detection of flares.

### — How?

- The plan is to integrate point-of-care devices (i.e. devices used for testing and measurement) at home with labs to enable patient self-measurement of liver enzymes, CRP and leukocytes. There are currently tech firms on board to develop three such devices. A pilot with the device for testing CRP will launch in October
- In the case of an abnormal result, a message would be sent to a study rheumatology nurse together with the patient's joint self-assessment result

**Overview:** *DRG "restart"*

### — Why?

- Since 2007, hospitals have been paid for inpatient care using a combination of a diagnosis-related group (DRG) system (with limited success and penetration), individual contracts and global budgets. The centre is currently funded by global budgets. As a by-product of this, there is currently no performance comparison measure between hospitals
- The Institute of Rheumatology is the national reference centre for Rheumatology and famously sees the most complex cases, some refractory to conventional treatments. Due to the current funding mechanism, the centre is not reimbursed in a manner that reflects the nature of the care provided to its patients. Instances such as this have led to a national healthcare budget deficit ~30 billion CZK <sup>(a)</sup>
- Reimbursement according to diagnosis-related group (DRG) is designed to allot payment according to case-mix. The most frequent reasons for introducing DRG-based payments are to increase efficiency and contain costs. This change to the reimbursement methodology at the centre would result in more funding for service provision to complex cases, and therefore better RA care <sup>(c)</sup>

### — How?

- According to the WHO, piloting the system, particularly through selected hospitals and in combination with shadow billing and/or selected DRG groups, is advisable <sup>(c)</sup>

## What advice would you give less specialised centres?

**Overview of advice:** Consider collaboration between Rheumatologists, Gynecologists and Nutritionists

### Why?

- RA is more likely to affect pre-menopausal women than any other demographic group. There is also increased risk of developing the condition after menopause. Given this, rheumatologists at the centre believe that there is insufficient collaboration between gynaecologists and rheumatologists to meet the needs of this patient group <sup>(a)</sup>
- RA research has explored links between gut microbiota and the risk of developing RA <sup>(d)</sup>. Based on the outcomes of such research, this interdisciplinary collaboration may be necessary

### How?

- MDT collaboration through meetings, ward rounds and communication such as that which exists for cardiology, neurology and orthopaedics would be an effective way of partnering with these specialists



**Sources:** (a) KPMG interviews with HCPs treating RA and associated comorbidities (b) Rečka et al. (2015) Czech Republic: Health system review. *Health Systems in Transition*, 2015 17(1):1–165 (c) Hospital payment systems based on diagnosis-related groups: experiences in low- and middle-income countries. Inke Mathauer & Friedrich Wittenbecher. *Bulletin of the World Health Organization* 2013;91:746-756A (d) Expansion of intestinal *Prevotella copri* correlates with enhanced susceptibility to arthritis. *Elife*. 2013 Nov 5;2(0). pii: e01202. doi: 10.7554/eLife.01202. PMID: 24192039.

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# Case study 1

## Anti-TNF therapies in RA (ATTRA) Patient registry

### Overview

- The ATTRA project is a collection of national clinical registries of all patients in the Czech Republic on biologic therapies for the following indications
  - Rheumatoid arthritis (RA)
  - Ankylosing spondylitis (AS)
  - Psoriatic arthritis (PSA)
  - Juvenile idiopathic arthritis (JIA)
  - Systemic lupus erythematosus (SLE)
- The registries have been maintained since 2002 when there were initially 6 participating centres of biologic therapy; now there are 40 participating centres

**Note:** 1. Using the MedDRA (Medical Dictionary for Regulatory Activities) terminology makes it possible to use data from the ATTRA registry in common analyses of European registries  
**Sources:** (a) <http://attra.registry.cz/index-en.php>

### What is the rationale?

- To monitor the progress and results of biological therapy applied to inflammatory rheumatic diseases <sup>(a)</sup>
- To place emphasis on long-term follow-up of patients (even after the termination of biological therapy) as well as on the possibility to compare the results of biological therapy with a control group <sup>(a)</sup>

### What are the key features?

- Data is captured at the first appointment, and then at 3, 6, 12, 18 and 24 months from this first instance. Thereafter, data is captured annually
- The 40 centres of biologic therapy have access to the database on a secured network

### The following data is captured:

- Questionnaire calculations: SF36
- Demographic data
- Baseline comorbidity data
- Previous medical history
- Diagnosis
- Treatment; past, current and newly started therapies, including any adverse events [classified using the MedDRA (Medical Dictionary for Regulatory Activities) terminology] <sup>1</sup>
- Swollen joints
- Disease activity score: DAS 28

### What are the key features? (cont.)



### Information website for HCPs and patients

- <http://attra.registry.cz> provides information to HCPs and the public on the background of the registry as well as education on the different diagnoses captured



Snapshot of diagnosis information page

### Secure data entry website for HCPs

- [https://trials.cba.muni.cz/trialdb2/interface\\_form\\_s/login\\_attra.asp](https://trials.cba.muni.cz/trialdb2/interface_form_s/login_attra.asp)



Snapshot of registry entry button

### What are the outcomes so far?

- Data captured has been used in over 120 national clinical research trials
- Outcomes data for biologics is requested at regular intervals by the national health authority in order to support ongoing funding for biologics

## Anti-TNF therapies in RA (ATTRA) Patient registry (cont.)

### Benefits



#### Benefits to the patients:

- Personalised care: patient demographics (including locality) are captured in order for care to be organised so that they don't have to travel more than 40 – 50 km from their home address

#### Benefits to the rheumatology team:

- Data captured feeds into various research projects which aim to inform future care practices.

“Continuous data assessment and feedback are provided to physicians and health care management, meeting the requirements of evidence-based medicine” <sup>(b)</sup>

- Systematic data capture allows the centre to interrogate their own data to see whether they are being consistent in the way they treat patients. This allows them to evaluate whether any deviations from protocols and norms were justified

### Challenges



#### Barriers to prescription

- Biologics can only be prescribed in the registered centres of biologic therapy

#### Adoption of technology

- There is opposition to the regular use of technology by some rheumatologists which has an effect on the quality and completeness of data captured



Capturing data on this scale is extremely useful in informing future care practices



– Rheumatologist



Sources: (a) KPMG interviews with HCPs treating RA and associated comorbidities (b) <http://attra.registry.cz/index-en.php>

# Case study 2

## Rapid access clinics

### Overview

#### Early arthritis clinic

- The centre operates an early arthritis clinic once weekly to review all patients referred with first-time presentation of symptoms

#### Clinically suspect arthralgia clinic

- There is also a concurrent 'clinically suspect arthralgia' (CSA) clinic for undifferentiated arthralgia

#### Seronegative arthralgia clinic

- Patients who are seronegative are monitored for potential development of RA and are sometimes given treatment as a prophylactic measure

Sources: (a) KPMG interviews with HCPs treating RA and associated comorbidities

### What is the rationale?

- To address the challenge faced by the healthcare system around lengthy waiting times for outpatient appointments
- To review all patients who are referred to the centre and ensure timely diagnosis and treatment initiation

### What are the key features?

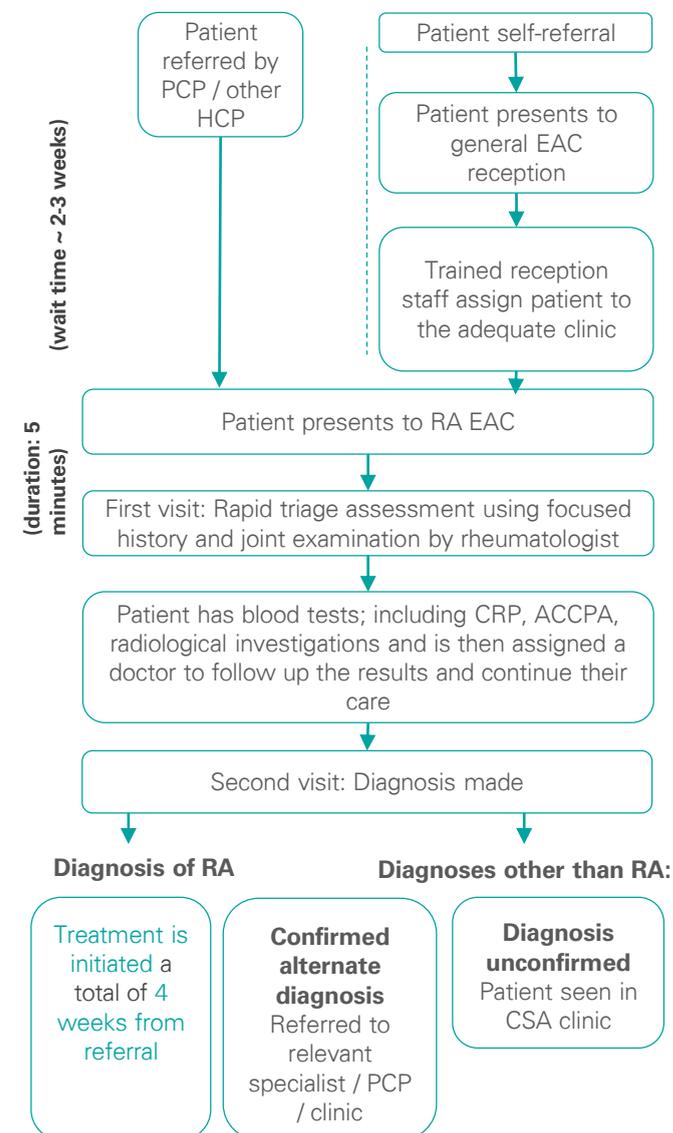
<b>Frequency</b>	All clinics occur once a week
<b>Timings</b>	Early arthritis clinic: monthly Clinical suspect arthralgia: every three months Seronegative: every 3-6 months
<b>Patient demographic catered to</b>	Patients with arthralgia; Patients referred by PCPs, orthopaedists, neurologists; Self-referred patients
<b>Staff members involved</b>	
<b>Members of the core MDT</b>	Rheumatologist
<b>Others</b>	Trained receptionists for initial 'mini-triage'

### Which guidelines are used?

- Referral guidelines for PCPs, written by rheumatologists at the centre

### What are the key features? (cont.)

#### Early arthritis clinic (EAC) patient pathway



Continued overleaf

## Rapid access clinics (cont.)

### What are the key features? (cont.)



### What are the outcomes so far?



Prior to introducing physician-led triage, only 10-20% of early referrals went on to be diagnosed with RA. Following this intervention, ~40% of those who are referred early are found to have RA

### Benefits



#### Benefits to patients

All patients who present to the clinics are seen but those with higher risk of RA are assessed earlier by an experienced rheumatologist leading to earlier diagnosis and treatment

Improve the accessibility and quality of care provided to patients

#### Benefits to the Rheumatology team

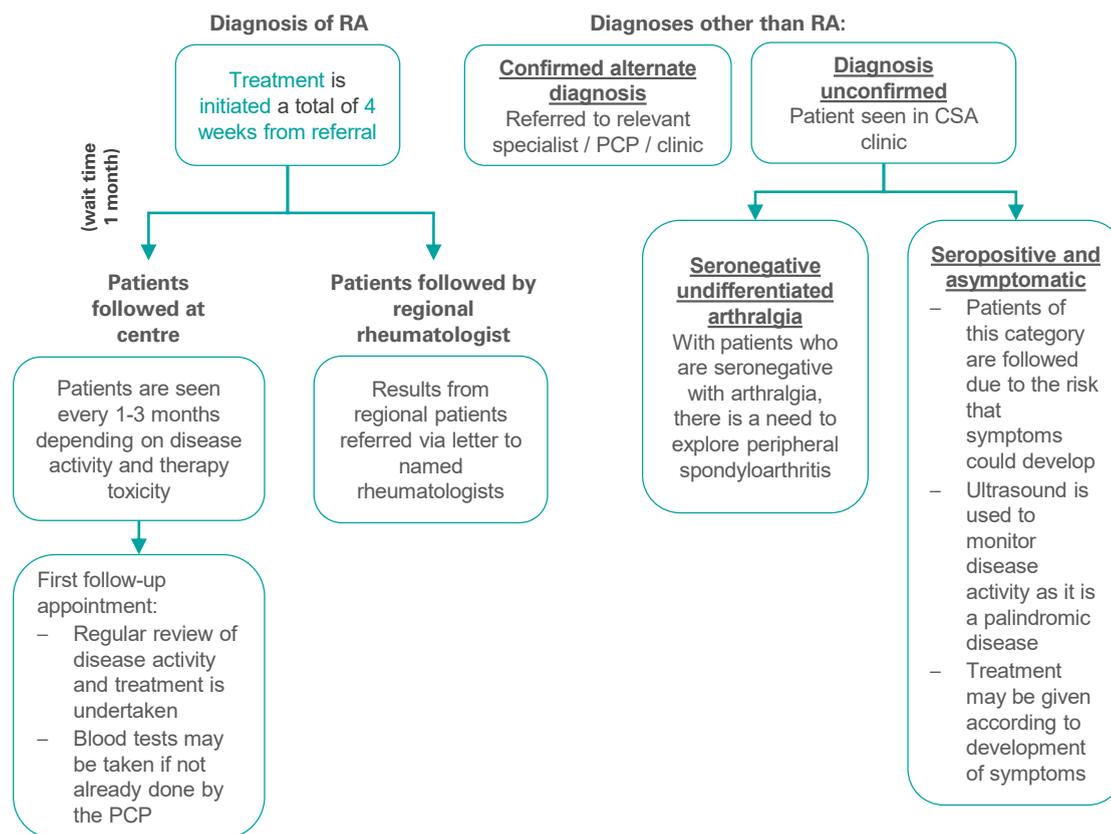
Effective early streamlining of patients according to diagnosis

Early triage combats the problem of inappropriate referrals; e.g. the triage

The rheumatologist is able to differentiate between RA and aggravated osteoarthritis

Rapid assessment relieves the burden of high workload

### Patient pathway (cont.)



Sources: (a) KPMG interviews with HCPs treating RA and associated comorbidities

## Rapid access clinics (cont.)

### Challenges



#### Inappropriate referrals

Referrals are reliant on the knowledge of the physician making them i.e. mostly the PCP

Although the prevalence of RA is 1%, incidence is around 1-3 cases per year per individual PCP, therefore they have limited exposure to cases

#### Capacity

The centre operates on the national policy that no patient is denied care, therefore all patients are seen in the clinic, including those who self-refer. This poses time and capacity constraints on the team and adds to waiting times

As a result of this, there is a natural attrition of patients who don't turn up to first appointment because the waiting time is too long

#### Shared care with community physicians

- There is a lack of direct contact with PCPs and some PCPs are inexperienced with ongoing RA care. As such, interim care (e.g. taking blood tests prior to outpatient appointments) is sometimes missed
- This will only come to light at the first follow-up appointment and means some rheumatologists still have to do blood tests at appointments.
- This is time consuming for both the HCP and patient

Sources: (a) KPMG interviews with HCPs treating RA and associated comorbidities

### Tips to replicate this intervention



- It is important to discuss and establish clear criteria for access to early referral clinics. This is to ensure that medical secretaries know which patients are eligible to be seen in the clinic
- There needs to be dedicated time set aside for an experienced rheumatologist to triage patients.
- Emphasis must be laid upon very short consultations in order to maximise use of time
- Consider drafting in other HCPs to assist with the work-up to ensure the specialist is able to focus on joint assessment and taking a targeted history



If I could change one thing it would be to have more care available for the number of patients  
- Rheumatology nurse



It is obvious that early treatment improves outcomes  
- Rheumatologist



# Case study 3

## Role of the Physiotherapist

### Overview

- The Institute of Rheumatology have physiotherapists specialised in delivering RA-specific therapy
- They provide RA-specific physical therapy as prescribed by the rheumatologists, as well as providing education to patients on exercise and mobility

### What is the rationale?

- To provide expert physical therapy to patients with RA, tailored according to their needs and disease activity

### What are the key features?

#### Role

- Assess and evaluate patient mobility
- Devise mobility management plans
- Resource mobility aids to patients
- Provide patient education
- Research



*Snapshot of physiotherapy consultation room*

#### Care delivery setting

- Inpatient and outpatient

#### Timings/ Duration

- Frequency and content of therapy prescribed by Rheumatologist
- Inpatient: seen on day 2 of stay for ~ 1 hour
- Outpatient: seen following rheumatologist consultation for ~ 45 minutes. They are given a management plan to go home with for the 3 – 6 months until their next visit

#### Patient group catered to

- Patients with complex mobility requirements (inpatient setting)
- Ambulatory patients (outpatient setting)

- Patients are referred for the following problems:
  - Limitations in mobility and ability to carry out activities of daily living (ADLs)
  - Limited range of motor movement of joints, especially small joints
  - Pain and swelling

### What are the activities undertaken?

#### Services offered:

- Soft techniques
- Laser / electro- therapy
- Supply of mobility aids
- Patient education



*Snapshots of large gymnasium*



*Snapshots of smaller gymnasium (location of group workouts)*

Sources: (a) KPMG interviews with HCPs treating RA and associated comorbidities

## Role of the Physiotherapist (cont.)

### What are the activities undertaken? (cont.)



#### Collaboration:

Collaboration with physiotherapy colleagues

- Physiotherapists call one another ad hoc to discuss patient progress
- The head of physiotherapy communicates the weekly MDT outcomes to the rest of the team

Collaboration with occupational therapy colleagues

- Patients with OT needs are identified by the physiotherapist and can then be referred to the rheumatologist for prescription of OT, following discussion with the patient to obtain their consent

Collaboration with rheumatology colleagues

- Weekly call with the rheumatologist to discuss particular patients and their treatments

Collaboration with PAGs

- Revma Liga has a once-weekly group exercise session for patients which the physiotherapist can recommend patients attend

### What are the outcomes so far?



- Patients are identified for and can benefit from additional occupational therapy care



*Centre display of creative designs made by patients which are sold at an annual auction*

### Benefits



#### Benefits to patients

- Patients report that the effects of receiving specialised physiotherapy are better compared to receiving generalised care from community physiotherapists
- Group therapy sessions provide them with a sense of community

#### Benefits to the Rheumatology team

- The specialised physiotherapists have awareness of painful joints and how increased disease activity, especially flares, may impact mobility



It is very rare to be specialised in rheumatology as a physiotherapist, but the benefit is that we know the specifics

- Physiotherapist



Sources: (a) KPMG interviews with HCPs treating RA and associated comorbidities



# Role of the Physiotherapist (cont.)

## Challenges



### Timely referral to the physiotherapist

- Sometimes some patients are referred at the point where they have already experienced deformities and this makes it harder to provide mobility assistance

### Difficulty ensuring patient engagement

- At present, there is no effective way to monitor if patients are complying with their management plans in between outpatient visits
- There is difficulty with providing regular care to patients from far-flung regions

### Time constraints

- Physiotherapists would like to be able to work every day with patients and provide good care, however they find that they have limited time to do so

Sources: (a) KPMG interviews with HCPs treating RA and associated comorbidities

## Tips to replicate this intervention



- Be strict in the personalisation of care
- Provide specialist training to physiotherapists
- Encourage patients to be more proactive
- Have regular feedback within a multidisciplinary team setting

“ To be a good physiotherapist or HCP in any role, you need to motivate people

- Physiotherapist



# Case study 4

## Collaboration with PAG – Revma Liga (Czech League against Rheumatism)

### Overview

- The Czech League against Rheumatism is a non-profit organisation which represents people with rheumatologic diseases. It is the largest rheumatism PAG in the Czech Republic
- The organisation was founded by patients treated at the Institute of Rheumatology
- Patients are actively encouraged to join the group by the rheumatologists at the centre

Sources: (a) <http://www.revmaliga.cz/>



### What is the rationale?



#### Patient-focused objectives:

- Providing a support network of 'experienced' patients

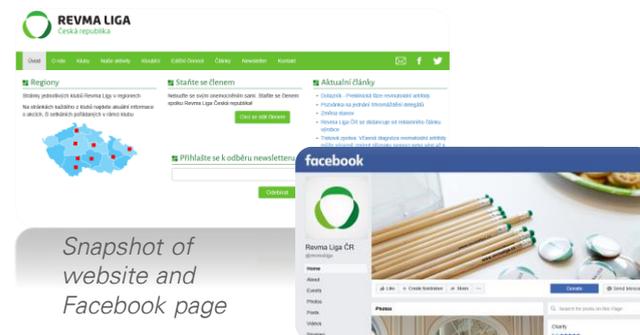
#### Revma Liga objectives:

- For the past 25 years the main goal of the organisation has been to increase awareness for rheumatism

### What are the key features?



- The organisation was founded ~25 years ago by patients from the Prague Institute
- They operate with the following aims:
  - Raising awareness of rheumatic diseases
  - Fighting for a full and equal life of disabled people
  - Creating regional RL clubs within the Czech Republic
  - Cooperating with international organisations of the same focus
- Patients can access the PAG through the following channels:
  - Peer recommendation
  - HCP recommendation
  - Online (e-mail website, Facebook, Twitter)



Snapshot of website and Facebook page

### What are the key features? (cont.)



#### Services offered:

- Weekly patient activity groups
- National 'Rheumatism challenges'
- Rehabilitation stays

The centre collaborates with Revma Liga on some of the above projects such as the "Let's run to:" intervention; which promotes competitive physical activity amongst patients



Snapshot of an advert for a sporting challenge

## Collaboration with PAG – Revma Liga (Czech League against Rheumatism) (cont.)

### What are the outcomes so far?



- Increased patient engagement with other patients
- Uptake of local PAG group activities and sessions

### Benefits



#### Benefits to the patients:

- Patients are able to engage with other patients and gain a sense of community
- There is localised regional support available nationally
- The PAG encourages patients to have a proactive attitude towards self-management versus medicalised management

#### Benefits to the rheumatology team:

- Able to 'outsource' support for patients by referring them to the PAG and encouraging participation in activities

### Challenges



#### Patient engagement

- Accessibility of activities to patients (i.e. ensuring activities are on offer in multiple localities)



Adding the element of competition to physical activity is a really good way to get patients moving and keep them moving

– Rheumatologist



Sources: (a) KPMG interviews with HCPs treating RA and associated comorbidities

# Case study 5

## Dedicated comorbidity care services

### Overview

- The centre has links to dedicated comorbidity specialists in Cardiology and Neurology
- They conduct weekly 'in-reach' ward rounds for rheumatology inpatients with comorbidities
- In addition to this 'in-reach' service, there is an on-site Osteocentre which specialises in osteoporosis detection and management

**Notes:** 1. Conventional disease-modifying anti-rheumatic drugs  
**Sources:** (a) KPMG interviews with HCPs treating RA and associated comorbidities



### What is the rationale?

- To ensure patients receive a comprehensive comorbidity review during their inpatient stay
- To alleviate the burden of comorbidity care on the rheumatology team

### What are the key features?

#### Comorbidity 'in-reach' service

<b>Care delivery setting</b>	Inpatient
<b>Services offered</b>	— Comprehensive comorbidity assessment
<b>Timings/Duration</b>	— Once weekly
<b>Staff members involved</b>	— Cardiologist — Neurologist — Orthopaedist
<b>Patient group catered to</b>	— Patients with RA with moderate – severe disease activity, requiring inpatient hospitalisation, with additional comorbidities

#### Osteocentre

<b>Care delivery setting</b>	Inpatient and outpatient
<b>Services</b>	— BMD baseline measure taken at triage appointment — Bone loss prevention and bone anabolic therapy
<b>Timings/Duration</b>	— Patients assessed once every six months
<b>Patient group catered to</b>	— Pre-menopausal and post-menopausal women — All patients on cDMARDs <sup>1</sup> and glucocorticoid therapy

### What are the outcomes so far?

#### Comorbidity 'in-reach' service

- Routine review of patients by comorbidity specialists results in early detection and prevention as well as access to timely and accurate treatment of RA associated comorbidities

#### Osteocentre

- Improvements in patient-reported back pain have been seen 3-6 months following initiation on bone anabolic therapy

## Dedicated comorbidity care services (cont.)

### Benefits



#### Comorbidity 'in-reach' service

##### Benefit to patients

- Patients have rapid and regular access to comorbidity care during their inpatient stay, meaning better management of comorbidities

##### Benefits to the Rheumatology team

- The team can focus on providing rheumatology care with their dedicated time and resources
- They benefit from the added expertise of comorbidity specialists, allowing holistic care to be provided to inpatients

#### Osteocentre

##### Benefits to patients

- Those found to have accelerated bone loss on cDMARDs and are switched to biologics have a reduced mortality risk
- Bone anabolic therapy is one of the few effective treatments of glucocorticoid-induced osteoporosis and is available at the centre

##### Benefits to the Rheumatology team

- Treatment decisions can be assisted by BMD measurements which can be tracked and monitored

Sources: (a) KPMG interviews with HCPs treating RA and associated comorbidities

### Challenges



#### Comorbidity 'in-reach' service

##### Frequency of review

- Inpatients are reviewed once weekly by comorbidity specialists, meaning that any additional reviews or advice must be sought via ad hoc telephone communication

#### Osteocentre

##### Treatment compliance

- Difficult to convince patients to start treatment on top of their existing RA medication

##### Limited treatment duration and efficacy

- Bone anabolic therapy can only be given for 2 years and is only beneficial to patients engaged in exercise
- Benefits of treatment are limited by the success of treating underlying RA

### Tips to replicate this intervention



#### Comorbidity 'in-reach service'

- Interdisciplinary collaboration is necessary outside of the dedicated review times to ensure continued delivery of high-quality care e.g. addressing the insufficient collaboration between gynaecologists and rheumatologists

#### Osteocentre

- This intervention must run in conjunction with physiotherapy as this is essential to maintain bone health
- Ongoing research is vital to investigate other causes of bone loss in RA



Not many doctors provide patients with their osteoporosis risk score or their risk of contracting other comorbidities with RA

- Rheumatologist



Physical therapy is the most important form of prevention of osteoporosis progression

- Rheumatologist





# Rigshospitalet Hospital

Copenhagen, Denmark



CONTENTS



APPENDIX  
CENTRE REPORTS

# Summary



## Context

- **Leading rheumatology hospital in Denmark** situated at the Glostrup location of the Rigshospitalet (The National Hospital)
- **Strong focus on research** and evidence-based practice being integrated into their care, with the majority of attending physicians and other health professionals involved in research (EULAR Centre of Excellence)
- **Well-organised department** means that rheumatologists can use their time flexibly and efficiently according to patient needs
- **Personalised patient care** is fundamental to their approach focusing on clinical risk factors, disease progression and tailored to individual patient needs
- **Strong relationship with the Danish Rheumatism Association**, a patient advocacy group (PAG) with whom they partner on a number of initiatives to raise awareness and educate the wider population and patients about RA



## Key strengths in the delivery of RA care

- **Early arthritis clinic** is a dedicated area for newly referred patients to attend for a full and timely diagnostic assessment
- **Systematic assessment and data collection** using an online national registry platform to register patients and record history, patient-reported outcomes, clinical examination, investigation results, and treatment history
- **Sleep outpatient clinic** providing non-pharmacological therapies for patients with RA suffering from sleep disturbance
- **Provision of holistic care** including access to a wide range of healthcare professionals (HCPs), patient educational materials and support with lifestyle factors



## Key challenges faced in delivery of RA care

- **High system demand** and resource requirements, as Danish law requires patients to be diagnosed within 30 days of their initial referral
- **Need for flexible access to care** as clinic opening hours may not meet the needs of all patients, especially those in the labour market
- **Patients may be overloaded** with information due to a short time from referral to diagnosis; information overload includes information about their diagnosis, the disease and their proposed treatment

Sources: (a) KPMG interviews with HCPs treating RA and associated comorbidities

# RA Danish healthcare system overview



## Danish healthcare system overview:



**Public health service:** The government provides universal healthcare access and is responsible for regulation, supervision, planning and quality monitoring, while service delivery falls under the responsibility of the regions and municipalities (five regions and 98 municipalities). Publicly financed health care covers all primary, specialist, hospital, and preventive care, as well as mental health and long-term care services.

**Private insurance:** ~2.5 million<sup>(a)</sup> (or 43% of)<sup>(2)</sup> Danish people have access to voluntary health insurance (VHI) in 2018, which is almost exclusively provided by not-for-profit organization 'danmark'<sup>(c)</sup>. Additionally, ~1.5 million people hold supplementary insurance to gain expanded access to private providers.

**Funding:** Healthcare expenditure represented 10.6%<sup>(c)</sup> of GDP in 2015. Public system financing accounted for 84%<sup>(b)</sup> of this spending which mainly comes from a national health tax (set at 8%<sup>(c)</sup> of taxable income), while out-of-pocket payments accounted for 14% and the remaining 2% was paid by VHI. Revenues are allocated to regions and municipalities mostly as block grants (these grants finance 77%<sup>(c)</sup> of regional activities), while ~20% comes from municipal activity-based payments (through a combination of local taxes and block grants from the national government).

**Hospitals:** ~97%<sup>(c)</sup> of hospital beds are publicly-owned. Danish individuals are required to register with a primary care physician (PCP) who provides primary care and also performs the gatekeeping role for access to specialist care and hospitals. The practice structure is gradually shifting from solo to group practices, typically consisting of two to four PCPs and two to three nurses<sup>(c)</sup>.

**Electronic Health Records (EHR):** Denmark has the highest penetration of information technology in healthcare among EU countries with the highest eHealth adoption among PCPs in the EU<sup>(b)</sup>. Each region uses its own EHR system for hospitals, with adherence to national standards for compatibility and all citizens have a unique electronic personal identifier.

## Rheumatoid arthritis in Denmark:



### Patients:

- Prevalence<sup>1</sup>: 0.75%<sup>(d)</sup> (overall)
- Prevalence<sup>1</sup> is higher in women (1.06%<sup>(d)</sup>) compared to men (0.41%<sup>(d)</sup>)

### Physicians:

- ~400<sup>(e)</sup> rheumatologists in Denmark over 28<sup>(f)</sup> rheumatology departments
- There are ~3,500 PCPs<sup>(g)</sup> (constituting 19% of all physicians) distributed across 2,100<sup>(g)</sup> practices

### Guidelines:

#### RA:

- EULAR
- National guidelines for treatment with TNF- $\alpha$  blockers (2000)<sup>(h)</sup>
- DANBIO (nationwide rheumatology registry) guidelines for treatment of RA with biological agents (2006)<sup>(h)</sup>

#### Comorbidities:

- International EULAR guidelines

#### PAGs / Medical Societies:

- Danish Society for Rheumatology
- The Danish Rheumatism Association

## RA challenges in Danish healthcare system

- Only 15-19% of RA patients achieve remission in routine care<sup>(i,3)</sup>. Treat-to-target is a concept used in designing therapeutic strategies, with treatment modalities oriented towards achieving a well-defined, clinically relevant end-target
- There is considerable variation in avoidable hospitalisations for chronic conditions between regions<sup>(b,4)</sup>.

**Notes:** 1. Cumulative prevalence (for the whole sample) adjusted for age or age and sex, from a random sample of the population in the southern part of Denmark in 2004; 2. Based on Q3 2018 population estimates by Statistics Denmark; 3. Based on a study on patients who were registered with RA for the first time in the nationwide Danish DANBIO database between 2006–2013; 4) Not specific to patients with RA

**Sources:** (a) Danmark Sygeforsikring Website; (b) State of Health in the EU – Denmark, OECD, 2017; (c) The Danish Health Care System, The Commonwealth Fund, 2018; (d) Prevalence of Rheumatoid Arthritis in the Southern Part of Denmark, The Open Rheumatology Journal, 2011; (e) Medicolink website; (f) Danish Society of Rheumatology Website; (g) Primary Care Review of Denmark, OECD, 2016; (h) DANBIO—powerful research database and electronic patient record, Oxford Academic, 2010; (i) Monitoring patients with rheumatoid arthritis in routine care: experiences from a treat-to-target strategy using the DANBIO registry, Hetland, et al., 2014

# The Rheumatology unit

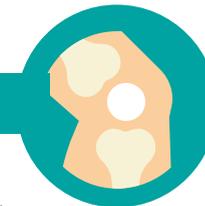
The Center for Rheumatology and Spine Diseases covers rheumatology services in the entire Capital region and the Rigshospitalet Glostrup site is one of the 5 locations of this department, providing specialist rheumatology care in arthritis for the area

## The hospital



<b>Type</b>	Public hospital	<b>Locations</b>	East Denmark Two sites Blegdamsvej and Glostrup (where this rheumatology department is situated)
<b>Core services</b>	55 departments across the two sites	<b>Population served</b>	Capital Region of Denmark (>1.6 million)
<b>Size</b>	12,000 employees across 50 different professions and ~20 physicians dedicated to the Rheumatology unit with ~1,300 beds <sup>(a)</sup>		

## The rheumatology unit



<b>Services</b>	Expertise within clinical studies, epidemiological research based on the DANBIO database, methodological and clinical studies with ultrasonography, magnetic resonance imaging, radiography evaluation and soluble biomarkers as well as symptom management and life style issues. Departments include early arthritis diagnostic clinic, outpatient clinics and inpatient services, as well as a sleep clinic	<b>Collaborations</b>	Danish departments of rheumatology, radiology and biochemistry, as well as Danish research groups (e.g. mutual arthritis research group); international researchers and research groups (e.g. EULAR centre of excellence); international scientific working groups, including Outcome Measures in Rheumatology (OMERACT); Research projects such as NORD-STAR research project; Danish Registry and The Danish Rheumatism Association (PAG)
<b>Teaching/ research scope</b>	Copenhagen Centre for Arthritis Research (COPECARE). Emphasis on ensuring that research results are translated into clinical practice and disseminated through education and training to patients and colleagues. Development and implementation of regional, national and international recommendations for improved diagnosis, medical treatment and use of imaging	<b>Funding and Resources</b>	Funding is received from both public and private foundations / institutions

Sources: (a) Rigshospitalet website [Danish only]

# The Rheumatology unit (cont.)

## Overview of Services



Service Division	Outpatient service	Ambulatory care service	Inpatient service
<b>Duration of stay</b>	Early arthritis clinic: 1 day; general follow-up: approx. 30 minutes	Dependent on patient needs	Dependent on patient needs
<b>Hours of availability</b>	08:00– 15:00, Monday – Friday Wednesday 08:00-17:00	08:00– 15:00, Monday – Friday Wednesday 08:00-17:00	24 hours a day, 7 days a week
<b>Capacity (no. of beds/rooms)</b>	31 beds	10 beds	15 beds in Glostrup location
<b>No. of patients seen</b>	4,800	31,500	2,000
<b>Patient type catered to</b>	All patients from newly diagnosed to established RA	Patients on biologics	Emergency patients with flares / complication requiring hospital admission
<b>Services offered</b>	Ultrasound (US) unit; access to specialist rheumatologists; involvement in clinical trials; infusion of biologics / administration of IA injections (US guided or non-US guided)		
<b>Specific tools</b>	DANBIO, hospital electronic medical record		

Sources: (a) KPMG interviews with HCPs treating RA and associated comorbidities

# The team

## Core team profiles

- 14 rheumatologists
- 13 trainee rheumatologists
- 10 rheumatology residents
- 2 research lab technicians
- 11 rheumatology nurses
- 3 rheumatology research nurses

## Affiliate team profiles

- Physiotherapist
- Occupational therapist



## Key features of the care delivery team

- All diagnosis, treatment and management of patients with RA is **rheumatologist-led**
- **Rheumatologists** spend up to 50 mins with each patient and make decisions on treatment and wider care
- **Rheumatology nurses play an important role** as the main point of contact for patients; provide education; assist in IV drug injections e.g. biologics; and pastoral support
- **Strong emphasis on research** to inform clinical practices for RA and associated comorbidities. Collection of samples and inputting comprehensive clinical information are part of day-to-day working meaning that large amounts of data are collected on the DANBIO database and utilised in research

## Governance and processes

### Team meetings:

- Daily midday meetings for the rheumatologists to meet and discuss cases

### Protocols:

- There are specific protocols aligned to local guidelines, many of which are based on real-world evidence from DANBIO registry

### Patient records:

- DANBIO is linked to the Danish Registry system which is an EHR that contains all patients records

Sources: (a) KPMG interviews with HCPs treating RA and associated comorbidities

# Overview of interventions in place for RA

## Awareness & Prevention

Symptom identification



## Diagnosis & Referral

In secondary care



## Treatment and Management

Medical management

Non-medical management



## Follow-up

Monitoring of chronic disease/flare up



Interventions

### Education of primary care physicians

- The hospital have made efforts to help educate Primary Care Practitioners (PCPs) to improve the quality of referrals and accelerate access into care

### Early and rapid access to care

- New patients are seen within 2 - 5 days of being referred from primary care (e.g. GP referral). There is also a physician telephone hotline available to speed up the referral process.

### Early arthritis clinic

- A streamlined process where referred patients are comprehensively addressed soon after referral and usually over a single visit

### Integrated ultrasound (US) clinic

- The clinic participates in the development and implementation of agreed ultrasound competency assessments (EFSUMB and EULAR)

US scans are a core part of the diagnostic process and the centre has extensive national and international teaching experience in ultrasound

### Use of MRI

- MRI is integrated into clinical practice, and teaching is also given at conferences

### Systematic data collection

- DANBIO is a national registry to monitor patients with inflammatory arthritis that is integrated into routine clinical practice, standardising data collection for longitudinal assessment of patients
- The registry can be used for clinical and research purposes, linking to other national disease registries

### Research-led treatment

- Evidence-based practice are integrated into everyday clinical care

### Joint consultations with hand surgeons

- Monthly / bi-monthly meetings with rheumatologists and hand surgeons to assess cases potentially requiring surgery

### Dedicated room for acute patients

- Room in the outpatient department ring-fenced for emergency cases, such as patients with severe flares

### Development of Danish Biobank

- Samples collection has been integrated into clinical practice, feeding into a national biobank for international research

### Focus on empowering patients

- Encouraging patient input through feedback questionnaires
- Giving patients the ability to provide self-reported outcomes data into the online DANBIO registry from home

### Provision of holistic care

- Holistic care is provided by nurses and other HCPs, through access to a local rehab unit, and through collaboration with PAGs

### Remote consultations

- Patients who are stable can be monitored through telephone consultations, but also have same-day access to care if required

### Personalised follow-up plans

- Once patients achieve remission, their care is individualised according to patient need and clinical judgement of disease manifestation / progression

### T2T strategy

- The centre follows T2T objective of reaching remission in 6 months and tailors medication to achieve this goal

### Continual research and collaboration with national registries

- The centre is running multiple national and international studies monitoring and assessing detection, diagnosis, disease activity and progression in patients

Sources: (a) KPMG interviews with HCPs treating RA and associated comorbidities

# Overview of interventions in place for RA comorbidities

## Awareness & Prevention

Symptom identification



## Diagnosis & Referral

In secondary care



## Treatment and Management

Medical management

Non-medical management



## Follow-up

Monitoring of chronic disease/flare up



Interventions

### Focus on early detection

- Early detection of RA is established and integrated into clinical practice amongst both primary care and specialist physicians. The result is a reduced risk of developing CVD and other comorbidities

### Optimising treatment of comorbidities

- There is continuous research and education into optimising diagnosis and treatment to better meet guideline requirements and achieve improved patient outcomes

### Psychological assessment

- The DANBIO registry contains a series of PROs that help to assess patients' psychological well-being during consultation
- These parameters and data points are assessed by rheumatologists prior to patient consultations

### Sleep outpatient clinic

- Clinic developed to identify the causes and severity for sleep disturbances in patients with IJD and offer non-pharmacological treatment to patients with IJD. Since little scientific work is done in non-pharmacological treatment of sleep in patient with IJD, the clinic also facilitate evidence-based research

### Personalised remote management

- Developing personalised text messages, which are created by the patients themselves, which help to increase motivation and physical activity, with the aim of reducing sedentary time and cardiovascular disease (CVD) risk

### Smoking cessation services

- As part of the REU-STOP randomized controlled trial, patients with RA who smoke are offered 6 weeks of nicotine replacement therapy alongside motivational interviewing <sup>(b)</sup>

### Patient annual review

- Patients are scheduled for a yearly assessment to screen for comorbidities
- The annual review is recorded through the DANBIO system and integrated with other national disease registries to enable wider tracking of comorbidities for both clinical and research processes

Sources: (a) KPMG interviews with HCPs treating RA and associated comorbidities (b) REU-stop - Effect of Intensive Smoking Cessation Intervention on Smoking Cessation and Disease Activity in Patients With Rheumatoid Arthritis.

# These interventions have improved outcomes



How do you quantify the benefits in RA?

## Objective measures (KPIs):

- The department has an online system called DANBIO with the ultimate goal to register all rheumatic patients treated with biological agents in Denmark, ensuring effective monitoring of treatment indication, efficacy and safety. The system is integrated into their Danish patient registry system within which they can cross-check and locate patient data
- T2T goals are measured using the following indicators:
  - CRP, extra-articular manifestations, erythrocyte sedimentation rate
  - Joint examination (number of swollen joints)
  - Increased remission rates
  - Decreased drop-out rates

## PROMs:

- Composite scores: DAS 28, SDAI, CDAI
- Global scales: VAS (global, joint pain & fatigue scores)
- Functional measures: MHAQ, HAQ, SF-36 (physical, bodily, general health, vitality, social function, mental), FACIT; EQ-5D-5L

## Centre routinely measures comorbidity outcomes by:

- Objective measures (KPIs)
  - CVD: cholesterol, lipid levels, blood pressure
  - Respiratory: respiratory function tests, x-ray, CT
  - Depression: PHQ-9
  - Osteoporosis: DXA, x-rays



How have these interventions improved patient outcomes?

## RA

- Benefit: earlier diagnosis, better management of disease resulting in fewer flare episodes and reduced levels of structural damage
- Quantitative output: Number of patients in remission; change in DAS 28 score

## Comorbidities

- Better management of lifestyle factors e.g. sleep / fatigue

Sources: (a) KPMG interviews with HCPs treating RA and associated comorbidities

# How can care be improved?



## What is next for the centre?

### Overview: Collaborating with PCPs

- **How?** Although PCPs successfully manage a number of MSK-related issues currently, they could benefit from further education on how to better diagnose and refer patients with suspected inflammatory arthritis. This would help to ensure that patients are referred correctly to the centre and therefore can be seen, diagnosed and treated in a timely manner

### Overview: Empowering patients to monitor their own disease

- **How?** Patients have access to the DANBIO system from home and therefore can remotely input PROMs and symptom details (e.g. number of painful or swollen joints). The hospital has recently trialled launching a mobile application for self-reporting which has received positive feedback from patients for ease of access. The app will now be offered to all patients with RA as a standard component of care

### Overview: Implementing research outcomes into clinical guidelines

- **How?** The centre is currently running a number of research studies covering RA disease management, the management of comorbidities, and lifestyle factors in RA. As the results of the trials are published, the centre will progress to implementing findings into clinical guidelines and practice (e.g. behavioural interviewing to increase physical activity in patients with RA)

### Overview: Reviewing PROMs for funding structure

- **How?** Currently, the centre is funded through the allocation of a “block” budget to the centre i.e. the centre receives a lump sum of funds, rather than funded per unit activity. This is a trial funding structure with the Danish government and requires the centre to demonstrate their “value add” to patients and therefore the case for future funding. In order to maintain this funding arrangement, the centre must continue to review and re-evaluate whether they are using the most appropriate PROMs for monitoring and tracking quality of care

### Overview: Focusing on treating patients in remission

- **How?** Patients at the centre are quickly diagnosed managed according to Treat to Target (T2T), and therefore a large proportion of patients are in remission. Ongoing research into the management of patients in remission e.g. dose-tapering of biologics in patients with stable RA and recent history of constant treatment regimen, will inform the principles of management of patients with RA in the future

Sources: (a) KPMG interviews with HCPs treating RA and associated comorbidities

# How can care be improved?



## What advice would you give less specialised centres?

**Overview of advice:** Encourage the use of ultrasound in diagnosis and treatment

- **Why?** Ultrasound is an effective tool in the diagnosis and treatment of patients with RA. It can help to solve discrepancies between patient-reported disease status and clinical assessments. It can be used for further examination when an attending physician can be unsure of presence of synovitis, but is also of use for ultrasound-guided injections (e.g. intra-articular (IA) steroid injections)
- **How?** All trainee rheumatologists should be trained in the use of ultrasound as incorporating this imaging method into daily practice can help to confirm a diagnosis and start treatment earlier

**Overview of advice:** Set up a system to effectively capture data

- **Why?** Continual data collection is essential in ensuring effective monitoring and measurement of patient disease status, treatments and outcomes. Rheumatologists can use the data capture for longitudinal assessments but also as a tool to quickly assess patients status prior to consultations. The data can also be used for both national and international research purposes, helping to impact the treatment of RA in the future
- **How?** Designing a data capture system can be expensive and difficult for a smaller centre / centres with fewer resources. However, collaborating with the MoH or PAGs could help relieve the burden, or for smaller centres, a simple system can be designed to meet the specific needs of the centre

Sources: (a) KPMG interviews with HCPs treating RA and associated comorbidities

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# Case study 1

## Early arthritis clinic

### Overview

- A comprehensive pathway to cover all patients with suspected inflammatory arthritis
- Highly streamlined model where referred patients receive their complete diagnostic assessment (including ultrasound as standard) and review at a single site over the course of a single day
- Patients are also started on their treatment on the same day, and can choose to receive education on their diagnosis then, or return after 2 weeks

Sources: (a) KPMG interviews with HCPs treating RA and associated comorbidities



### What is the rationale?



- The hospital receives a large number of referrals from PCPs and is required to comply with the Danish government's legal requirement to diagnose and start treatment within 30 days of the initial referral
- In order to cope with this demand, the hospital has developed a comprehensive, streamlined diagnostic clinic which serves a single point of access for patients to be assessed in a consistent manner

### What are the key features of the intervention?



- Patients who are referred to the centre follow a structured pathway
- Firstly, patients undergo investigative procedures including blood tests and an ultrasound scan
- Secondly, patients are assessed by the medical team for their diagnosis to be confirmed
- They are then seen by a rheumatology nurse who provides counselling / education
- If a patient feels overwhelmed by receiving the diagnosis or the amount of new information they are encouraged to return for another appointment in 2 weeks' time
- Patients are followed up in the routine RA management pathway, with appointment frequency and treatment tailored to individual patient needs
- Once stabilised and in the routine RA management pathway, patients will be followed up on an annual basis with the medical team and twice-yearly basis with the nursing team

**Frequency** Clinic runs 5 days a week (Mon-Fri)

**Timings** 08:00 – 15:00

#### Staff members involved

**Members of the core MDT** Ultrasonographer  
Junior rheumatologists  
Senior rheumatologists  
Nurses

**Others** Phlebotomy  
Administrative staff

### What are the activities undertaken?



#### Blood tests

- Patients are required to have blood tests to identify the presence of markers for RA / other rheumatic disorders

#### Ultrasound scan

- All patients receive an US scan prior to medical assessment
- The US clinic is fully integrated [see case study 5]

#### Medical assessment

- Following the biochemistry assessment and US scan, all patients are then assessed by a trainee rheumatologist
- The patient will then be reviewed by a senior rheumatologist to confirm the diagnosis of RA or other rheumatic disease and treatment will be initiated

#### Nurse appointment

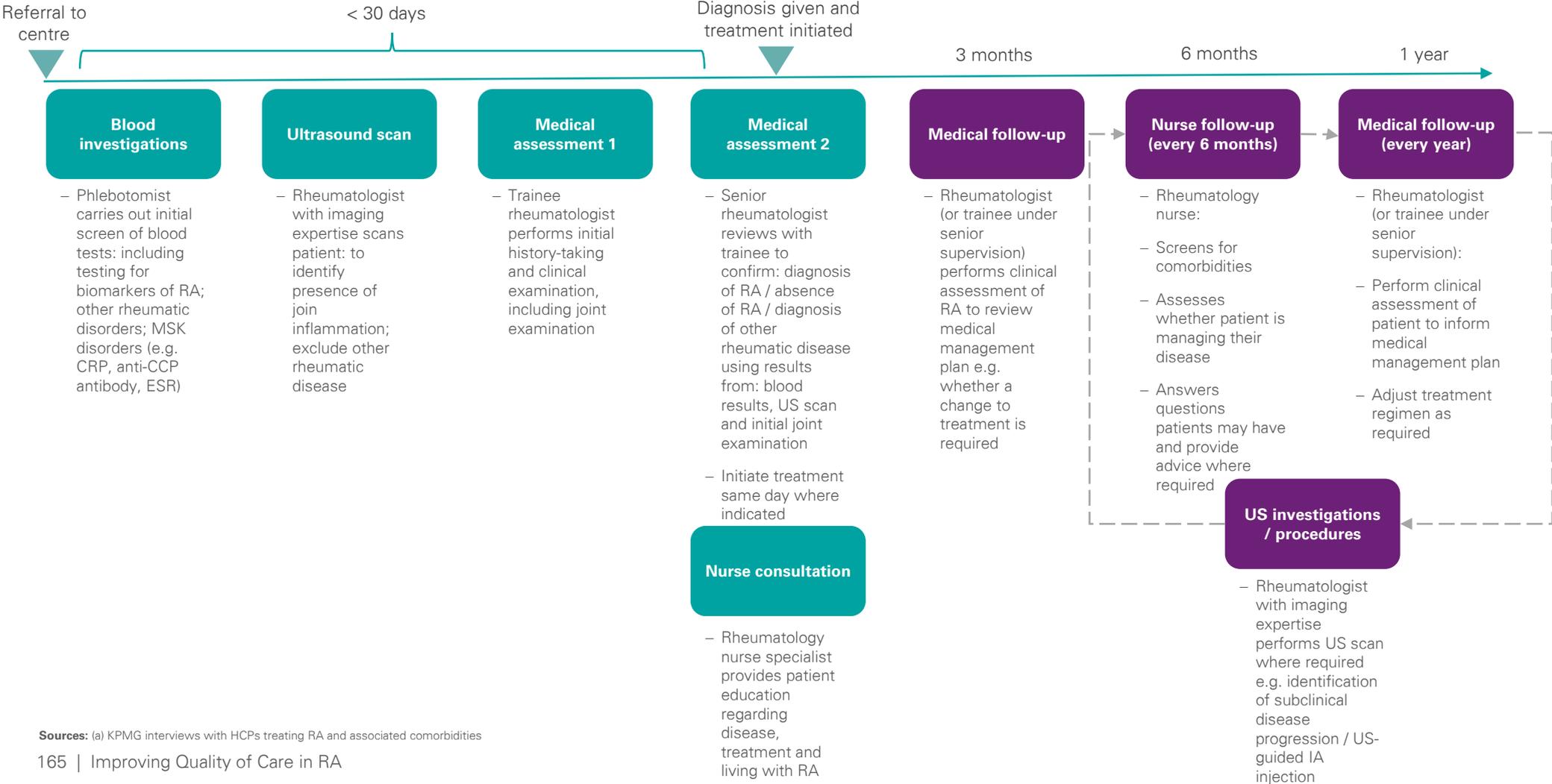
- All patients diagnosed are then seen by a rheumatology nurse who will provide education and counselling on the diagnosis of RA, their treatment, and living with RA

# Early arthritis clinic (cont.)

What are the activities undertaken? (cont.)

## The patient pathway

Key: ■ Early arthritis clinic ■ Routine RA management



Sources: (a) KPMG interviews with HCPs treating RA and associated comorbidities

## Early arthritis clinic (cont.)

### What are the outcomes so far?



- Faster patient diagnosis and the centre is able to meet the 30-day time to treatment requirement mandated by the Danish government
- More patients achieve and maintain remission sooner due to starting treatment earlier in the disease process

### Benefits



#### Benefits to patients

- Rapid access to specialist RA care
- Greater convenience due to the streamlined process

#### Benefits to the Rheumatology team

- Robust, consistent and efficient way of assessing patients and enrolling them into the system
- Trainee rheumatologists are able to gain exposure to a large number and variety of patients and establish diagnostic skills required in RA

### Challenges



- There are a number of referrals e.g. patients with osteoarthritis (OA) which will need to be filtered out of the inflammatory arthritis pathway. Patients with OA or another non-inflammatory arthritis are referred back out to the community or to the relevant specialist clinic within the hospital
- Patients can sometimes 'overloaded' with information as they receive their diagnosis and are prescribed treatment within the same day, this is not enough time for some patients to process this information. These patients have the opportunity to have a follow up appointment approximately 2 weeks after the diagnosis

### Tips to replicate this intervention



- Look for opportunities to streamline the patient pathway through assessment, diagnosis and initiation of treatment
- Conduct blood tests and US scan in advance of medical assessment to aid accurate diagnosis and save time



Investigations are performed before seeing the rheumatologist enabling him or her to give the diagnosis and start treatment on the same day

- Senior rheumatologist



Doctors determine the diagnosis and then the patients come to us as we will be the primary contact for them, providing education and support

- Nurse



Sources: (a) KPMG interviews with HCPs treating RA and associated comorbidities

# Case study 2

## Systematic data collection

### Overview

- The DANBIO database is one of the most comprehensive observational registries in rheumatology in the world. The database collects information about “ordinary” patients with RA undergoing treatment in routine care
- The aim is to collect information on all patients, though there is greater coverage of those on biologics
- Data is used to ensure efficient treatment of individual patients and furthermore in scientific studies

Sources: (a) KPMG interviews with HCPs treating RA and associated comorbidities

### What is the rationale?



- Patient information and consistent data collection is essential in measuring the outcomes of treatment and management of patients with RA, especially due to the chronic nature of the disease
- The DANBIO is a national database that has been created to collect data from comprehensive assessment and treatment of rheumatic patients

### What are the key features of the intervention?



#### Overview

- This DANBIO platform was launched in 2000
- All RA patients are to be registered on the platform, though a proportion of those diagnosed before 2000 are not picked up
- This is an integrated tool in routine practice which helps to measure disease progress and treatment outcomes
- When patients arrive at the hospital there is a touch screen with a series of questionnaires (PROs and some composite measures); they are also taught by their rheumatologists to count their swollen joints and input this information
- 70-80% of patient (98% of patients on biologics) are registered on DANBIO
- It is mandatory for patients registered on the DANBIO to input data 1-2 times a year. Many choose to enter data at each visit
- In 2006 DANBIO merged with Danish Patient Registry and became web-based providing instantaneous feedback to the attending doctor on patients holistic disease status

#### Measures

- Obligatory questions are highlighted such as swollen joints, CRP, pain and other functional measures and composite scores (DAS, SDAI, CDAI)

- PROs surrounding quality of life, psychological well-being and sleep are used (HAQ, PEST, EQ-5D, FACIT, ISI, BRAF)
- Physicians can then assess these prior to the consultation to understand the current state of the patient and the treatment history and efficacy and tailor the consultation to the needs of the patient

#### Treatment efficacy

- The registry interface provides graphs and other visual indicators (e.g. colour rating for level of disease control – red, yellow and green) which help the physician to understand disease status and treatment outcomes rapidly
- T2T guidelines are effectively measured through this

#### Research

- Information from the Danish patient registry
- Since 2015, a nationwide biobank, Danish Rheumatology Biobank has been linked to DANBIO to provide an rich data resource for current and future research projects
- Both DANBIO and Danish Rheumatology Biobank are frequently used for national, clinical and epidemiological research

#### Training

- Regular courses are held to update attending HCPs and administrative staff on how to use DANBIO and any updates to the registry

#### Accessibility

For physician and nurses:

- Information from DANBIO is easily accessible online for all rheumatologists across Denmark in a visual manner

For patients:

- DANBIO can be accessed from a touchscreen in the hospital but also online from the home.
- The hospital have run a pilot with an app, which patients can complete PROs and enter other information such as joint count



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## Systematic data collection (cont.)

### What are the outcomes so far?



- Data captured is utilised in research and will continue to be used in future research at a centre, national and international level. So far DANBIO data has been used to create 100-120 publications

### Challenges



Some patients experience difficulties in counting their swollen joints and therefore require additional training

Accessing the DANBIO at home can also be an issue, especially for more senior patients



Sources: (a) KPMG interviews with HCPs treating RA and associated comorbidities  
(b) [https://danbio-online.dk/Danbio-yearly-report-2007-eng.pdf/at\\_download/file](https://danbio-online.dk/Danbio-yearly-report-2007-eng.pdf/at_download/file)



### Benefits



#### For the patient

Patients are empowered to play an active role in their management and treatment outcomes, both inputting data on screens in the hospital and remotely in the home

#### For physicians and nurses

Physicians can assess disease progression and treatment outcomes prior to consultations

Physicians are able to save time due to the user-friendliness of the interface – providing most relevant information on progress of the patient on one screen

#### For the hospital

Comprehensive assessment for consistent management of patients across baseline measures

Data can be leveraged for research purposes and in conjunction with the Danish Biobank for national and international projects

The database can be used as a vehicle for quality improvement within the department

#### For the wider RA community

The system is available across all centres in Denmark

enabling nationwide standardisation of assessment

Effective way of collection of national data for RA patients

### What's next



#### DANBIO app

- DANBIO have launched a successful pilot showing the efficacy of patients using an app to input their data into the DANBIO system. The pilot will now rolled out to all patients



The system will come up with a questionnaire for the patients to answer just prior to their consultation

– Rheumatologist



# Case study 3

## Access to holistic care

### Overview

- The centre collaborates with different departments and associations to provide holistic care centred around patient needs
- Holistic care provided via:
  - Nurse consultations (at diagnosis and follow-up)
  - Patient hotline / nurse telephone service
  - On-site physiotherapy and occupational therapy
  - Additional support for clinical trial patients
  - On-going research into different aspects of holistic care
  - Direct access to specialist rehabilitation centre
  - Provision of patient association materials

Sources: (a) KPMG interviews with HCPs treating RA and associated comorbidities

### What is the rationale?

- Chronic diseases, such as RA, impact many different aspects of a patient's lifestyle including ability to work, engage in physical exercise, etc.
- Patients often have concerns regarding the wider non-medical aspects of their disease management
- Patients with RA, therefore, require non-medical holistic management alongside traditional treatment
- The provision of non-medical input such as nursing care, physiotherapy and occupational therapy improves quality of life and patient satisfaction

### What are the key features?

- Patients are able to access a number of different departments, services and healthcare professionals collectively offering holistic care covering a wide range of needs
- The centre has collaborations with PAGs and other departments in the hospital
- Patients are supported across their whole journey throughout the lifespan of their disease

### What are the activities undertaken?

#### Nurse consultations:

- Nurses provide patient education, support and holistic management at both diagnosis and follow-up
- Nurses will provide advice regarding living with RA, treatment of RA and information about medication

### What are the activities undertaken?

#### Patient hotline:

- Patients are able to use the telephone service between 08:00 - 15:00, staffed by nurses for advice regarding their RA management
- Nurses will answer questions regarding care, provide advice or set up an appointment to see the rheumatologist if required

#### On-site physiotherapy and occupational therapy:

- The rheumatology department is able to make referrals to physiotherapy and occupational therapy at the hospital
- The decision to refer is made on a case-by-case basis and nurses or physicians can make the referral(s)

#### Support for clinical trials patients:

- There is a large focus on research at the centre and many of the RA patients are enrolled onto trials
- Patients on trials are allocated 30-minute slots with nurses during the course of the trial, for additional nursing support

#### On-going research:

- Several studies at the centre are evaluating different aspects of holistic care for RA patients e.g. comparing the effect of physical activity programmes on fatigue in RA patients, smoking cessation

#### Specialist rehabilitation centre:

- The centre refers patients to a specialist rehabilitation centre, run by the PAG and financed by the region, and receives funding to provide medical resource to the centre (4 days of a rheumatologist per month with a special interest in rehabilitation medicine)

#### Patient association support:

- The Danish Rheumatism Association produces a wealth of information regarding living with RA and self-management of the disease
- The centre actively utilises these resources in patient counselling e.g. nurse consultations



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## Access to holistic care (cont.)

### What are the outcomes so far?



- Better quality of life for patients e.g. improved sleep, greater ability to perform activities of daily living

### Benefits



#### Benefits to patients

- Receive a variety of information and advice regarding their treatment and disease
- Improved access to HCPs from different disciplines
- Improved management of the disease and wider lifestyle factors

#### Benefits to the Rheumatology team

- Ability to focus on area of expertise i.e. medics are able to focus on medical care etc.

### Challenges



- Collaboration and sharing between disciplines / departments e.g. occupational therapy input on lifestyle issues into overall medical care

### Tips to replicate this intervention



- Locate different services within the community to provide holistic care closer to home
- Build and encourage collaboration with PAGs
- Empower the nursing team to provide holistic care through increased capacity or enhanced role within care

### What's next?



#### Research

- Continue research in holistic care management, e.g. in physical activity and fatigue, smoking cessation, physical activity and sedentary hours

#### Clinical guidelines / care models

- Implement outcomes from research in holistic care into clinical guidelines / care models for the management of RA

#### Patient feedback tool

- Develop patient feedback tool to collect data on patient experience, on a regular basis, throughout the centre
- Utilise DANBIO to collect patient experience data; patients currently fill in questions relating to holistic issues and this could be build out to include broader patient experience / feedback questions



I love this job because I have extra time with the patients and the patients get the follow-up they want

- Clinical trials nurse



Patients have lots of issues with their RA that medications do not treat

- Rheumatologist



Sources: (a) KPMG interviews with HCPs treating RA and associated comorbidities

# Case study 4

## Sleep outpatient clinic

### Overview

- The hospital has a dedicated outpatient clinic to offer services that help to assess and manage sleep disturbance
- The clinic offers non-pharmacological treatment to patients with RA and inflammatory diseases such as physical education and cognitive behavioural therapy (CBT)

**Sources:** (a) KPMG interviews with HCPs treating RA and associated comorbidities; (b) Goes A, Reis L, Silva M et al. Rheumatoid arthritis and sleep quality. *Revista Brasileira de Reumatologia*; 57:294-298 2017; (c) Sangle S, Tench C, D'Cruz D. *Curr Opin Pulm Med*; 21(6); 553-556; (d) Malhotra A and Loscalzo J. Sleep and Cardiovascular Disease: An Overview. *Prog Cardiovasc Dis*; 51(4):279-284; (e) Geenen R, Overman CL, Christensen R, et al. EULAR recommendations for the health professional's approach to pain management in inflammatory arthritis and osteoarthritis. *Annals of the Rheumatic Diseases* 2018;77:797-807.

### What is the rationale?



- Around 60 - 80% of patients with RA suffer from poor sleep or insomnia(b)
- The trigger is often the patient's diagnosis. Whilst patients learn to cope with their day-to-day chronic disease, learning to adapt to their life with RA, patients appear to mentally overcome their diagnosis but often their sleep disturbances prolong
- Sleep disturbances can lead to exacerbation of RA symptoms (pain and fatigue)
- Literature has also shown links between inflammatory processes in rheumatic diseases and sleep disorders(c)
- Improving quality and amount of sleep can support management of RA and improve quality of life

### What are the activities undertaken?



#### Treatment

- The purpose with the sleep outpatient clinic is also to investigate possible options for evidence-based non-pharmacological treatments, as treatment with hypnotic drugs or other pharmaceutical treatments may have side effects. Currently the team investigates the effect of CBT-I, as it seems to have a larger and longer effect on sleep than pharmaceutical treatments, presumably because patients learn skills they can use to manage sleep at later times

#### CBT-I

- Cognitive and behavioural responses to sleep disturbances, and some of the practices people adopt to cope, can create a vicious cycle by prolonging or exacerbating the very problems they are trying to solve. The cognitive-behavioural approach to insomnia aims to alter behaviours that sustain or add to sleep disturbances and correct cognitions that drive these behaviours
- It consist of several sessions, adapted to the patient's needs: (1) the behavioural components of CBT-I include two well-developed and empirically supported treatments, stimulus control and Sleep Restriction Therapy; (2) the cognitive component of CBT-I is based on the theory that a person's beliefs and the way one thinks about, perceives, interprets, or assigns judgment to situations in life affects emotional experiences; (3) the last component of aims to reduce physiological hyperarousal, defined as high activity in the sympathetic nervous system, and cognitive hyperarousal. Training in relaxation techniques, implementing a scheduled worry time, creating a time to unwind before sleep, and employing cognitive therapy strategies address physiological and cognitive hyperarousal
- CBTi is first line treatment for EULAR and ACR (d)

### What are the key features?



- The clinic started 4 years ago and is designed to provide a non-pharmacological offering for patients suffering from sleep disturbances
- DANBIO helps to screen for sleep disturbances through a standardised questionnaire, which is then analysed by the attending rheumatologists and nurse who will refer to the sleep outpatient clinic when needed
- CBT-I (cognitive behavioural therapy for insomnia) is a multi-component treatment based sleep education, stimulus control, sleep restriction, cognitive therapy and relaxation
- Sleep questionnaires are used to evaluate the treatment



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## Sleep outpatient clinic (cont.)

### What are the outcomes so far?



- Strong engagement from rheumatologists and nurse in the centre leading to frequent referrals into the clinic

### Benefits



#### Benefits to patients

- Improvements in sleep can have positive impact on quality of life by improving symptoms around fatigue and pain
- Patients receive practical guidance on how to develop good behaviours, routines and coping mechanisms for dealing with sleep disturbances

#### Benefits to the rheumatology team

- The rheumatology team has access to another discipline that can help to solve an issue around RA management without recourse to pharmacological interventions / changes to management
- Improving sleep can help the team address other issues relating to RA by improving motivation and adherence

### Challenges



- RA is a chronic disease and the psychological effects can disrupt sleep for a long time after patients are in remission or have adapted to coping with their condition
- Sleep deprivation can aggravate the disease, creating uncertainty around the appropriate pharmacological dose to achieve remission – leading to under-dosing / over-dosing and suboptimal management of disease activity(b)

### Tips to replicate this intervention



- Encourage all patients to increase their physical activity as this reduces inflammation, which can have a secondary effect on comorbidity risks (CVD and diabetes)
- Have a dedicated healthcare professional to this training and they will be able to provide CBTi to patients with RA
- Ensure they gain as much experience as possible. The more experienced the therapist the better the effect of the CBTi
- Ensure the patients' needs and motivations are central to the formulation of their coping strategies and plans to improve their sleep



Around 60 - 80% of patients with RA have a significant problem with sleep



- Nurse, Sleep clinic



**Sources:** (a) KPMG interviews with HCPs treating RA and associated comorbidities (b) Chronobiology: How Sleep Deprivation Is Influencing Rheumatoid Arthritis Outcomes. Rheumatology Advisor



# Case study 5

## Integrated ultrasound (US) clinic

### Overview

- Ultrasound can be an important component of the diagnostic and clinical management of RA
- The integrated US unit provides access to specialist US equipment and highly trained rheumatology specialists on a routine and ad-hoc basis

### What is the rationale?

- US scans are used within the diagnosis of RA and other diseases e.g. arthritis, and throughout the management of the disease
- The centre must comply with a 30-day time referral to first treatment, which is set by law in Denmark
- Therefore, a standardised process for diagnosis has been established [see case study 1] and US is part of this process, thus an integrated US clinic is warranted

### What are the key features?

#### Frequency and clinic availability

Clinic opening hours 8-15; and serves patients on a routine and ad-hoc basis; patients are typically seen within 1 week of referral

#### Services offered

Diagnosis  
Pharmacological and non-pharmacological management  
Monitoring of disease activity (where indicated)

#### Staff members involved

5 senior rheumatologists  
1 trainee rheumatologist

#### Target patients

Diagnosis – suspected inflammatory arthritis patients  
US-guided procedures

### What are the activities undertaken?

#### Training

- Trainee rheumatologists rotate through the unit and complete a 2-week training placement
- Trainees are taught to recognise the presence of a disease and when to refer patients onwards / back to PCPs

#### Research

- Specialist input is utilised when standardising US quality in clinical trials e.g. reducing inter-reader variability as a factor affecting the quality of results

#### Diagnosis

- All patients progressing through the diagnostic pathway are scanned before their appointment with the medical team [see case study 1]

#### Interventions

- Patients with RA may require intra-articular glucocorticoids injections
- Guided IA injections can be performed with the assistance of an US machine which increases the accuracy of the administration and the patient's response to the injection. Intra-articular injections are also proven to be more effective when compared to oral steroids and preferred by patients overall

#### Confirming diagnosis / disease activity

- Discrepancies regarding disease activity between patients and doctors can arise i.e. the patient may present with worsening pain but no physical signs of disease manifestation
- US scans can help to confirm active inflammation not detectable on clinical examination, or reassure patients that there is no disease manifestation



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## Integrated US unit (cont.)

### Benefits



#### Benefits to patients

- Patients are reassured when they are given their diagnosis as they are able to “see their joints and disease”
- Clinicians are able to educate patients regarding their disease and potential diagnosis using US imaging as a visual aid
- Diagnosis is achieved in a timely manner as all patients are scanned in the early arthritis clinic meaning their diagnosis can be confirmed at the first rheumatologist assessment
- Better perception of treatment outcomes i.e. patients may respond better to US-guided IA injections as opposed to non-US guided ones

#### Benefits to the Rheumatology team

- Streamlined diagnostic process increases quality and efficiency of care provided at the centre
- Ability to resolve discrepancies with patients i.e. identification of subclinical synovitis as rheumatologists are able to actively identify symptoms / disease progression and show the patient which provides an objective measure
- Ability to make more appropriate treatment decisions to the benefit of both patients and the team

### Benefits (cont.)



- Improved patient adherence as clinicians can visually show patients their disease status and use this as a tool to encourage adherence to medication(s)
- The US unit provides training opportunity for trainee rheumatologists to be upskilled in US-imaging / disease identification

### Challenges



- Access to US imaging specialists; the centre has 5 rheumatologists with special interests in US imaging. Increases in demand would require recruitment of a suitably experienced rheumatologist, which may present a challenge
- More junior rheumatologists / trainees can rely heavily on US with a high rate of referral, leading to significantly increased demand

### What's next?



- Currently trainee rheumatologists rotate through the unit for a 2-week period. This will be extended to provide more comprehensive training for trainees
- Ongoing research into the integration of US in standard RA management



Conducting the US before the first appointment with the rheumatologists has helped us to reduce time to diagnosis

- Senior rheumatologist



Sources: (a) KPMG interviews with HCPs treating RA and associated comorbidities





# Hôpital Cochin

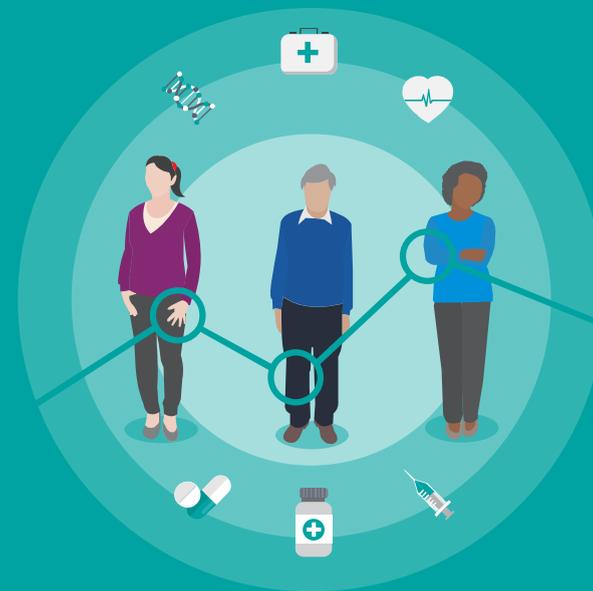
Paris, France



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# Summary



## Context

- **Commitment to standardised care** for all patients within Cochin and its extended network
- **Regular professional development meetings** as part of the RHEVER network (3 times a year)
- **Locally authored guidance** on standardisation of reporting. RHEVER network published guidance on the minimal required data to be recorded during an RA consultation <sup>(b)</sup>
- **Screening for comorbidities** through the COMEDRA (COMorbidities, EDucation in Rheumatoid Arthritis) programme. This is a comorbidity programme for RA, based in the 'Hôpital de jour' ('day hospital') which enables effective management and monitoring of comorbidities. It is an example of the implementation of positive outcomes of a research study into practice
- **Personalised care** through adapting the visit type and schedule to patient needs via set up of the Day Hospital (ambulatory care services), in addition to inpatient services and a multiple outpatient clinics
- **Focus on patient and family education** through the ETP (Education thérapeutique du patient) programme; an education programme for both patients and carers to help understand and manage RA and associated comorbidities
- **Research centre** demonstrating commitment to improving patient care through ongoing research and innovation with dedicated research HCPs <sup>(a)</sup>



## Key strengths in the delivery of RA care

- **An established professional network**, RHEVER (Réseau Hôpital et Ville en Rhumatologie) with private community-based rheumatologists enabling the standardisation of care for all patients outside of the hospital setting
- The network was pioneered at Cochin and aims to minimise unnecessary care touch points for patients between primary and secondary care <sup>(a)</sup>
- Standardisation limits variations in the quality of care received throughout the network. This decreases the dropout rate among patients <sup>(a)</sup>
- **Evidence-based standardised guidance** on reporting and data capture is in use across a network i.e. 'minimal required data to be recorded during an RA consultation' <sup>(b)</sup>
- Study of documentation within RHEVER network showed that only 28% of RA diagnoses and DAS scores were documented <sup>(b)</sup>. Following implementation of this guidance, recording of DAS Scores improved to 52% of all records surveyed, compared to 28% previously <sup>(a)</sup>
- **Commitment to patient centricity** and enabling self management through tailored follow up according to patient needs (routine outpatient follow up vs thorough follow up assessment in the 'day hospital', offering of a comprehensive educational programmes e.g. ETP and COMEDRA and pioneering of education schemes for carers <sup>(a)</sup>
- This has resulted in improved outcomes for patient engagement with therapy



## Key challenges faced in delivery of RA care

- Patient Education at the point of diagnosis is critical. The 12 months following diagnosis has been described as the "reverse honeymoon period" as it the most difficult time to educate patients. During this time they are the most refractory to education management advice and support <sup>(a)</sup>
- Gaps in the standardisation of reporting need to be addressed in order to improve the quality of RA care across centres. The study performed by RHEVER has shown progress in this area, however the centre strives to improve further upon this outcome
- Lack of staff capacity for patient programmes has had a negative impact on motivation levels, with fewer rheumatology nurses able to take on additional roles. However programmes such as ETP have been shown to improve team cohesion and morale <sup>(a)</sup>
- Lengthy waiting times may act as a barrier to the quality of care delivered. Waiting times for first appointments can range from 3-6 months and in some cases up to 12 months for particular physicians

# RA French healthcare system overview



## French healthcare system overview:



### National health service:

The healthcare system is supported by a programme of social health insurance (NHI) which provides Statutory Health Insurance (SHI) for all populations across France. This is largely managed by the state

### Public-Private Model:

There is mixed delivery in the model of care. The majority of management and funding of healthcare comes from state resources with ~75% of hospital beds being provided by public or not-for-profit hospitals. However the private system (Voluntary Health Insurance (VHI)), supports made up for not for profit funds, provident intuitions and commercial institution. The remainder is paid for either by the patient or through any supplementary private health insurance

### Funding:

The NHI is partially funded by obligatory social security contributions (sécurité sociale), covering 70% of the healthcare expenditure. The remainder is paid for either by the patient or through any supplementary private health insurance. Many people take out top-up health insurance (l'assurance complémentaire santé) often organised by a 'mutual society' (mutuelle), or insurance provider<sup>(b)</sup>. However, some chronic diseases are reimbursed in full (100%) by the government according to a list of 30 conditions 'affections de longue durée' – also known as ALD 30.<sup>(h)</sup> RA is one of these conditions, which means 100% of RA care costs are covered by the sécurité sociale

## RA challenges in French healthcare system

- Regulation suggests that patients can only be supplied biologics within the hospital setting. However private physicians are reluctant to refer out of their care and this may limit access to biologics\*

## Rheumatoid Arthritis in France:



### Patients:

- Prevalence: ~0.31% - 1% (200,000 – 670,000) of the general population for RA<sup>(c)</sup>
- Up to 6 times more prevalent in women than men
- Higher age-specific prevalence in the 65–74 year age band<sup>(d)</sup>

### Physicians:

- **>2,300 rheumatologists in France<sup>(a)</sup>**
  - Rheumatologists work in 2 settings: hospital based (34%); non-hospital based i.e. private practice (46%)
  - Some work between hospital and private practice – known to have a “double hat”: 20%

### Guidelines:

#### RA:

- Haute Autorité de Santé (HAS)<sup>(e)</sup>
- FSR - French Society for Rheumatology guidelines published 2014<sup>(c)</sup>
- EULAR/ACR<sup>(f)</sup>

#### Comorbidities:

- CVD: Haute Autorité de Santé (HAS)<sup>(e)</sup>

#### PAGs/ Medical societies:

- Société française de rhumatologie<sup>(g)</sup> (French Society of Rheumatology)

**Sources:** (a) Conseil National de L'ordre des Médecins (National Council of Physicians), 2016 ; (b) KPMG internal sources (c) Gaujoux-Viala et al. (2014) Recommendations of the French Society for Rheumatology for managing rheumatoid arthritis; (d) Guillemin et al. (2005) Prevalence of rheumatoid arthritis in France 2001; (e) HAS (2007) Recommendations for Rheumatoid Arthritis care: diagnosis and management; (f) Smolen et al. (2017) EULAR recommendations for the management of rheumatoid arthritis with synthetic and biological disease-modifying antirheumatic drugs: 2016 update; (g) sfr.larhumatologie.fr; (h) 'Liste A.L.D. 30' available at [http://medicalcul.free.fr/fr\\_ald30.html](http://medicalcul.free.fr/fr_ald30.html)

# The Rheumatology unit

Hôpital Cochin has a whole osteoarticular department (Pôle ostéo-articulaire) which is split between Rheumatology, Orthopaedics, Pain Management and Rehabilitation within Rheumatology. During our site visit we interviewed physicians in the Rheumatology B unit<sup>(a)</sup>

The hospital			
<b>Type</b>	Public, part of the Assistance Publique-Hôpitaux de Paris (AP-HP) <sup>(a)</sup>	<b>Locations</b>	Southern 14 <sup>th</sup> district of Paris
<b>Core services</b>	Inpatient, outpatient, day hospital, bone disease assessment centre, rheumatology nurse-led programmes <sup>(b)</sup>	<b>Population served</b>	Parisian area (Île-de-France ) and beyond
<b>Size</b>	~3,000 patients	<b>Demographics</b>	Adult patients More than 40% of patients come from outside of the Parisian area
The Rheumatology B Unit			
<b>Services</b>	Consultation (outpatient service) Hôpital de jour (ambulatory service) which can include the COMEDRA comorbidity screening and monitoring programme Inpatient service – 27 beds On-site departments of radiology and rehabilitation specifically dedicated to musculoskeletal disorders <sup>(b)</sup>	<b>Collaborations</b>	Hôpitaux Universitaires Paris Centre (HUPC) – made up of 68 sites <sup>(b)</sup>  University of Paris (7 colleges of medicine) <sup>(a)</sup>
<b>Funding and Resources</b>	Government funding – includes social security payments and remuneration for services Paris-Descartes University, Faculty of Medicine Assistance Publique – Hôpitaux de Paris French Society of Rheumatology Industry <sup>(b)</sup>	<b>Teaching/ research scope</b>	Institut Cochin, employs scientists, teachers, clinicians & technicians. The current fields of research in the Rheumatology unit are: outcome measures; evaluation of natural history of rheumatic diseases; diagnostic criteria; disease severity; treatment <sup>(b)</sup>

**Notes:** 1. Calculated by applying national prevalence of RA to Parisian population (2,241,346 as at 19/04/2018)

**Sources:** (a) Hospital Cochin website; (b) KPMG interviews with HCPs treating RA and associated comorbidities; (c) "Mentions légales - Crédits." Ministry of Higher Education and Research.

# The Rheumatology unit (cont.)

## Overview of Services



Service Division	Consultations (outpatient service)	Hôpital de jour (ambulatory care service)	Hôpital traditionnel (inpatient service)
<b>Duration of stay</b>	20 – 30 minutes	1 day (no overnight stay)	> 1 day
<b>Hours of availability</b>	<ul style="list-style-type: none"> <li>– Monday – Friday</li> <li>– 08:00 – 20:00</li> </ul>	<ul style="list-style-type: none"> <li>– Monday – Friday</li> <li>– 07:30 – 18:00</li> </ul>	<ul style="list-style-type: none"> <li>– 24/7</li> </ul>
<b>Capacity (no. of beds/rooms)</b>	<ul style="list-style-type: none"> <li>– 7 rooms</li> </ul>	<ul style="list-style-type: none"> <li>– 10 beds on ground floor</li> <li>– 6 beds on 2<sup>nd</sup> floor</li> <li>– 11 beds on the 3<sup>rd</sup> floor<sup>(b)</sup></li> </ul>	<ul style="list-style-type: none"> <li>– 13 beds on the 2<sup>nd</sup> floor</li> <li>– 14 beds on the 3<sup>rd</sup> floor<sup>(b)</sup></li> </ul>
<b>No. of patients seen</b>	<ul style="list-style-type: none"> <li>– 6,848 patients seen in 2017</li> </ul>	<ul style="list-style-type: none"> <li>– 2,885 patients seen in 2016</li> </ul>	<ul style="list-style-type: none"> <li>– 703 patients seen in 2016</li> </ul>
<b>Patient type catered to</b>	<ul style="list-style-type: none"> <li>– Patients with mild-moderate RA i.e. likely to be in remission</li> </ul>	<ul style="list-style-type: none"> <li>– Patients with moderate RA receiving infusion therapies (biologics)</li> </ul>	<ul style="list-style-type: none"> <li>– Patients with severe RA and severe comorbidities requiring inpatient treatment and intensification of therapy</li> </ul>
<b>Services offered</b>	<ul style="list-style-type: none"> <li>– Multidisciplinary management of hospitalised patients is carried out in collaboration with the paramedical team</li> </ul>		
<b>Specific tools</b>	<ul style="list-style-type: none"> <li>– Regular follow-up consultations provided by rheumatologists, determined by patient pathology</li> <li>– Measuring and recording of DAS28 scores</li> <li>– Medication review</li> </ul>	<ul style="list-style-type: none"> <li>– Infusion therapies</li> <li>– Medication review</li> <li>– “One-stop-shop” for patient care <sup>(a)</sup></li> <li>– <i>Where applicable:</i> Full day care setting for COMEDRA<sup>1</sup> assessments i.e. screening, radiological investigations, blood tests, consultations</li> <li>– <i>Where applicable:</i> COMEDRA follow-up sessions</li> </ul>	<ul style="list-style-type: none"> <li>– Daily assessment</li> <li>– Daily MDT input</li> <li>– Radiological investigations</li> <li>– Blood tests</li> <li>– Modification/ intensification of management plan</li> </ul>

Notes: 1. For full COMEDRA explanation please see slide 175

Sources: (a) KPMG interviews with HCPs treating RA and associated comorbidities (b) <https://www.cochin-poa.com/les-services/rhumatologie/>

# The team

## Core team profiles

- 18 rheumatologists
- 40 rheumatology nurses
- 3 rheumatology researchers
- 2 pharmacists
- 1 service coordinator
- 2 comorbidity coordinators
- 2 physiotherapists
- 2 social assistants
- 1 psychologist
- 1 dietician
- 1 occupational therapist
- 1 orthopaedic surgeon
- 1 podiatrist

## Affiliate team profiles

- psychiatrist
- psychologist
- cardiologist
- pulmonologist
- endocrinologist/ diabetologist
- Referrals to comorbidity specialists are made from rheumatologists to the patient, who then takes ownership of this and takes the referral to their primary care physician (PCP) or existing community-based rheumatologists, who then refers to another specialist



## Key features of the care delivery team

- **Core team specialised in rheumatic diseases** (osteoporosis, osteoarthritis, RA, spondyloarthritis, sclerosis and chondropathies): rheumatologists can specialise in one or multiple areas and can split their time between private practice, research and other commitments
- **Research nurses:** there are rheumatology nurses within the department who are dedicated to research
- **Dedicated internal pharmacy office:** there are two full-time, specialised “clinician pharmacists” working together with undergraduate pharmacy students. They actively participate in inpatient care (in particular, checking drug treatment adherence)
- **Strong MDT presence:** MDT consists of the core team with multiple meetings in place adapted to patient profiles and requirements. There is an annual meeting for the Rheumatology departmental meeting to discuss research findings
- **Training and upskilling of staff:** all rheumatology nurses in the department are upskilled according to EULAR recommendations as standard. One rheumatology nurse has obtained an additional university qualification in rheumatology nursing and two rheumatology nurses have undergone 60-80 hours of training in order to become qualified ETP practitioners. Fellows in the department are encouraged to partake in research and perform literature reviews as a contribution to RHEVER meetings<sup>(a)</sup>

## Governance and processes

### Team meetings:

- Daily MDT meetings for inpatient care
- Weekly MDT meetings for ETP
- Monthly MDT meetings (grand rounds) to present interesting cases
- Bi-monthly interdepartmental meetings
- Annual research team meetings

### Protocols:

- RHEVER guidance on standardised reporting for RA and comorbidities
- COMEDRA protocols
- ‘Expert Rheumato’ guidance comes from a study and advises which comorbidities to screen for

### Patient records:

- EHR for Rheumatology department
- COMEDRA checklist is aligned to the EHR system in order to capture comorbidity data

### Pharmacy:

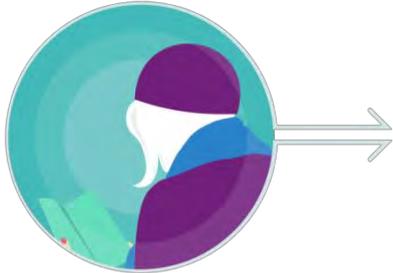
- Two specialised clinician pharmacists
- Centralised according to the hospital guidelines
- Links to the RHEVER network allow community physicians to prescribe biologics

Sources: (a) KPMG interviews with HCPs treating RA and associated comorbidities

# Overview of interventions in place for RA

## Awareness & Prevention

Symptom identification



## Referral & Diagnosis

In secondary care



## Treatment & Management

Pharmacological management

Non-pharmacological management



## Follow-up

Monitoring of chronic disease/flare up



Interventions

### General awareness of RA

- ‘Les Rhumatismes en 100 questions’<sup>(a)</sup> is an ‘FAQ’ information guide and website ([www.rhumatismes.net](http://www.rhumatismes.net)) for patients to answer common questions about Rheumatic conditions
- Widely disseminated to both patients and local HCPs (including community-based rheumatologists and PCPs<sup>(b)</sup>)

### Access to radiology investigations

- One of the first RA centres to offer echography and ultrasonography as an aid to diagnosis and consequent monitoring of disease activity<sup>(b)</sup>
- Allows accurate and timely diagnosis of RA as well as monitoring in follow-up

### Patient education and advice

- All patients are given the option to undertake ETP. ~10% accept.
- The programme is also offered to carers<sup>(b)</sup>

### Patient self-assessment guide

- Provided at first appointment for COMEDRA. Covers background and key features of joint examination to enable patients to self-assess and self-monitor disease activity<sup>(b)</sup> empowering patient to feel comfortable assessing and monitoring their own disease<sup>(c)</sup>

### Extensive MDT discussion

- Daily, weekly, monthly & bi-monthly meetings to ensure efficient decision making and rapid access to the right treatment

### Locally authored guidance

- RHEVER guidance to standardised reporting procedures enable effective disease monitoring within centre and across a network

### ETP: classical education

- Physician led education that covers treatment, medication, nutritional advice<sup>(b)</sup>

### Pharmacist-led therapeutic education

- Enables patients to understand and accept treatment
- Educational leaflet about each drug, consumption and possible side effects is also provided
- Delivery of this session is tracked via EPR<sup>(b)</sup>

### Paratherapeutic sessions

- As part of ETP, integrative services are provided (1-2 times a month). These include Tai Chi, psychomotricity, sophrology (relaxation techniques), socio-aesthetics and writing classes are offered by volunteers as a continuation of therapy

### Ad hoc prescription of Physiotherapy

- Offered to support patients in their mobility (b) empowering patients to maintain daily living and quality of life<sup>(b)</sup>

### Standardisation of reporting through RHEVER network

- Creation of standardised pro formas which ensure consistency in monitoring and follow-up<sup>(b)</sup>

### Monitoring of patient-reported outcomes of disease activity

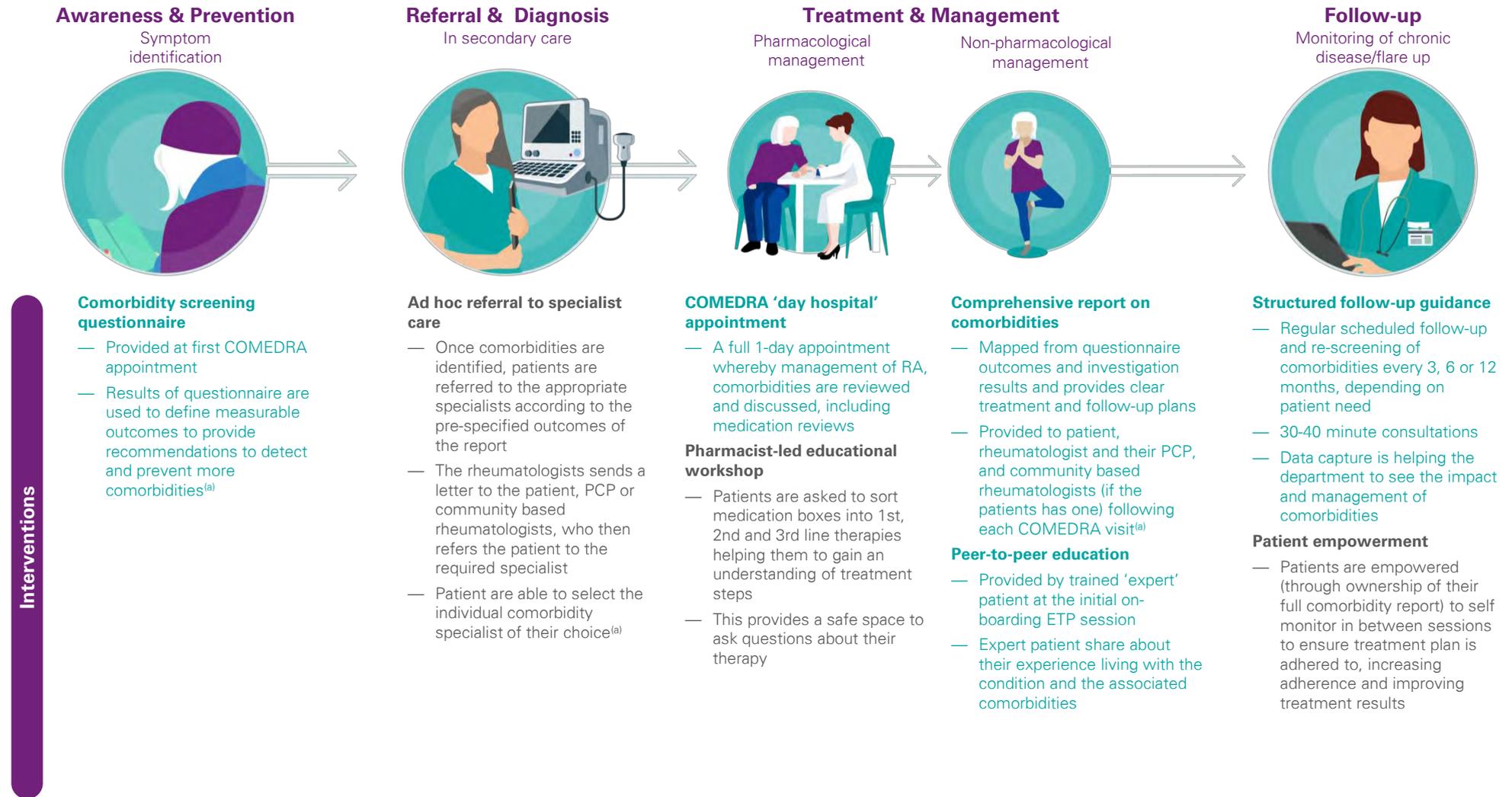
- Questionnaire which reviews patient symptoms over the 8 days preceding their outpatient appointment to help focus the consultation<sup>(b)</sup> to better understand disease activity and proactive management

### Patient self-monitoring of DAS and self-examination

- Patients are given a DAS calculator as part of the COMEDRA programme which enables them to monitor their
- Measurements are requested to be taken every 1-3 months to establish trends in disease activity and adjust treatment and management accordingly<sup>(b)</sup>

Sources: (a) KPMG interviews with HCPs treating RA and associated comorbidities (b) <http://www.rhumatismes.net/ind>

# Overview of interventions in place for RA comorbidities



Sources: (a) KPMG interviews with HCPs treating RA and associated comorbidities

# These interventions have improved outcomes



How do you quantify the benefits in RA?

**Objective measures (KPIs):**

- DAS 28
- Radiological imaging: Echography

**PROMs:**

- HAQ-DI questionnaire
- Pain VAS

**Centre routinely measures comorbidity outcomes by:**

- Objective measures:
  - Use of screening and monitoring questionnaires (e.g.RAPID-3 and calcium score)
  - Regular follow-up as part of COMEDRA programmes

**PROMs:**

- HAQ-DI
- RAPID 3

How have these interventions improved patient outcomes?

**RA (ETP)**

- Benefit: “Helps alleviate loneliness and self-esteem issues”, “Enables patients to exchange tips for improving their quality of life and day-to-day life”
- Quantitative output:

**Comorbidities (COMEDRA)**

- Benefit: Allows monitoring of comorbidities and comorbidity management
- Quantitative output: Increased detection and prevention of comorbidities



DAS 28 form



HAQ-DI questionnaire



Cochin's comorbidity screening and monitoring questionnaire

**“PROMs are key”**  
- Prof. Maxime Dougados

Sources: (a) KPMG interviews with HCPs treating RA and associated comorbidities

# How can care be improved?



## What is next for the centre?

**Overview:** The rheumatology unit at Cochin is undergoing restructuring to optimise delivery of services. The new unit will consist of two treatment centres: one with 12 inpatient beds, another with 12 ambulatory armchairs. Patients will be able to attend either a full day or half day review at the “Hopital du Jour”, depending on their disease severity and needs

- **Why?** The restructure is aimed at optimising efficiency, and will enabled tailored services based on the needs of the patients. Consolidation of services is also expected to provide better access to education for all patients with RA
- **How?** Changing the physical layout of the centre, provision of rheumatology nurse led care, and enabling identification of personalised patient needs.

**Overview:** The rheumatology team will soon employ technology as a means of recording and measuring PROMs

- **Why?** Technology-enabled reporting of PROMs is a means of empowering the patient, as well as lessening the administrative burden to both the patient and HCP of populating questionnaires on the day of consultation
- **How:** PROMs (HAQ, RAPID 3, comorbidities) will be collected prior the visit and/or the hospitalisation by the patient at home on a specific website; “AP-HP Portail Patient”. The results will then be available to HCPs when the patient is seen in the outpatient or inpatient setting

**Overview:** The rheumatology unit is aiming to grow the RHEVER network and increase engagement with local community based rheumatology practices in Paris

- **Why?** To ensure a greater volume of patients with RA are able to have access to the same standards and quality of care, including treatment with biologics where appropriate
- **How?** Using technology to empower the HCPs and patients outside of the main hospital setting, including apps to enable patient education and monitoring. Individuals throughout the network involved in management of patients with RA should also receive comprehensive training and education to truly understand the complications of the disease and how it impacts day to day life of the patients



## What advice would you give less specialised centres?

**Overview of advice:** It is important to be able to demonstrate the value of a day hospital visit, providing disease monitoring, follow up and education during a single appointment, through a robust base of clinical evidence

- **Why?** To ensure this service can be offered to patients with RA and the hospital receives a fair reimbursement
- **How?** Establishing a baseline measurement of the outcomes of patients with RA and comparing the difference for those enrolled in follow up provided in a “Hopital du Jour” setting

Sources: (a) KPMG interviews with HCPs treating RA and associated comorbidities

# Case studies

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# Case study 1

## Hospital and City Rheumatology Network: **RHEVER**

### Overview

- RHEVER (Réseau Hôpital et Ville en Rhumatologie) is a professional practice network established in 1999
  - It consists of 30 rheumatologists (in private practice and/or full-time hospital practice, some also work part time in hospitals) who meet to determine uniform reporting and care delivery standards across the network

**Note:** Hospital based rheumatologists from: Cochin Hospital, St. Joseph Hospital, Le Mans Hospital, Meaux Hospital and Mantes La Jolie Hospital. Private practice rheumatologists from: Ile De France and Amiens

**Sources:** (a) Interview with Professor Maxime Dougados; (b) Interview with Dr. C. Hudry; (c) The Most Frequent Fears and Beliefs of 226 Patients with Rheumatoid Arthritis or Spondyloarthritis. Using a Novel Questionnaire Gossec, L et al. Value in Health, Volume 18, Issue 7;

### What is the rationale?



- Objective is to improve the standards of patient care by better standardising practices among its members through educational activities and professional practice assessments (PPAs)
- The aim is to avoid “cross-treatment” of patients by multiple HCPs<sup>(a)</sup>
- This will also help to reduce patient drop-out rates between care settings

### What are the key features of the intervention?



- The RHEVER network hold meetings 3 times a year, in the evening to ensure full attendance
- All the members are invited and there is often a high turnout (at least 27/30 attend)
- At each meeting they evaluate general questions regarding RA treatment
  - E.g. ‘How to evaluate adherence’ and ‘The minimal required data to be recorded during a visit’

### Prior to the meeting:

Prior to each meeting, the members are sent a survey on the topic at hand and the results are analysed by the fellows from Hôpital Cochin through a systematic literature review which can then lead to the proposal of a study

### What are the key features of the intervention?



### During the meeting:

#### Outline Agenda

- 5PM: Light refreshments / dinner served
- 6PM: Review questionnaire responses
- 7PM: Fellow presents back findings of systematic literature review
- 8PM: Members discuss the outcomes of the review and discuss next steps (e.g. whether to undertake a study)
- 9PM: General discussion and Networking

#### After the meeting:

- Put agreed outcomes into practice
- Ad hoc communication between network members

### What are the outcomes so far?



- Standardised care: RHEVER determined ‘minimal required data to be recorded during a visit’ in 2005. This was used to standardise reporting across the network<sup>(b)</sup>
- Key barriers to comorbidity assessment were identified, including: lack of time, complexity of risk assessment, and lack of training
- A RHEVER study showed that EULAR guidelines are in fact sufficient for RA care delivery

## Réseau Hôpital et Ville en Rhumatologie (RHEVER) Network

### Benefits



#### RHEVER

- There are standardised recording pro formas and frameworks for data capture which are in use throughout the network. This ensures uniform data reporting in Private Practice and Hospital settings (i.e. at Cochin), leading to greater efficiency and transfer of data
- Patients have access to the full spectrum of treatment options. This is supported through the ability to prescribe biologics due to research links to the hospital
- RHEVER purports, through its studies and literature reviews, that assessing professional practice is possible within a network

### Challenges



#### RHEVER

- RHEVER identified key barriers to comorbidity assessment including: lack of time for HCPs, complexity of risk assessment, and lack of training for HCPs<sup>(c)</sup>
- Although recording is standardised, there is currently no uniform system for EMR (Electronic Medical Records) between Hôpital Cochin and the private practices



“This network has allowed me to exchange clinical knowledge with my peers and improve patient care”

– Rheumatologist involved with RHEVER



**Sources:** (a) KPMG interviews with HCPs treating RA and associated comorbidities (b) Joint Bone Spine. 2007 Mar;74(2):171-4. Epub 2007 Feb 5 (c) Arthritis Care & Research Vol. 65, No. 5, May 2013, pp 712–717

# Case study 2

## Education Programme for Patients and Carers: **ETP**

### Overview

- ETP (Education thérapeutique du patient) is a programme run by the team at Cochin to help patients with accepting their disease and to assist with comorbidity prevention<sup>(a)</sup>
- It is a government-accredited intervention. HCPs have to be certified in order to deliver it. (a 60-80 hour course is required to get a certificate in ETP)
- Able to be nurse-led

**Note:** 1. These patients and their carers have the opportunity to continue therapy to give patients a sense of self – aside from the 2 days, free of charge. Offered to complete the treatment and empower the patient.

**Sources:** (a) KPMG interviews with HCPs treating RA and associated comorbidities ; (b) <http://hopitaux-paris-centre.aphp.fr/nos-programmes-deducation-therapeutique/>; (c) Revue du rhumatisme 81 (2014) 303-312

### What is the rationale?

- Patient Therapeutic Education (ETP) is intended to help a person with chronic/ rare illnesses and those around them to maintain or acquire the skills they need to better care for themselves and better live their daily life<sup>(b)</sup>
- The goal of education is empowerment<sup>(a)</sup>

### What are the key features of the intervention?

**Frequency** 1 ETP session per month (for either RA, SpA, Sclerosis, Carers)  
1 therapeutic leisure- time session per week  
"Carer's Day" – held annually on 21st June (National Music Day in France). On this day they have education sessions in the morning and leisure sessions in the afternoon.

**Timings** 9am-5pm with a lunch break

**No. of participants:** 3-8 patients per session

### Staff members involved

**Members of the core MDT** 1 ETP lead rheumatologist, 2 ETP rheumatology nurses, pharmacists psychomotricity students

**Para-therapeutic Practitioners<sup>1</sup>** e.g. Sophrologists, Socio-aestheticians, writing volunteers.

### What are the key features of the intervention? (cont.)

'Classical education' is carried out over 2 days for patients and over 1 day for carers<sup>(c)</sup>

### Outline Agenda

AM:

- Rheumatologist presents an overview of RA including its causes, treatment and management
- At the end of the morning Dietitian talk to patients about nutrition

PM:

- Lunch
- Rheumatology nurses discuss blood test results, hygiene, vaccinations and travelling, emergency provisions for travelling
- Pharmacist hosts an interactive workshop to enable patients to understand treatment steps as well as some of the rationale behind treatment intensification

### Outline Agenda

AM:

- Focused on living day to day life with RA, with input of expert patients. Topics discussed in particular are fatigue, pain, intimacy and living with a partner, tips on how to cope with the disease e.g. Occupational Therapy considerations and modifications

PM:

- Psychomotricity session (focuses on the relation between the mind and movement)
- Closing session to ask participants if they have any questions and discuss the next steps

### Which guidelines are used?

Recommendations from the French Society of Rheumatology on RA management "Pour dépister et prévenir les maladies associées aux rhumatisme inflammatoire chronique" provide robust and clear guidance on the uses and implementation educational therapy<sup>(c)</sup>



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# Education Programme for Patients and Carers: ETP (cont.)

## What are the outcomes so far?

### Improved patient satisfaction

- A PHRC1 research programme conducted at Cochin showed that ETP improves patient satisfaction and outcomes<sup>(a)</sup>

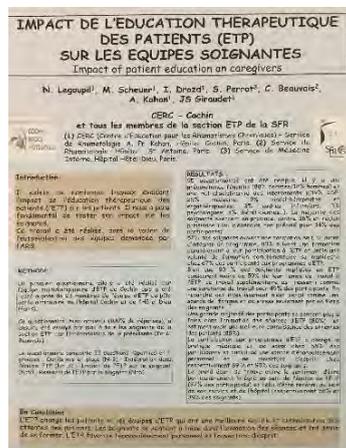
### Increased team cohesion

- The ETP team at Cochin conducted a study with a Medical society to test if ETP is good for the team undertaking it. This was presented as a poster at a conference 5 years ago. The results showed that ETP makes team more cohesive, offers a new way to view consultations and to move away from a paternalistic approach. This paper helped the department demonstrate to the health authorities that they were capable of continuing their ETP programme into the 2000s

Les Rhumatismes en 100 questions – an information guide booklet for patients which contains frequently asked questions on RA. It is also now available online as a website and also handed out as a bookmark so that patients can have easy access. It has been widely disseminated to both patients and local HCPs<sup>(a,b)</sup>



Webpage for 'Les Rhumatismes en 100 questions'



Poster presented at conference detailing the benefits for the RA team

## Benefits



### Benefits to patients

- With collective sessions, the benefit to patient is that other patients can ask the questions that they are scared to. The patient can also see that others have the same problems as them and can gain information about what they can do mediate these challenges

### Benefits to carers

- The Carer's Day is a drive from Hôpital Cochin to show they can offer original care to equip caregivers to cope better and anecdotal evidence shows that this has been very well received
- This also provides a forum for carers to discuss problems especially since there is reported frustration and disappointment surrounding the disease from the carers as well. The carers can share about these and learn how best to mediate and help overcome these

### Benefits to the Rheumatology team

- The Rheumatology team is more cohesive and aligned in their educational approach
- The programme feeds into the main goal of the department i.e. helping patients deal with chronic diseases

Note: 1. Programmes hospitaliers de recherche clinique

Sources: (a) KPMG interviews with HCPs treating RA and associated comorbidities; (b) <http://www.rhumatismes.net/index>

## Education Programme for Patients and Carers: ETP (cont.)

### Challenges



- Time constraints: Some patients want more time, however unfortunately ETP nurses have 'day jobs' aside from the programme
- Access: requires patients to travel to sessions which may sometimes be difficult and thus precludes them from attending
- Recruitment: all patients are given the opportunity to join but very few accept because few see the value as there is a perception and a lack of understanding around the added value of this programme
- Negative connotations of the word 'education'
- There are also many schemes on offer at many hospital sites so retention is a problem
- They also do not want to see patients further along in the disease than themselves as seeing deformations highlights the reality of their disease
- Problems with evaluating outcomes: due to staffing and availability constraints, there is no one available to analyse questionnaires and chase patients for responses

### Tips to replicate this intervention



- In order to run a programme that is officially recognised / accredited, such as ETP, the peers who may want to set up this type of activity may want to take up a qualification course. The hospital needs to provide the nurses with time and resources to be able to attend this training (e.g. adequate shift coverage)
- The intervention needs an enthusiastic and motivated team who are willing to give up their time to this programme (and not necessarily receive reimbursement)
- There is also a need for resources e.g. venue, equipment, refreshments
- Involvement of a pharmacist is key to allay patient fears and educate them

### Other recommendations



- Due to time constraints and patient needs, it would be ideal to have a ETP rheumatology nurse whose role is fully dedicated to ETP (teaching, training and management)

#### In an 'ideal' case:

- A face to face network of ETP rheumatology nurses would be beneficial to allow them to exchange practices
- A virtual learning platform would also be beneficial to allow HCP and patient access to videos / filmed interviews



Now that patients are more empowered, they are demanding more information. Because of these new behaviours, there is a need to manage that

- ETP rheumatology nurse



Patients don't want to go back to 'school' or the hospital, which is why we need to provide them access to practical activities which are more helpful

- ETP rheumatology nurse



It is important to propose but not to impose

- Rheumatologist involved with ETP



ETP is like haute couture for patients, not pret-a-porter...

- Rheumatologist involved with ETP



# Case study 3

## ETP in the community setting (Private Practice)

**As part of our fieldwork, we also went into the community and visited the practice of a rheumatologist from the RHEVER network who with his partners have set up an interesting rheumatology nurse-led ETP model**

### Overview

- ETP in the community setting has been pioneered at this particular private practice due the identification of an unmet patient need to have their fears allayed in the healthcare setting <sup>1</sup>
- The service is offered by a dedicated ETP rheumatology nurse as an adjunct to regular rheumatology consultations
- Patients have access to individualised and group education sessions as well as personalised follow-up
- The overall aim is to help patients understand the personal impact of the disease

**Note:** 1. This particular case was prompted following the outcomes of a study conducted under PHRC (Programmes hospitaliers de recherche clinique) on patient fears and beliefs for patients with RA which showed that “fear of the future is bigger for [patients with RA with comorbidities] than for patients with Cancer or MS”

**Sources:** (a) KPMG interviews with HCPs treating RA and associated comorbidities (b) <http://www.rhumatismes.net/index>



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### Who is involved?

- ETP rheumatology nurse: a community rheumatology nurse (with a professional qualification in rheumatology nursing) currently leads and provides the programme by herself. Her role covers education and screening for comorbidities and she also regularly attends patient consultations with the rheumatologists, especially for new patients
- Rheumatologist: the physician provides the initial referral. This is done ad hoc on a case-by-case basis in the first appointment following diagnosis. This enables appropriate selection of patients for the intervention
- Patients: individual or group sessions are provided. Participants are usually from a ‘very broad, well-educated’ patient population and are likely to have recently been diagnosed with RA

### What are the key features?

<b>Frequency</b>	Ad hoc – patients are referred to the rheumatology nurse by a rheumatologist from the practice on a case-by-case basis
<b>Timings / Duration</b>	45 minutes per consultation
<b>Staff members involved</b>	Rheumatologists from the practice (for referral) ETP rheumatology nurse
<b>Type of consultation</b>	Individual sessions and group sessions are provided. Sessions take place in a room at the private practice where patients can be seen with their family members

### What are the activities undertaken?

#### Topics covered

- Knowledge of the disease
- Pharmacological and non-pharmacological treatments and adherence
- Understanding of blood test results
- Caution and safety principles for immunosuppressive treatment
- Pain management and management of flares
- Day to day living
- How to discuss the disease with family and friends
- Quality of life, particularly the impact on personal and professional life
- Leisure time and hobbies
- Medication

Note: content covered during individual sessions may overlap with group sessions. However, this can ensure ideas and concepts are reinforced(a)

#### Outputs

- The rheumatology nurse will provide the patient with a report prior to starting treatment and which also covers their comorbidities. The patient can then pass on the letter to their PCP if they wish<sup>(a)</sup>

## ETP in the community setting (Private Practice) (cont.)

### What are the outcomes so far?



- The programme has been in place for the last 4 months and will be evaluated at 1 year to assess the outcomes and the business model
- So far, it has received positive feedback from both patients and HCPs
- The community ETP rheumatology nurse intends to set up a feedback questionnaire for patients in order to evaluate the service

### Benefits



- The programme has created a better relationship between patients and the dedicated rheumatology nurse - patients feel comfortable enough to email in any questions they may have and the rheumatology nurse attends the consultation of the patient with the rheumatologists ensuring consistent involvement and knowledge of their patients disease across care settings
- Patients feel that it is more personalised as it is delivered in a community setting

### Challenges



- There may be reduced uptake by rheumatology nurses as there is no funding for this programme and it is therefore voluntary
- The variable workload means it may be hard to budget time and resources appropriately for the programme. The ETP rheumatology nurse in this particular case would sometimes see no patients or up to 5 patients on a given day
- Additionally the rheumatology nurse does not have a proper office and therefore has to find an additional space in the hospital to see patients
- Wider HCP involvement is limited at present as the rheumatologists in private practice are often busy when the sessions take place. The practice have recently submitted an official application to the French health authority to request funding to set up group sessions with 2 specialist rheumatologists

### Tips to replicate this intervention



- Ensure the rheumatology nurses have peers with whom they can discuss as the doctors can sometimes be very busy



Now that patients are more empowered, they are demanding more information. Because of these new behaviours, there is a need to manage that

- ETP rheumatology nurse



# Case study 4

## COMorbidities, EDucation in Rheumatoid Arthritis: **COMEDRA**

**There are 2 comorbidity monitoring programmes in place at Cochin; COMEDRA (for Rheumatoid Arthritis) and COMESPA (for Spondyloarthritis). For the purposes of this case study, we will focus on COMEDRA**

### Overview

- The COMEDRA study demonstrates the benefit of a rheumatology nurse-led programme on RA comorbidity management and the impact of patient self-assessment of disease activity on RA treatment intensification <sup>(a)</sup>
- The COMEDRA programme at Cochin is the implementation of the outcomes of the COMEDRA study in practice, with one day sessions where patients undergo screening and tests for comorbidities
- While the nurse-led programme was carried out in the research study, COMEDRA has now transitioned into a doctor-led programme in clinical practice <sup>(b)</sup>

Sources: (a) Ann Rheum Dis. 2015 Sep;74(9):1725-33 (b) KPMG interviews with HCPs treating RA and associated comorbidities



### COMEDRA research study (rheumatology nurse-led)<sup>(a)</sup>



- The COMEDRA study was conducted in the rheumatology research centre at Cochin in 2015
- It was undertaken to evaluate the impact of a nurse-led programme on comorbidities and the impact of patient self-assessment of disease activity on the management of RA

### Method

- 970 patients were enrolled in a prospective, randomised, controlled, open-label, 6-month trial
- In the comorbidity group (n=482), the rheumatology nurse checked comorbidities and sent the programme results to the attending physicians
- In the self-assessment group (n=488), the rheumatology nurse taught the patient how to calculate his/her Disease Activity Score which had to be reported on a booklet to be shared with the attending rheumatologist
- The number of measures taken for comorbidities and the percentage of patients recording a change (initiation, switch or increased dose) in disease-modifying antirheumatic drugs (DMARDs) in the 6 months follow-up period of the study defined the outcomes of the trial

### COMEDRA research study (rheumatology nurse-led)<sup>(a)</sup>



### Outcomes

- The number of measures taken per patient was statistically higher in the comorbidity group
- DMARD therapy was changed more frequently in the self-assessment group
- Given these outcomes, the team at Cochin decided to apply the COMEDRA programme into practice, opting for a doctor led model taking into consideration the way the French healthcare system works

### COMEDRA in daily practice



- This is the programme currently in use at Cochin
- Adapted from the COMEDRA research study to be implementable in clinical practice
- It is led by doctors, with the support of a programme coordinator

# COMorbidities, EDucation in Rheumatoid Arthritis: COMEDRA (cont.)

## What are the key features?



Frequency: Ongoing: Started last June 2017 at the day hospital (Hopital de jour). Full day-care (1st appointment) is only needed every 3-5 years

Timings: Whole day (10am – 4pm)

Participants: 36 patients with RA (102 patients in total for RA and SpA). 2-4 patients per room / bay of beds in a 'day care'

Inclusion criteria: 'Fragile patients' i.e. those on biologics. Usually all patients who are referred agree to take part

HCPs involved: Rheumatologist, Rheumatology fellows, programme coordinator, day-hospital coordinator

Materials required: Patient information video, USB (patient's), questionnaire to be populated by patients and staff, DAS calculator

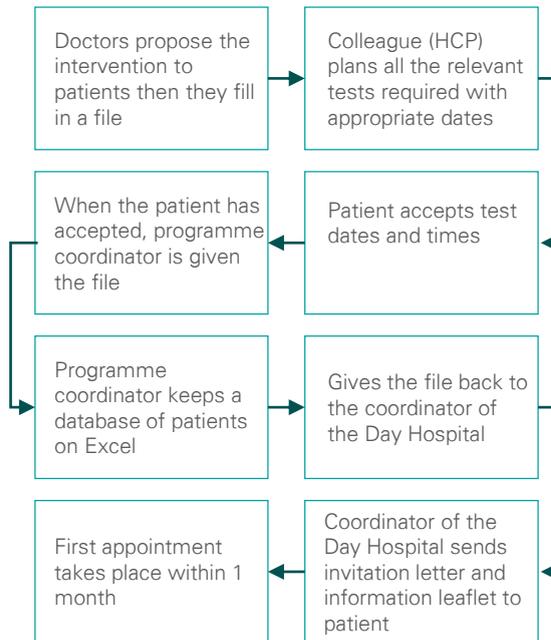
Funding: Receive a reimbursement from the government for each patient per session. A higher amount is given for the full 'Day Care' session

## What are the key features? (cont.)



### The referral pathway for COMEDRA:

There is a clearly mapped journey for patients with RA and the monitoring of comorbidities at Cochin. This has been based upon the methodology of the COMEDRA study



Snapshot of patient file used throughout programme



Snapshot of information leaflet which is sent to patient



Snapshot of checklist for tests which is completed by the programme coordinator

Note: 1. Programmes hospitaliers de recherche clinique  
Sources: (a) KPMG interviews with HCPs treating RA and associated comorbidities (b) <http://www.rhumatismes.net/index>

## COMorbidities, EDucation in Rheumatoid Arthritis: COMEDRA (cont.)

### What are the key features? (cont.)



#### At the first appointment:

##### Outline Agenda

##### AM:

- Programme coordinator provides patients with a comorbidity screening questionnaire<sup>1</sup> to complete
- The patients are then shown a self-examination video (~10 minutes) and are given the opportunity to download it onto a USB stick as advised in the invitation letter
- DAS28 score of each patient calculated by coordinator and mapped onto a form

##### PM:

- Final report provided to the patients at the end of the day by the coordinator
- This report is a summary of the questionnaire outputs, the responses are checked by the registrar throughout the day

Note: 1. This screens for the patients' history of the following disease areas; past medical history, family medical history, medication history, vaccinations, cardiovascular history, respiratory history, gynaecological/urological history, dermatological history, dentistry, gastrointestinal history and orthopaedic history. The questionnaire also captures calcium calculations, HAQ, previous DAS28 scores and disease activity over the preceding week

Sources: (a) Ann Rheum Dis. 2015 Sep;74(9):1725-33

### What are the key features? (cont.)



#### Monitoring and Follow-up:

##### Monitoring

- Each patient is given a DAS calculator and a pack which contains guidance and forms to help them assess their RA, together with the coordinator's contact details. This is sponsored by an industrial
- Patients are asked to self-measure DAS once a month, every time they get blood tests results (ESR measured every 3 months in France) or when patients flare. Therefore physicians will always have an ESR result at least every 3 months if it is not possible to measure monthly

- The patients are given a log to record their results and this is reviewed together with the doctors at their next appointment

- Painful > swollen: Patients are taught to self-examine and are usually more able to detect painful joints than swollen ones

##### Follow-up

- Every 3 months, every 6 months or every year
- Rheumatologists decide on the frequency of follow-up appointments depending on disease severity



Self-examination video

Final report given to patient

## COMorbidities, EDucation in Rheumatoid Arthritis: COMEDRA (cont.)

### Benefits



- This has enabled increased timely identification and prevention of comorbidities
- It has promoted increase awareness of the importance of comorbidities within RA and their monitoring
- COMEDRA has provided guidance to HCPs on the management and monitoring of comorbidities
- Patients have received timely diagnosis and treatment of comorbidities

### Challenges



#### At the level of the Healthcare System

- There is no reimbursement for rheumatology nurses and very few rheumatology nurses
- There is a lack of capacity and flexibility for rheumatology nurses who are involved in COMEDRA study to participate in the daily practice
- This is due to the fact that rheumatology nurses do not necessarily have the same responsibilities as the doctors

### Challenges (cont.)



#### At the hospital level

- Delivery is not standardised across centres
- Currently Cochin does not have a trained rheumatology nurse which would not only help with the COMEDRA implementation but also other programs which nurses are not adequately qualified to run. This increases the burden of time limited physicians (rheumatologists)
  - When the COMEDRA doctor-led programme started, Cochin had 1 of the original COMEDRA research rheumatology nurses on board meaning practice was seamlessly transitioned from research into practice
- Need to embark more Rheumatologists to manage patients ongoing

#### In a Community/ Private Practice setting

- There is a heavy burden on the care delivery of patients with RA in the secondary care setting. This could be alleviated with the use of COMEDRA self-assessment questionnaire for comorbidities, helping maintain patients to outpatient visits

### What are the outcomes so far?



- Because this programme has originated from a study, it has applicability across France, and therefore it is not only Cochin patients benefit from this intervention
  - It has also been used at other centres e.g. Toulouse
- Study outcomes have also been used to inform national and international guidelines e.g. NICE guidelines



Sources: (a) KPMG interviews with HCPs treating RA and associated comorbidities



# Sint Maartenskliniek

Nijmegen, Netherlands



# Summary



## Context

- **Leading hospital in the Netherlands for rheumatology** recognised as a EULAR Centre of Excellence as well as the best Elsevier Rheumatology practice in the Netherlands. The centre was awarded best practice outpatient clinic in 2016
- **Strong collaborative culture** that encourages communication amongst all healthcare professionals (HCPs) involved in RA care
- **Rapid access to appointments** < 2 weeks wait-time to access all aspects of RA care through a one-stop-shop model (consultation, radiology, blood tests, pharmacy)
- **Evidence-based centre guidelines** to diagnose and treat rheumatology diseases through 20+ protocols, with related performance indicators that are updated annually
- **Strong research focus** within the department in collaboration with Radboudumc University teaching hospital
- **Innovative policies** to improve quality of care within the centre such as preference policy for biologics<sup>1</sup>, intervision sessions with rheumatologists, dose reduction studies with biologics, research on treatment concordance and experiments with flat fee RA pricing



## Key strengths in the delivery of RA care

- **Continuous education and behavioural change training** for all HCPs to help them provide the best advice to patients with a unified 'one voice' approach
- **Smart clinic design and a one-stop-shop to streamline care** with a carefully considered clinic design to optimise the time patients have to spend with HCPs
- **Role of the pharmacist** is a key component of care delivery: collaborating with prescribers to provide high-quality pharmaceutical care combined with cost-effective use of medication
- **Effective measurement and tracking of practice to improve quality of care** by establishing clear goals and standards of care through defined in-centre protocols and guidelines; and by gathering baseline and measure improvements in quality of care
- **Creation of national satellite sites** to spread best practice nationally through embedding practices into other rheumatology hospital departments across the Netherlands



## Key challenges faced in delivery of RA care

- Increasing burden on administration tasks to measure outcomes for care and better coordinate service between levels of care
- Increasing costs of maintaining electronic database system across the department
- Difficulty in measuring, tracking and monitoring the level of rheumatology care in other departments across the Netherlands due to lack of availability of data collection and computation in other hospitals
- Training primary care physicians (PCPs) to improve quality of referrals of patients to the centre

Sources: (a) KPMG interviews with HCPs treating RA and associated comorbidities; (b) Clinical and Experimental Rheumatology 2008; 26: 343-346.

# RA Dutch healthcare system overview



## Dutch healthcare system overview:<sup>(b)</sup>



### Focus:

The Dutch government has three main goals for the healthcare system: quality of care, accessibility to care and affordability of care. Extra attention is now being paid to integrated care for chronic diseases and care for people with multi-morbidities, and the shift of care to lower levels of specialisation: e.g. from hospital care to PCP care to practice nurse to self-care.

### Access to healthcare:

Essential healthcare services are within easy reach for almost the entire population, and waiting times for services in most cases meet national standards (four weeks for initial hospital consultation and for diagnostics, seven weeks for treatment).

### Service provision:

Public health services are primarily the responsibility of municipalities and include prevention, screening and vaccination.

### Interventions:

A programme of experimental models of integrated care for the elderly going beyond the boundaries of existing legislation and financing structures is in place, with 125 specific projects taking place between 2008 and 2016.

### Funding:

Healthcare is principally (72%) financed through the compulsory health insurance contributions from citizens, with an additional 13% from general taxation.

The basic benefits package (basisverzekering) includes PCP care, maternity care, hospital care, home nursing care, pharmaceutical care and mental healthcare. The first €385 (in 2016) must be paid out of pocket, except for PCP consultations, maternity care, home nursing care and care for children under the age of 18.<sup>(c)</sup>

## Rheumatoid Arthritis in the Netherlands:



### Patients:

- Prevalence: 1.4%<sup>(d)</sup>
- RA is more prevalent in females (1.8%) than males (1.1%) and with increasing age<sup>(d)</sup>

### Physicians:

- The number of Rheumatologists per '000 population is 1/80<sup>(f)</sup>
- Physician Assistants can provide RA consultations, often for repeat or stable patients and can prescribe

### Guidelines:

#### RA:

- Royal Dutch Society for Physical Therapy: KNGF-Guideline for Physical Therapy in patients with RA<sup>(e)</sup>

#### Comorbidities:

- Royal Dutch Society for Physical Therapy: KNGF Guideline – Cardiac rehabilitation (identification of RA as an independent risk factor for cardiovascular diseases)

## RA challenges in the Dutch healthcare system

- Limited number of rheumatologists due to a reduced number of doctors training in recent years<sup>(b)</sup>
- The treat-to-target model is not automatically adopted in the elderly patient population due to a more short-term management approach with less emphasis on the prevention of joint erosions

## Dutch healthcare system overview:<sup>(b)</sup>



The Dutch healthcare system underwent revision in 2006. More competition and less regulation in the sector now means that health insurers and healthcare providers have more freedom in negotiating the prices of treatments and services. Also, patients can choose their own health insurance and healthcare providers.<sup>(a)</sup>

**Notes:** includes RA and rheumatism

**Sources:** (a) <https://www.zorgverzekering.org/eng/general-information/dutch-healthcare-authority/> (b) [http://www.euro.who.int/\\_data/assets/pdf\\_file/0016/314404/HIT\\_Netherlands.pdf](http://www.euro.who.int/_data/assets/pdf_file/0016/314404/HIT_Netherlands.pdf) (c) <https://www.zorgverzekering.org/eng/general-information/> (d) <https://www.volksgezondheidszorg.info/onderwerp/reumato%C3%AFde-artritis-ra/cijfers-context/huidige-situatie> (e) <https://www.fysionet-evidencebased.nl/index.php/kngf-guidelines-in-english> (f) [https://www.nao.org.uk/wp-content/.../07/0809823\\_international\\_comparisons.pdf](https://www.nao.org.uk/wp-content/.../07/0809823_international_comparisons.pdf)

# The Rheumatology unit

Sint Maartenskliniek is a large public hospital situated in the south-eastern part of the Netherlands. It has links with five other satellites sites with which they share best practice interventions and learnings

## The hospital



<b>Type</b>	Public hospital founded in 1936	<b>Locations</b>	Primary location in Nijmegen with collaborations in other hospitals through satellite sites in 5 other locations
<b>Core services</b>	Main specialties: orthopaedics, rheumatology, rehabilitation anaesthesiology Support specialties: pharmacy, radiology, internal medicine, paediatrics, laboratory services	<b>Population served</b>	42,000 patients 10,000 Rheumatology patients across all satellite sites
<b>Size</b>	Annual turnover €175 m No of beds: 216 No. of medical specialists: 125	<b>Demographics</b>	Primarily patients from the Netherlands, with some German patients who cross the border

## Department of Rheumatology



<b>Services</b>	Rheumatology department focuses on inflammatory diseases and osteoarthritis. Services include consultations, radiology, blood tests, pharmacy  Waiting lists for appointments are less than two weeks, with referrals largely coming from PCPs and community rheumatologists for second opinion	<b>Collaborations</b>	Close collaboration with Radboudumc hospital with which they share a 'multidisciplinary' inpatient ward with 8 beds  Collaborations with other Rheumatology Departments in hospitals across the Netherlands to set up satellite sites in their Rheumatology Department: Boxmeer, Woerden, Nijmegen, Panningen, Geldrop
<b>Funding and Resources</b>	Funding and resources available from insurers. The rheumatology department is experimenting with flat-fee pricing for patients with RA, an innovative arrangement with Dutch insurers to have a fixed-fee for all patients with RA treated at the centre	<b>Teaching/ research scope</b>	Strong research focus with active patient involvement in research, 15 PhD students and 35 published articles per year on: dose optimisation of biologics, transition to biosimilars, efficacy of non-pharmacological treatments for osteoarthritis, psoriatic arthritis, Polymyalgia Rheumatica, gout and adherence/concordance of patients to medication

Sources: (a) KPMG interviews with HCPs treating RA and associated comorbidities (b) <https://www.maartenskliniek.nl/reumatologie>

# The Rheumatology unit (cont.)

## Overview of Services



Service Division	Outpatient service	Inpatient service
<b>Duration of stay</b>	1 – 5 hours depending on level of care needed (e.g. radiology scans or infusions)	
<b>Hours of availability</b>	8:00 am – 17:00 pm Monday – Friday	
<b>Capacity (no. of beds/rooms)</b>	23 consultation rooms	
<b>No. of patients seen</b>	New patients per year: 7,000 Follow-up appointments: 7,800 (includes Maartenskliniek and all satellite sites)	
<b>Patient type catered to</b>	<ul style="list-style-type: none"> <li>- Outpatients are given a referral consultation primarily by their PCP or community rheumatologists who would like a second opinion</li> <li>- All patients with RA receive structured follow-up at varying frequencies depending on disease severity (every 3 / 4 months for severe patients and once or twice a year for stable patients)</li> </ul>	<p>Inpatient services are provided by Radboudumc Hospital who have eight inpatient beds (the number of beds needed by Maartenskliniek has drastically decreased over the years due to early diagnosis and treatment of RA)</p>
<b>Services offered</b>	<ul style="list-style-type: none"> <li>- First appointment offered &lt; 2 weeks, with variance depending on standard referral (&lt;9 working days) or urgent referral (&lt; 2 working days)</li> <li>- During the patient visit the following services are provided: consultation with a physician or physician assistant and a rheumatology nurse, radiology, blood tests, infusions, medication collection in the pharmacy</li> </ul>	

Sources: (a) KPMG interviews with HCPs treating RA and associated comorbidities



# The team

## Core team profiles

- 23 rheumatologists
- 2 rheumatologist trainees
- 5 physician assistants
- 8 rheumatology nurses
- 4 pharmacists
- 23 pharmacy assistants



## Affiliate team profiles

- There is no affiliate team within the clinic as core focus is on rheumatology care
- Additional services relating to physiotherapy, occupational therapy and psychotherapy are outsourced as required

## Key features of the care delivery team

- **Strong focus on core expertise of RA care** with outsourced periphery care such as physiotherapy, occupational therapy and psychological services
- **Collaborative non-hierarchical culture** where all HCPs receive training on communication skills and latest research to ensure a consistent and collaborative 'one voice' approach
- **Protocols, performance indicators and tools** to measure, report and track outcome measures to support the improvement of standards of rheumatology care

## Governance and processes

### Team meetings:

- Weekly two-hour management team meetings
- Team meeting every week attended by all physicians and physician assistants from the satellite sites, including one rheumatology nurse based on a rota, in person at Maartenskliniek

### Protocols:

- Specific centre guidelines with 20+ protocols in place for all rheumatology conditions
- Each protocol has performance indicators which are measured and tracked through the online data warehouse
- Protocols updated annually

### Patient records:

- Digital patient records in place since 2012 managed in the departmental online data warehouse with varying levels of access for HCPs

### Pharmacy:

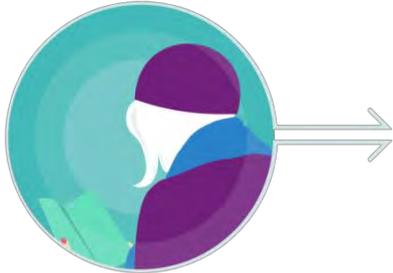
- Outpatient pharmacy within the rheumatology department where all medication is distributed, including those required for comorbidities

Sources: (a) KPMG interviews with HCPs treating RA and associated comorbidities (b) [http://www.euro.who.int/\\_\\_data/assets/pdf\\_file/0016/314404/HIT\\_Netherlands.pdf](http://www.euro.who.int/__data/assets/pdf_file/0016/314404/HIT_Netherlands.pdf)

# Overview of interventions in place for RA

## Awareness & Prevention

Symptom identification



## Referral & Diagnosis

In secondary care



## Treatment & Management

Pharmacological management

Non-pharmacological management



## Follow-up

Monitoring of chronic disease/flare up



Interventions

### HCP training and coaching

- Tailored training courses and coaching for rheumatology nurses, physicians and pharmacists on protocols, latest research and communication techniques, conducted by external coaches and internal RA team members

### Behavioural change programmes

- Goal-oriented workshops for the Rheumatology Department to successfully implement specific programmes

### Telephone triage

- Rheumatology nurse-led telephone triage system to respond to patient queries within 24h or 48h depending on patient segmentation

### Protocols to standardise quality of care

- 20 + protocols to standardise quality of care across the patient pathway
- Daily measurement of protocol performance indicators to collect clinical outcomes

### Creation of national satellite sites

- Maartenskliniek best practice spread to volunteering rheumatology departments in Dutch hospitals
- 5 satellite sites already established across the Netherlands

### Streamlining diagnostic assessment

- Rapid access to ultrasound and blood tests available on site during the allocated appointment timeframe on an ad hoc basis following the protocol guidelines

### One-stop shop

- Patient-friendly outpatient clinic where all aspects of RA care can be received in one appointment depending on patient need (e.g. radiology, medication)

### Prescription policy

- Medication prescription 'preference policy' for biologics detailed in protocols to improve both patient outcomes and improve cost efficiencies

### Role of the pharmacist

- Close collaboration between pharmacists and RA care
- Pharmacists provide individual pharmaceutical care, medication surveillance during dispensing, and help set and monitor the medication policy

### Smart clinic design

- Smart layout of RA outpatient clinic facilitates the patient flow: 5 story underground carpark to ease access, close proximity of each care station to streamline services

### Strong internal communication

- Frequent team meetings to ensure transparency, a non-hierarchical culture and a 'one voice' approach to ensure high-quality patient care

### Role of the rheumatology nurse

- Rheumatology nurses conduct first 45 min. consultation, and a subsequent consultation for 20 minutes, prior to physician appointment. The rheumatology nurses measure disease activity DAS28, capture data and upload results on online data warehouse for the physician, and discuss quality of life with patient

### Effective measurement and tracking of practice to improve quality of care

- Data collected to measure current baseline of care; objectives and documented process established in the protocols and tracked through performance indicators
- Results are gathered for gap analysis and root causes explored to start improvement plan

### Shared services

- Physician Assistant (PA) position created to share patient load with doctors, leading consultations with follow-up patients and write prescriptions
- In satellite sites, shared services are conducted with rheumatology nurses

### Strong links with patient associations

- Collaboration with four patient associations in the local area
- Participation suggested to patients with RA

Sources: (a) KPMG interviews with HCPs treating RA and associated comorbidities

# Overview of interventions in place for RA comorbidities

## Awareness & Prevention

Symptom identification



## Referral & Diagnosis

In secondary care



## Treatment & Management

Pharmacological management



Non-pharmacological management



## Follow-up

Monitoring of chronic disease/flare up



Interventions

### National guidelines

- Guideline on RA CVD comorbidity screening implemented nationally on the PCP level, removing the need for comorbidity screening at Maartenskliniek

### PCP trainings

- Symposium led every 5 years to educate PCPs and related specialists on RA associated comorbidities such as gout and cardiovascular risks
- Frequent informal training events with local PCPs

### PCP hotline

- Direct PCP hotline with an advertised telephone number on the clinic website
- Daily rota for rheumatologists to 'man' the hotline for any PCP queries in a dedicated room

### Screening

- Following national guidelines, PCPs evaluate for RA associated comorbidities and refer to specialist
- ~ 27% of patients have comorbidities, standard of care provided is uniform across all patients

### Close collaboration with Radboudumc

- Maartenskliniek inpatient ward relocated to Radboudumc as a 'multidisciplinary' patient ward
- Shared IT systems with Radboudumc to facilitate patient referrals; shared HCP roles and responsibilities; joint research projects on RA and associated comorbidities, in particular with RA and cardiovascular comorbidity management

### Medication management

- Key objective is to reduce the number of medications required for patients with RA
- Research conducted on dose reduction studies for biologics

### Role of the pharmacist

- Monitors whether preventive medication is necessary with current treatment and checks comorbidity medication

### Role of the PCP

- Comorbidity management primarily conducted by liaising with the PCP, or specialists in secondary care if required

### Focus on research

- 35 academic studies published per year in partnership with Radboudumc hospital on treatment dose optimisation and adherence
- Educational research on RA comorbidities shared in an informal setting within the clinic every two – three weeks

### Smoking cessation support

- Smoking cessation and lifestyle advice provided by rheumatology nurses in consultations if required

### Online data warehouse

- Online data warehouse used to measure, track and improve quality of care, including some aspects of comorbidity management such as preventive medication
- Robust IT systems have varying levels of access depending on the stakeholder for physicians, rheumatology nurses and pharmacists
- Shared IT system with the Radboudumc university hospital and satellite sites to facilitate data exchange and to measure quality of care

### Patient participation in research

- Through the STAP (Key to Active Participation policy) project, the clinic aims to have active involvement of patients in research; with participation as advisors in at least 80% of the clinical studies conducted

Sources: (a) KPMG interviews with HCPs treating RA and associated comorbidities (b) STAP project

# These interventions have improved outcomes



## How do you quantify the benefits in RA?

### Objective measures (KPIs):

- DAS 28 (disease activity measurement tool)
- Lab testing utilisation (health assessment questionnaire focused on Quality of Life)
- Physician assistant referral
- Unused capacity %
- Time to letter to PCP
- Time to first appointment

### PROMs:

- HAQ questionnaire
- Patient satisfaction score

*Please refer to case study four for more information (pp. 19 – 21)*



## How have these interventions improved patient outcomes?

### RA

#### Benefit:

- Evidence-based clinical research collated to formulate protocols and establish a direction of travel to achieve high-quality of care

#### Quantitative output:

- Short waiting times, good patient outcomes and high patient satisfaction

*[Please refer to case study four, 'Measuring, tracking and improving for better care', for more information]*

**“Tracking measurable outcomes helps us continuously improve RA care”**

- Rheumatologist

Sources: (a) KPMG interviews with HCPs treating RA and associated comorbidities

# How can care be improved?



## What is next for the centre?

### Overview: System upgrades in the electronic prescription model

- **How?** Upgrade the electronic prescription model so that physician and physician assistants can make combined prescriptions of RA medication and preventive medication when needed

### Overview: Online appointments available for patients to book consultations

- **How?** Establish an online portal that patients, PCPs and community rheumatologists can access to book an RA consultation appointment at the clinic

### Overview: E-consultation appointments for patients

- **How?** Establish an online portal where patients can book online video consultations with the physicians and physician assistants

### Overview: E-monitoring for patients

- **How?** Facilitating patient access to their own healthcare records online in real time to allow patients to self-monitor their disease

## What advice would you give less specialised centres?

### Overview of advice: A collaborative and non-hierarchical culture, protocols to standardise the quality of care, and a robust measuring and reporting framework is important to track and improve RA care

- **Why?** Standardise high-quality of care and minimise the gaps in care
- **How?** Ensure frequent communication between HCPs, provide coaching and training, standardise processes and collect KPIs and Patient Reporting Outcomes (PROMs) to benchmark and improve quality of care

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Set up satellite sites to spread best practice nationally 216



# Case study 1

## Continuous education and behavioural change training

### Overview

- The rheumatology department provides training and behavioural change coaching for all HCPs to help them provide the best care, treatment and advice to their patients
- Trainings are personalised and tailored for each type of HCP: physicians, physician assistants, rheumatology nurses, pharmacists and pharmacy technicians
- Strong emphasis on training, education and feedback aims to create a culture of continuous improvement based on a shared understanding of the importance of a 'one voice' approach

Sources: (a) KPMG interviews with HCPs treating RA and associated comorbidities

### What is the rationale?



- Evidence from latest research findings, developments and outcomes from the centres' protocols around the best communication techniques helps HCPs provide the best possible care to the patient by adequately explaining their disease, symptoms and treatment
- This has led to the development of a 'one voice' approach which is used for communication with patients but also to educate PCPs about symptoms to ensure early diagnosis
- Providing frequent forums for HCPs to engage and discuss feedback on protocols facilitates a non-hierarchical culture focused on continuous improvement

### What are the key features of the intervention?



#### HCP continuous education

- 3-year educational course on communication skills led by a communication expert for HCPs
- Regular HCP coaching to aid understanding, compliance and adherence to centre protocols
- Regular focus groups with RA team to examine behaviours, such as over diagnosis and prescription
- Rheumatologists hold an annual conference called 'Measuring and Dining' where latest information on published research, protocol adherence, and successful interventions is presented, discussed and reflected upon
- Rheumatology nurses receive regular training on 'motivational interviewing', including taught courses and 'on-the-job' coaching by providing feedback following patient consultations
- Pharmacist and pharmacy technician education on communication skills to best explore the needs of the patient

#### Behavioural change training

- External communication coach regularly coaches RA team on communication skills to:
  - Improve communication skills to obtain the most relevant information from patients to deliver great care
  - Improve communication with PCPs to ensure early and accurate referrals
- Behavioural change workshops to successfully implement change programmes such as protocol implementation and treatment switch
- RA physicians have each taken a personality test to influence how the training sessions are conducted

#### Three-step intervention of 1.5 hours for behavioural change management:

- Feedback for individual on assessment of patient characteristics and outcomes of performance
- Short introduction on effects of behaviour change on predictive value was given and consequences
- Alternative diagnostic algorithm was given

### What are the outcomes so far?



#### Culture of continuous improvement

- Non-hierarchical culture between all HCPs facilitates collaboration with focus on continuous improvement for all HCPs

#### 'One voice' approach to patient care

- Continuous education and behavioural change training allows HCPs to speak with one voice, creating greater clarity for patients

#### Successful protocol adoption

- With the support of the behavioural change workshop for HCPs, protocols have successfully been implemented in Maartenskliniek and the satellite sites



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APPENDIX  
CENTRE REPORTS

## Continuous education and behavioural change training (cont.)

### Benefits



#### Benefits to patients

- Patients receive clear and aligned communication from all HCPs at the clinic
- Patient education and messaging on how to administer pharmaceutical treatment is reinforced at each consultation with the same message from each HCP
- Thanks to multiple forums to gather insights on RA symptoms PCPs are able to identify early symptoms and refer to RA specialist in a timely manner

#### Benefits to Rheumatology team

- Non-hierarchical culture creates a more productive work environment with all staff
- Greater communication skills amongst all RA staff leads to better conversations with patients and PCPs, contributing to tailored care and increased referrals
- Behavioural change management programme facilitates successful implementation of interventions as HCPs have a forum to voice resistance and provide evidence to counter interventions if desired

### Challenges



- Aligning more than 50 stakeholders, including all HCPs, management and support staff, to a non-hierarchical culture of continuous learning and development takes time and sustained effort
- Motivating and engaging all HCPs in behavioural change management programmes to adhere to certain protocols, such as prescription preference policy
- Time and effort to plan, prepare and organise internal trainings dependent on individual good will

### Tips to replicate this intervention



- Collaborate with external experts to provide communication skills and behaviour change management training
- Ensure all RA staff receive formal training or 'on-the-job' feedback to improve listening skills and communication
- Formalise frequent learning and sharing sessions with the RA specialists, where best practice is shared, discussed and reflected upon



Communication skills are very important because if you know the needs of the patient you can give tailored advice to help them deal with their RA

– Rheumatology nurse



Sources: (a) KPMG interviews with HCPs treating RA and associated comorbidities

# Case study 2

## Smart clinic design and a one-stop shop to streamline care

### Overview

- A carefully considered clinic design to streamline the patient journey
- Clinic layout organised to optimise the time patients have to spend with HCPs
- Patient journey organised around a one-stop shop concept to allow patients to receive all required aspects of RA care in one appointment
- Technology-enabled solutions to allow pharmacists to spend more time discussing medication with the patients

Sources: (a) KPMG interviews with HCPs treating RA and associated comorbidities

### What is the rationale?



- Facilitating patient access to the clinic, reducing the time spent travelling between each care station, and allowing more time with the rheumatologist physicians, the physician assistants, the rheumatology nurses and the pharmacists improves the overall patient experience
- More communication time with the patient through technology-enabled solutions allows HCPs to have a trusted relationship with their patient and provide tailored care

### What are the key features of the intervention?



#### Clinic layout to facilitate access

- Clear signposting and short distances between each care station, e.g. reception, consultation, radiology and pharmacy
- Short distance between infusion room and storage to streamline efficiency for HCPs
- Five-storey car park underneath the hospital allows patients to easily access the outpatient clinic directly through the lift

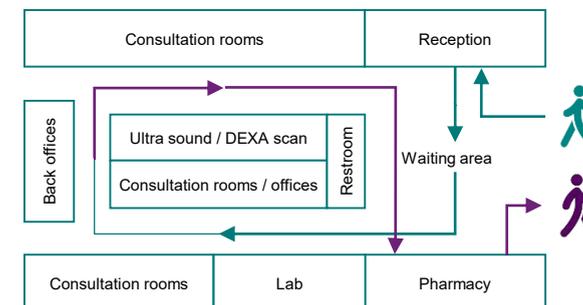
#### HCP and patient communication

- Pharmacy designed in 6 individual booths so that the pharmacist can spend 8 minutes with each patient to discuss their medication and comorbidities while a robot selects, labels and drops the medication next to the pharmacist
- 23 individual consultation rooms, including one dedicated room for the PCP hotline where a physician answers incoming telephone enquiries from PCPs for a direct expert consultation to ensure effective diagnosis and referral of newly suspected patients, but also rapid access for follow-up patients with complications

- HCPs follow shared decision-making with the patients where both patient and doctor are experts (prescription still follows the preference policy for biologics)

#### One-stop shop patient journey

- Patient journey designed around a one-stop shop concept so that patients can rapidly access all components of their RA care:
  - In reception patients fill out questionnaires, such as the health assessment questionnaire (HAQ) and patient-reported outcome measures (PROMs)
  - Lab and imaging tests can be done during the visit and results are shared immediately with the physician
  - During their visit, patients can pick up all necessary medication at the pharmacy



### What are the outcomes so far?



#### High patient satisfaction

- Easy access to care through the smart clinic design and maximised time with HCPs such as rheumatology nurses, physicians and pharmacists
- Waiting list for appointments < 2 weeks

#### High PCP awareness of RA symptoms

- Dedicated room for PCP hotline has led to rapid referrals and early diagnosis of RA

## Smart clinic design and a one-stop shop to streamline care (cont.)

### Benefits



#### Benefits to patients

- Patients can access all aspects of their care in one visit and do not have to go to a repeat appointment if they need a blood test, and ultrasound or to pick up their medication
- Patients can get all of their medication in the rheumatology outpatient at the end of their visit
- Patients can easily access the outpatient clinic and do not have to walk long distances due to the availability of parking spaces and direct access to the clinic through the lift

#### Benefits to Rheumatology team

- HCP communication time with the patient is optimised by clinic layout, technology and roles and responsibilities of other HCPs
  - For example as the rheumatology nurse measures disease activity physicians can focus on a particular patient concern during their consultation
- Clear signposting and efficient layout of the clinic helps navigation for both patients and HCPs

### Challenges



- Designing and renovating the layout of the clinic takes time and investment
- Reliance on technology as all patient records are electronic so if the IT infrastructure encounters a problem it may be difficult to maintain the day-to-day activities of the clinic
- The majority of patients do not have RA, but many can be managed in primary care following some specialist advice

### Tips to replicate this intervention



- Coordinate a logical patient flow throughout the clinic to optimise the patient journey
- Collaborate with each HCP to delegate and assign clear responsibilities to individuals
- Ensure that HCPs have sufficient time to talk with each patient to discuss quality of life, medication and any particular issues or concerns



We have carefully thought through the layout of our clinic to make it a pleasant experience for the patient

– Rheumatologist



Sources: (a) KPMG interviews with HCPs treating RA and associated comorbidities

# Case study 3

## Role of the pharmacist

### Overview

- Close collaboration between pharmacists and prescribers to provide high-quality of pharmaceutical care combined with cost-effective use of medication
- Outpatient rheumatology pharmacy provides patients with all necessary medication
- Results achieved by intense collaboration, strong focus on measuring quality and innovation with new interventions

Sources: (a) KPMG interviews with HCPs treating RA and associated comorbidities

### What is the rationale?



- The provision of high-quality and cost-effective pharmaceutical care strengthened by integrating pharmacists with wider RA team and ensuring close collaboration with prescribers
- Pharmacy designed to increase the amount of time spent with the patient, including discussion of pharmaceutical treatments required, associated comorbidities and adherence to treatment

### What are the key features of the intervention?



#### Integration of pharmacists and RA team

- Pharmacists are integrated as core members of the RA team, collaborating closely with other HCPs to ensure a holistic approach to care

#### Prescription preference policy with biologics

- Uniform medication policy to standardise and promote safety, increase process control, obtain purchasing buying power
- Policies established based on medical content comparing expensive RA medication with respect to: efficacy, safety, side effects, life expectancy, indications, correct patient use and cost-effectiveness

#### Monitoring policy

- Pharmacist monitors physician prescriptions to measure and track biologic prescription and ensure protocol adherence through the department's online data warehouse

#### Medication surveillance during dispensing

- Pharmacist's check the prescription, challenging the prescriber if needed based on the protocols
- Preventive medicines and comorbidity management are surveilled, if needed the pharmacist will contact the PCP or local pharmacy if they have a concern regarding a comorbidity medication

#### Medication adherence

- The pharmacist verifies both prescriber adherence to the protocol and patient adherence to drug administration
- Patient medication adherence tracked through a sensor lid that records when the lid is opened (or not) for a subset of patients

#### Patient education on pharmacological treatments

- Pharmacy layout facilitates an 8-minute conversation with the patient where the pharmacist provides uniform patient education on drug administration such as how to perform injections
- Processes are streamlined and carried out by robots where possible to fully optimise pharmacists' time in conversing with patients

#### Cost-effectiveness of medication

- Pharmacy focuses on providing the best possible care while lowering costs through three interventions:
  - Pooling of biologics
  - Dose optimisation
  - Introduction of biosimilars

### What are the outcomes so far?



#### High-quality cost-effective care

- Rheumatologists, pharmacists and internal team management work together to achieve more efficacious, safer and cost-effective treatment

#### Robust data on RA pharmaceutical treatment

- Department focus on measuring through continuous monitoring has led to robust data for clinical research on RA care outcomes

## Role of the pharmacist (cont.)

### Benefits



#### Benefits to patients

- Easy access to medication for holistic medical management available during their clinic visit
  - Some patients from Radboudumc are attracted to Maartenskliniek's pharmacy due to the quality of service provided
- Pharmacists have the time to review their prescription and provide education on drug administration (with each pharmacy appointment lasting around 8 minutes)

#### Benefits to Rheumatology team

- High-quality pharmacological treatment due to close collaboration between pharmacist and prescriber
- Increased patient adherence due to frequent patient education touchpoints with all HCPs and ongoing monitoring and surveillance of efficacy
- Efficiency benefits due to waste reduction with pooling of biologics and dosage control

### Challenges



- Setting up the pharmacy has required time, investment and increased headcounts
- Availability of funding in the future is questioned as smart purchasing of medication may not be sustainable for anticipated investment requirements

### Tips to replicate this intervention



- Close collaboration between pharmacist and HCPs and management to coordinate how RA care is provided at the centre
- Provide continuous patient education throughout their touchpoints with HCPs in the practice, for example during each time slot with rheumatology nurses, physicians and pharmacists
- Provide feedback loops within RA care to survey and monitor treatment prescriptions
- Standardise processes through protocols to ensure consistent high quality of care
- Regularly monitor and track quality of care through online data warehouse, accessible to all HCPs with varying levels of access
- Optimise logistics through robotics to help free up the time of pharmacists to interact with patients face-to-face
- Consider the layout of the pharmacy to increase the level of interaction with the patient



Our outpatient pharmacy is fully integrated within the department, we are the last check point with the patient and ensure all medication is correct and that the patient understands their treatment requirements

– Pharmacist



Sources: (a) KPMG interviews with HCPs treating RA and associated comorbidities

# Case study 4

## Measuring, tracking and improving for better care

### Overview

- Clear goals and standards of care defined to establish intentions and improve quality of RA care, including some aspects of comorbidity management
- Defined protocols with performance indicators establish the data requirements to gather, baseline and track performance
  - This is reported in an online data warehouse to provide clinical insights on standards of care
- Database warehouse utilised for clinical research to improve quality of care and treatment efficacy

Sources: (a) KPMG interviews with HCPs treating RA and associated comorbidities

### What is the rationale?



- Quality of effective RA care is complex to measure and improve
- Clear protocols and indicators are needed to measure the quality of care with a robust IT system to track these measures
- Strong data points on the quality of care allows the centre to baseline current standards, conduct a gap and root cause analysis to establish interventions to improve the quality of care and reach intended goals

### What are the key features of the intervention?



#### Established goals to achieve high-quality of care

- Quality of care defined within the centre is: care that is timely, accessible, effective, safe, cost-effective, patient-centred and transparent
- Medical, administrative and financial goals are defined to set a trajectory to improve care
- Management goals established for resourcing and efficiency, assess unused capacity outpatient clinic, referral to physician assistants, medication preference

#### Defined protocol performance indicators

- Diagnostic and treatment protocols have been established for rheumatic diseases to inform the data points to gather and baseline standards of care
- In several protocols physicians proactively look for and prevent comorbidity in at-risk patients:
  - Gastric ulcer prophylaxis when using NSAIDs
  - Osteoporosis prevention when prescribing prednisone in higher dosages
  - Glucose measurement around start of prednisone to diagnose pre-existing diabetes mellitus

### Online data warehouse

- Robust online data warehouse used to measure, track and improve quality of RA care and some aspects of comorbidity management, in particular with preventive medication
- Patient records feed into this database, as they have been digitalised since 2012 and available with varying levels of access to HCPs
- Mix of prescribed drugs tracked through the online data warehouse to prevent comorbidities

### Measuring and reporting

- Robust measuring and reporting framework conducted through IT support with the online data warehouse, the rheumatology nurse-led clinimetric centre where disease activity is recorded during each appointment and other reporting tools

### Intervision sessions with rheumatologists

- Frequent intervision sessions (a group learning session with a chairperson) where the anonymised patient outcomes of each rheumatologist are benchmarked to discuss best practice and improve level of care

### What are the outcomes so far?



### Clear data available on RA performance indicators

- Accessible digital records and trained staff willing to receive feedback help to ensure continuous data is available on performance indicators
- High quality of care showcased by the following measures:
  - 85% DAS28 and HAQ
  - Low mean DAS28 CRP of 2.13
  - 68% of patients in clinical remission
  - 82% low disease activity

## Measuring, tracking and improving for better care (cont.)

### Benefits



#### Benefits to patients

- Quality of care is benchmarked and updated with protocols and indicators to continuously improve the level of RA care provided
- High quality of care visible by the data collected on patient results and clinical benefits

#### Benefits to Rheumatology team

- Clear data on established protocol indicators with a view on the historical progression
- For example, the following results were gathered from a Maartenskliniek case study from 2007-2018:
  - RA Mean DAS28 CRP 3.1 → 2.3 → 2.1
  - Lab testing in general – 43%
  - Physician assistant referral from 4% → 62% of patients with RA
  - Unused capacity from 12% → 4%
  - Time to letter to PCP from 6 to <2 weeks
  - New patients seen <2 weeks
  - Patient satisfaction >8.0
  - Production increase per FtE increase 8%
- Robust and evidence based data facilitates decision making within the rheumatology department

### Challenges



- Quality of reported data faces several challenges with bias due to case mix, lack of precision in recording the data and conflicting views in benchmarking physician performance
- Overhead cost increases due to increased capacity required to input and measure data
- Behaviour hard to change with HCPs due to tunnel vision and risk averse behaviour, particularly in regards to utilising IT systems to measure and track care and engage in intervision sessions

### Tips to replicate this intervention



- Dedicated long-term efforts to establish IT systems that can measure and track performance indicators
- Train staff to optimally use IT infrastructure to leverage data, analysis and outcomes to improve day-to-day practice
- Improve standards of care by utilising reported outcome measures for clinical research



We constantly try to improve the care we provide by tracking and benchmarking anonymised patient outcomes, and then discussing them in InterVision sessions with our Rheumatologists

– Rheumatologist



Sources: (a) KPMG interviews with HCPs treating RA and associated comorbidities



# Case study 5

## Set up satellite sites to spread best practice nationally

### Overview

- Maartenskliniek has spread their best practice by setting up satellite sites in 5 other hospital rheumatology departments across the Netherlands



Sources: (a) KPMG interviews with HCPs treating RA and associated comorbidities

### What is the rationale?



- Share best practice and good outcomes of RA care as a EULAR Centre of Excellence with other outpatient rheumatology departments in the Netherlands
- Build a network of common good practice for RA care and improve patient outcomes across the country
- Implement data IT systems to collect and measure data on disease activity, treat-to-target (T2T) and all other protocol performance indicators to baseline care and set improvement targets

### What are the key features of the intervention?



#### Protocols

- Establish guidelines in volunteering hospitals that have rheumatology departments with outpatient services to set up the same high standard of care as the Nijmegen site
- Share Maartenskliniek protocols and embed in the centre, with some flexibility depending on centre circumstances (e.g. RA team profile, centre capabilities and capacity)
  - For example, as satellite centres do not have the funding for physician assistants, they have implemented 'shared services' with the specialised rheumatology nurses so that physicians are still able to share their patient load

#### IT systems

- Establish shared IT systems with the satellite sites to facilitate communication and help embed Maartenskliniek monitoring framework to create a baseline and improve quality of care

### What are the key features of the intervention? (continued)



#### Inclusion

- Establish a centre liaison officer to oversee integration of Maartenskliniek protocols, processes and ways of working
- Ensure frequent communication and face-to-face meetings between the Nijmegen site and the satellite centre
- Include all staff in the transformation, ensuring that feedback is gathered on how to best adapt and optimise the protocols to fit the hospital setting

#### Collaborate with hospital

- Collaborate with the volunteering hospital to successfully integrate the 'best' ways of working
- Leverage other hospital departments for treatment and management of RA's associated comorbidities
- Ensure clear means of communication with pharmacists, cardiologists, pulmonologists and other specialties within the hospital

#### Staff sharing

- If possible, share HCPs between Maartenskliniek and a satellite site so that learnings can be transferred 'on the ground'
  - Apart from at the Woerden satellite site, physicians spend 50% at Nijmegen and 50% at a satellite site
- When this is not feasible physicians at the satellite site are asked to attend and participate in departmental meetings every week in Nijmegen at Maartenskliniek

#### Training

- Train all staff to follow the same protocols and processes
- Include all staff in other training programmes, such as communication skills, behavioural change programmes



CONTENTS



APPENDIX  
CENTRE REPORTS

## Set up satellite sites to spread best practice nationally (cont.)

### Benefits



#### Benefits to the community

- Best practice in RA care is spread nationally and standardised
- There are shorter waiting times due to increased presence of Maartenskliniek sites and collaboration and referral if capacity issues

#### Benefits to the patient

- Patients are able to access Maartenskliniek sites closer to home

#### Benefits to the Rheumatologists

- Education of 'rheumatologists of tomorrow' through a multi-location model, collaboration with other hospitals and a knowledge-based approach

### What are the outcomes so far?



- Easy access for patients with more locations nearby and reduced referral waiting times for initial diagnosis and consultations
- Increased availability of data on RA care as protocols and indicators are implemented
- Improved patient-reported outcomes

### Challenges



- Ensuring flexibility in adapting Maartenskliniek protocols with the circumstances of the centre
- Motivating HCPs to spread their time across two sites, which often means longer commutes
- Integrating two separate systems and ways of working, in particular implementing Maartenskliniek's IT system
- Maintaining strong communication links with the hospital and Maartenskliniek's Nijmegen site

### Tips to replicate this intervention



- Establish clear communication channels with satellite sites
- Nominate a liaison officer in charge of coordinating the set-up and functioning of the satellite site
- Ensure a 'one voice' Maartenskliniek approach
- Promote a culture of continuous learning where feedback is often discussed



We are very proud of our collaboration with other outpatient clinics to increase patient access and spread high-quality RA care across the Netherlands

– Rheumatologist



Sources: (a) KPMG interviews with HCPs treating RA and associated comorbidities

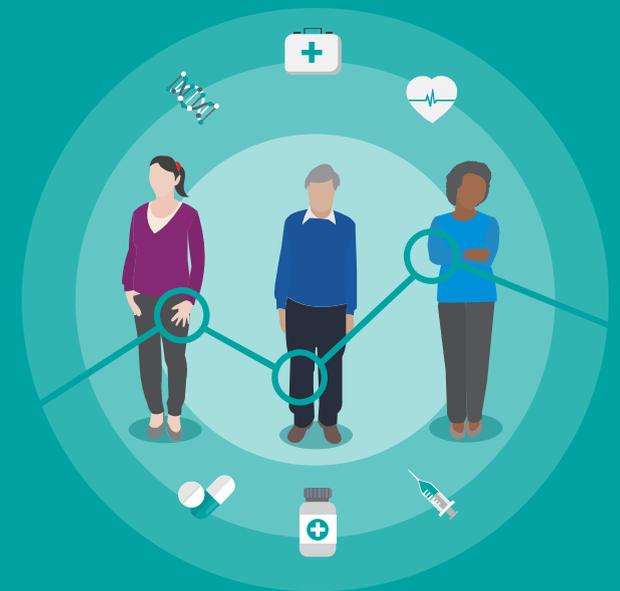


# Diakonhjemmet Hospital

Oslo, Norway

May 2018

[kpmg.com/uk](http://kpmg.com/uk)



# Summary



## Context

- **Leading hospital for rheumatology in Norway** with the largest department for joint diseases in the country and a forerunner in research and recommendations
- **Strong focus on rehabilitation services** being the home to two national services, one for hospitalization of patients (5 beds) and for research and development and dissemination of knowledge
- **Rapid access to integrated services** through triaging process to ensure patients are seen quickly and have dedicated time with the rheumatologist
- **Evidence-based practices and a strong research focus** with the majority of treating physicians involved in research programmes/studies; EULAR Centre of Excellence (CoE) since 2008; currently running ~10 protocols which lead to evidence-based practices
- **Personalised patient care** specifically tailored to each individual patient's needs through assessing the holistic management within multidisciplinary team
- **Specialities in comorbidity management** and assessment which is supported through research and integrated into day-to-day practice
- **Focus on education and training** with dedicated centre for patients, in-house training of physicians, and wider education for the rheumatoid arthritis (RA) - community and beyond



## Key strengths in the delivery of RA care

- **Learning and coping centre** is a specific centre dedicated to the education of RA patients (and other patient groups) in an informal, non-medical setting, holding group and peer-to-peer learning sessions around treatment, management and comorbidities
- **Dedicated primary care coordinator** whose role is to improve the collaboration between the hospital and primary care physicians (PCPs) in Oslo, which is done through talks, newsletters, training and educational sessions
- **Preventive cardio-rheuma clinic** has a cardiologist employed by the rheumatology department. This cardiologist has integrated the cardiovascular screening into patient assessments in the rheumatology outpatient clinic
- **Use of ultrasound** is of great importance to help with the diagnosis and treatment of patients, with specific use for pain management and assessing and locating areas of joint inflammation
- **Norwegian National Unit for Rehabilitation for Rheumatic Patients with Special Needs** provides rehabilitation for severe cases of RA and related rheumatic diseases and the **Norwegian National Advisory Unit on Rehabilitation in Rheumatology** provides dissemination of evidence and knowledge about rehabilitation to other departments of rheumatology in Norway. Both these National services are integrated in the department
- **Enhanced role of the nurse** as a key point of contact for the patients, helping to conduct a number of assessments including both composite and clinical measures prior to the rheumatologist's consultation



## Key challenges faced in delivery of RA care

- Spending enough time with patients and balancing this with research requirements
- Quality of referrals from primary care physicians (PCPs) and awareness of screening, management and follow-up of comorbidities in RA patients
- Maintaining patient's motivation to adhering and coping with a chronic disease and its impact on daily life, and gaining a full understanding of all the factors that are having an impact on their care
- Having capacity to cater to the large number of patients who are referred to the hospital from Oslo and elsewhere in Norway

# RA Norwegian healthcare system overview



## Norwegian healthcare system overview:



**Public health service:** The government is responsible for providing universal healthcare to the population, giving equal access to healthcare regardless of demographics. Primary health and social care are the responsibilities of the municipalities. The ministry of health owns most of the hospitals and provides directors to the board of regional health care authorities (RHAs). A few hospitals like Diakonhjemmet Hospital are private non-profit hospitals fully integrated in the public healthcare services

**Private insurance:** 8% of the population holds supplementary voluntary health insurance (VHI), mainly bought by employers (91% of all private commercial insurance) for providing employees quicker access to publicly covered elective services and choice among private providers. Private health insurance is provided by for-profit insurers, covering <5% of elective services and no acute services.

**Funding:** Health care expenditure represented 9.9% of GDP in 2015. Public system financing accounts for 85% of this spending and comes from general tax revenue, national and municipal taxes. Social security contributions finance public retirement funds, sick leave payment and reimbursement of extra healthcare costs. The ministry of health plays an indirect role through legislation and funding mechanisms(a). The government typically funds 50% of all operations, with the hospital having to make up the further 50% through reaching a threshold.

**Hospitals:** Public hospital trusts are state-owned, with few being privately owned and those owned by not-for-profit humanitarian organizations provide publicly funded services as part of RHAs plans for providing acute care. The private for-profit hospital sector is small (<0.2% for inpatient and <0.1% for outpatient). Private non-profit hospitals are also given defined responsibilities as hospitals owned by the Ministry of Health. Both inpatient and outpatient services are financed by the system of diagnosis-related groups (DRG)

**EHR:** National strategy for HIT was initiated in 2016. Each individual is given a unique personal identification number which is used for referrals and communication with laboratories and radiology series.(a)

## Rheumatoid Arthritis in Norway:



### Patients:

- Prevalence: 0.4-0.5% between the ages 20-79 (based on ACR 2007 criteria) <sup>(b)</sup>
- Higher age specific incidence and prevalence with >50% of new cases are 60+ <sup>(b)</sup>
- 4 – 5 times more prevalent in women <50; reduces to 2:1 > 50 years <sup>(c)</sup>

### Physicians:

- 200-300 rheumatologists in Norway over 16 centres <sup>(c)</sup>
- Average of 1127 patient per PCP in 2015, who are the gatekeepers to specialist care <sup>(a)</sup>

### Recommendations:

#### RA:

- Norwegian Rheumatologists are following EULAR recommendations <sup>(d)</sup>
- National recommendations and management procedures published through the Norwegian Society for Rheumatology (e.g. early RA)

#### Comorbidities:

- International EULAR recommendations/ guidelines

### Patient Advocacy Groups (PAGs) / Medical Societies:

- Norwegian inflammation network (NORIN) <sup>(e)</sup>
- Norwegian Society of Rheumatology <sup>(c)</sup>

## Challenges in Norwegian healthcare system <sup>(a)</sup>

- Health information technology (HIT) in primary care is fragmented and some areas of services lack resources and equipment for its implementation
- Low number of beds is a policy effort to toward outpatient and day care settings and make municipalities accountable for reducing the need for specialised hospital care – however for RA the availability of four in 1,000 is below the OECD European mean of five beds in 1,000 inhabitants

Sources: (a) [international.commonwealthfund.org/countries/norway/](https://international.commonwealthfund.org/countries/norway/) (b) Clin Exp Rheumatol 2003 (suppl. 31); S118-S122 (c) KPMG interviews with HCPs treating RA and associated comorbidities (d) Smolen et al. (2017) EULAR recommendations for the management of rheumatoid arthritis with synthetic and biological disease-modifying antirheumatic drugs: 2016 update; (e) <https://norinnetwork.no/>

# The rheumatology department

Diakonhjemmet Hospital is a large private non-profit hospital situated in the Western part of Oslo



## Diakonhjemmet Hospital

<b>Type</b>	Diakonhjemmet Hospital is a private, non-profit corporation owned by the Diakonhjemmet Foundation	<b>Locations</b>	Southern Eastern Norway in the south-western part of Oslo
<b>Core services</b>	<p>General hospital services:</p> <ol style="list-style-type: none"> <li>Fields of internal medicine, surgery and radiology, as well as laboratory services with a wider range of outpatient services</li> <li>Psychiatry</li> </ol>	<b>Population served</b>	<p>135 000 inhabitants south-western part of Oslo<sup>(b)</sup> for general hospital services</p> <p>Special hospital services for rheumatology and orthopaedic surgery About 600,000 inhabitants in Oslo<sup>(a)</sup> Regional functions in the South-Eastern part of Norway and wider national responsibilities for complicated rehabilitation programs<sup>(c)</sup></p>
<b>Size</b>	1,300 employees	<b>Demographics</b>	Adult patients

## The rheumatology department

<b>Services</b>	<p>Secondary care service hospital: inpatient, outpatient services with an infusion unit and in-house cardiologist</p> <p>Holds two nationwide services: National Advisory Unit on Rehabilitation in Rheumatology (NKRR) and National Unit for Rehabilitation for Rheumatic Patients with Special Needs (NBRR). NBRR has an accreditation from CARF (Commission on Accreditation of Rehabilitation Facilities)<sup>(b)</sup></p>	<b>Teaching / research scope (cont.)</b>	<p>Three main research areas: general medical research in rheumatology with a strong focus on imaging modalities; cardiovascular prevention and research in patients with rheumatic joint diseases; rehabilitation research in rheumatology with a focus on outcomes research (National Advisory Unit on Rehabilitation in Rheumatology (NKRR))</p>
<b>Teaching / research scope</b>	<p>Very strong research focus. The department has been a EULAR Center of Excellence since 2008 and this status was recently maintained for another 5 years (2018-2023). Three main research areas: general medical research in rheumatology with a strong focus on imaging modalities; cardiovascular prevention and research in patients with rheumatic joint diseases; rehabilitation research in rheumatology with a focus on outcomes research (National Advisory Unit on Rehabilitation in Rheumatology (NKRR))<sup>(b)</sup></p> <p>Very strong research focus. The department has been a EULAR Center of Excellence since 2008 and this status was recently maintained for another 5 years (2018-2023)</p>	<b>Collaborations</b>	<p>The department is leading several national projects as the NOR-DMARD study, the NOR-DRUM study, ARCTIC-REWIND, the Norwegian part of NOR-STAR – and was leading the ARCTIC and NOR-SWITCH studies – published in BMJ and Lancet, respectively, in 2016 and 2017.</p> <p>Patients are covered by the national insurance scheme which provides funds to the hospital at a block rate of 50% and then this is supplemented by achieving a minimum activity level</p>
		<b>Funding and Resources</b>	

Sources: (a) KPMG interviews with HCPs treating RA and associated comorbidities ; (b) <http://diakonhjemmetsykehus.no/#1/diakon/forside/om-sykehuset/brief-information-in-english> (c) <http://atacc-ra.com/collaborators/participating-centers/oslo/>

# The rheumatology department (cont.)



## Overview of services

Service Division	Outpatient care	Inpatient ward	Infusion unit	Physiotherapy / occupational therapy 'Rheuma Active'
<b>Duration of stay</b>	30 – 60 mins	~2 days	As long as is required for infusion process	For the session
<b>Hours of availability</b>	<ul style="list-style-type: none"> <li>– 9:00am – 6:00pm</li> <li>– 30mins per appointment (45mins for new referrals)</li> </ul>	<ul style="list-style-type: none"> <li>– 24-hour service</li> </ul>	<ul style="list-style-type: none"> <li>– 8:00am – 4:00pm</li> </ul>	<ul style="list-style-type: none"> <li>– 7:30am – 4:00pm</li> </ul>
<b>No. of staff available</b>	<ul style="list-style-type: none"> <li>– About 20 rheumatologists (part-time clinical, part time research)</li> <li>– 6 trainee doctors</li> <li>– Secretaries</li> </ul>	<ul style="list-style-type: none"> <li>– 4 doctors (3 senior consultants)</li> <li>– 10 nurses</li> <li>– Physiotherapists (ad hoc)</li> <li>– 3 ½ medical secretaries</li> </ul>	<ul style="list-style-type: none"> <li>– 5 nurses</li> <li>– 3 nurses everyday</li> </ul>	<ul style="list-style-type: none"> <li>– 19 (including physio, occupational therapists, social workers, nurses, coordinators and secretaries) for both the outpatient and the inpatient ward</li> </ul>
<b>Capacity (no. of beds/rooms)</b>	<ul style="list-style-type: none"> <li>– 26 consultation rooms</li> </ul>	<ul style="list-style-type: none"> <li>– 8 beds for RA and related diseases</li> </ul>	<ul style="list-style-type: none"> <li>– 7 chairs</li> </ul>	<ul style="list-style-type: none"> <li>– Whole department</li> </ul>
<b>No. of patients seen (per year)</b>	<ul style="list-style-type: none"> <li>– 35,000 consultations / hospitalisations</li> <li>– 3000 new patients</li> </ul>	<ul style="list-style-type: none"> <li>– 800 discharges from the ward</li> </ul>	<ul style="list-style-type: none"> <li>– 15-18 patients/day</li> <li>– &gt; 3,000 infusions a year</li> </ul>	<ul style="list-style-type: none"> <li>– Difficult to estimate since integrated in the multidisciplinary management of patients</li> </ul>
<b>Patient type catered to</b>	<ul style="list-style-type: none"> <li>– All RA patients, other inflammatory joint diseases, osteoarthritis, but also non-inflammatory musculoskeletal pain conditions</li> </ul>	<ul style="list-style-type: none"> <li>– Active disease, severe complications, infections and medications</li> </ul>	<ul style="list-style-type: none"> <li>– Those requiring IV drug (biologic / biosimilar) infusions</li> </ul>	<ul style="list-style-type: none"> <li>– Patients referred from hospital rheumatologists (predominantly outpatients and those following surgery)</li> </ul>
<b>Services offered</b>	<ul style="list-style-type: none"> <li>– Ultrasonography for all patients</li> <li>– DEXA machine</li> <li>– Preventive cardio-rheuma clinic with a dedicated cardiologist</li> <li>– Physiotherapy and occupational therapy</li> </ul>	<ul style="list-style-type: none"> <li>– 24h care for treatment</li> <li>– Personalised education for patients around their treatments and care given by the multidisciplinary team</li> </ul>	<ul style="list-style-type: none"> <li>– Infusion</li> <li>– Education for patients</li> <li>– Clinical trials (previously NOR-SWITCH, currently NOR-DRUM)</li> </ul>	<ul style="list-style-type: none"> <li>– Holistic multidisciplinary approach to care</li> <li>– Physiotherapy</li> <li>– Occupational therapy</li> <li>– Social care support</li> </ul>
<b>Specific tools</b>			<ul style="list-style-type: none"> <li>– Full assessment of patients</li> <li>– NOR-DRUM study (Therapeutic drug monitoring RCT)</li> </ul>	<ul style="list-style-type: none"> <li>– Standardised programmes and educational materials</li> </ul>

Source: (a) KPMG interviews with HCPs treating RA and associated comorbidities

# The rheumatology department (cont.)



Additional services			
Service Division	National Unit of Rehabilitation for Rheumatic patients with Special Needs (NBRR)	National Advisory Unit on Rehabilitation in Rheumatology (NKRR)	Organisation of research
<b>Duration of stay</b>	3 model of stays <ul style="list-style-type: none"> <li>– 1<sup>st</sup> visit (5-10 days)</li> <li>– 2<sup>nd</sup> visit (long-term treatment 14, 19 or 21 days)</li> <li>– 3<sup>rd</sup> visit (optional, follow-up stay)</li> </ul>	– No beds – advisory unit	<p>The department does not have a separate unit for research which is currently organized into two different pillars. The PhD fellows and postdocs/senior researchers are organized within the main department with reporting line to the head of the department, whereas the researchers in Norwegian National Advisory Unit on Rehabilitation in Rheumatology report to the leader of this unit. However, it is planned to establish a unit for research and innovation within the department and to enhance collaboration between the researchers in the two “pillars”.</p>
<b>Hours of availability</b>	– 24/7	– n/a	
<b>No. of staff available</b>	– Treating physician; full-time rheumatologists; rheumatology nurses; physiotherapists; psychologists; OTs; social worker	– 26 people are employed, many in part-time position and many on external funds	
<b>Capacity (no. of beds/rooms)</b>	– 5 beds	– n/a	
<b>No. of patients seen (per year)</b>	– 100 inpatient stays	– n/a	
<b>Patient type catered to</b>	– Patients needing extreme specialist care (5 key criteria to be met)	– n/a	
<b>Services offered</b>	<ul style="list-style-type: none"> <li>– Holistic approach to care</li> <li>– Bio-psycho-social</li> </ul>	<ul style="list-style-type: none"> <li>– Rehabilitation policy advice</li> <li>– Website with resource bank of assessment tools</li> <li>– Communication and educational services, mainly to other rheumatology departments, but also to the primary health care system.</li> </ul>	
<b>Specific tools</b>	– Multidisciplinary team approach	– n/a	

## Organisational changes (ongoing or planned within 2019-2020)

- Number of beds will be reduced in the inpatient ward and stronger collaboration with the National Unit for Rehabilitation for Rheumatic Patients with Special Needs (NBRR) will be implemented.
- A new daycare service will compensate for the reduction in number of beds in the inpatient ward.
- The outpatient clinics in Rheumatology and Orthopaedic surgery will be merged into an Outpatient Center for Orthopaedic Surgery and Rheumatology (COR)
- A reorganisation of Rheuma Active is being considered

Source: (a) KPMG interviews with HCPs treating RA and associated comorbidities

# The team

## Core team profiles

- 5 professors (3 rheumatologists, one physiotherapist and one occupational therapist)
- 1.5 statisticians
- 2 externally funded research rheumatology nurses
- Postdocs
- Senior researchers
- PhD students

It has been estimated that the hospital pays for about 10 people in the department (rheumatology nurses, secretaries, physiotherapists) who are supporting clinical research. It is important to recognize that research and education are legal responsibilities in the Norwegian health care system

## Affiliate team profiles

- Psychiatrist
- Psychologist
- Pulmonologist
- Endocrinologist / diabetologist



## Key features of the care delivery team

- **Rheumatologists are central** to the efficient diagnosis, treatment and management of patients with RA
- **Most rheumatologists are part-time researchers** combining research and high-level clinical practice, but the department also has full-time highly dedicated clinicians
- **Large group of rheumatologists** with different interests and fields of expertise and evolving pursuits
- **Strong multidisciplinary team (MDT) and approach to care** to ensure holistic management of the patients' urgent needs within the hospital, but also long-term care, which is essential in such a chronic disease
- **Strong research focus and evidence-based initiatives integrated into care systems**
- **Focus on research and holistic care into comorbidities care** specifically looking especially at cardiovascular disease (CVD) and osteoporosis
- **Strong emphasis on rehabilitation services**
- **Dedicated cardiologist within the rheumatology clinic**
- **Dedicated rheumatologists focusing on osteoporosis**

## Governance and processes

### Team meetings:

- The team of leaders of the different units meet for 90 minutes every Wednesday
- Every morning rheumatologists and leaders of units meet
- Wednesday & Friday difficult cases are presented (need for biologics and severe cases)
- Additional meetings in units on regular basis (e.g. NBRR twice a week to discuss cases)

### Protocols:

- Local electronic procedures are used
- Patients are routinely monitored through entering clinical data as well as patient reported outcome measures into GoTreatIt which is a comprehensive electronic health record system that integrates with a dedicated information database for CVD
- Receives referral letters and sends discharge letters directly to the PCPs

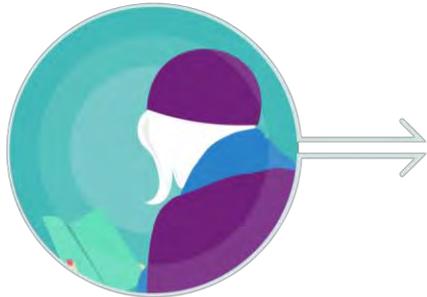
### Pharmacy:

- Fully integrated into the multidisciplinary treatment for the patient

# Overview of interventions in place for RA

## Awareness & Prevention

Symptom identification



## Referral & Diagnosis

In secondary care



## Treatment & Management

Medical management

Non-medical management



## Follow-up

Monitoring of chronic disease



### Dedicated primary care coordinator

- To strengthen the communication and coordination between primary and secondary care through education and training about RA diagnosis and referral

### Early and rapid access to care

- PCPs can email/ call the centre to ensure patients suspected of having RA are seen rapidly, with same-day appointments

### Educating the wider RA community

- Spreading best practice knowledge and learnings from the hospital to regional areas such as the importance of rehabilitation and cardiovascular risk assessments, through online and in-person visits

### Continual improvement of primary care

- Regular updates for internal team on research findings and developments as well as training sessions, including practical sessions on joint examination

### Comprehensive diagnostic assessment

- Detailed assessment using both clinical and composite measures, with automatic computation and analysis which can be shared in real time with patients
- All patients may receive imaging (ultrasound) supporting diagnosis of early RA or disease activity assessment

### Patient segmentation and allocation for rapid diagnosis

- Patients are categorized on severity and seen immediately if suspected onset of RA. This helps rapid diagnosis and treatment of new patients

### Joint inflammation evaluation

- Ultrasound used to help speed diagnosis and consequently to solve clinical problems and assist in all examinations

### Highly efficient outpatient service

- Patients are triaged and allocated to available rheumatologists, for same-day appointments (1 ½ rheumatologist availability every day to cater for walk-ins)

### Multidisciplinary teams' approach to care

- Holistic assessment of patient's motivations and needs is embedded across and throughout care alongside clinical needs

### Research-led treatment

- Research findings and treatment are ingrained in the day-to-day practices of the centre

### Pain management

- One of their main focuses is to help assess and reduce the patient's pain

### Role of the rheumatology nurse

- The rheumatology nurses are in charge of many of the clinical activities, including T2T and monitoring of patients across care, playing an essential role in the assessment of outpatients

### Learning and coping centre

- Educational centre to increase patients' understanding of RA, required treatment and how to improve quality of life

### Rhuma Active

- Initial evaluation of individual needs to develop personalised programme
- Facilities include occupational therapists and physiotherapists
- National Unit for Rehabilitation for Rheumatic Patients with Special Needs (NBRR) Specific centre with a 3-step programme for severe patients with RA who need specialised care
- National Advisory Unit on Rehabilitation in Rheumatology (NKRR) National unit set up to communicate to all rheumatology departments and rehabilitation centres with evidence-based best practice (and to some extent also to primary care)

### Nurse hotline

- Direct line which patients can call for advice

### Continual longitudinal research and collaborations with national and international registries

- Centres are running multiple national and international studies constantly monitoring and assessing patients

### Patient tailored care

- Patients are at the centre of research and practice through having a patient panel and peer-to-peer learning, and engagement with patient association groups (PAGs) to ensure patient-centred care

### Use of ultrasound for pain management

- Some patients have an ultrasound conducted at each appointment helping give a full assessment and locate causes of pain alongside patient-reported outcomes and clinical examination

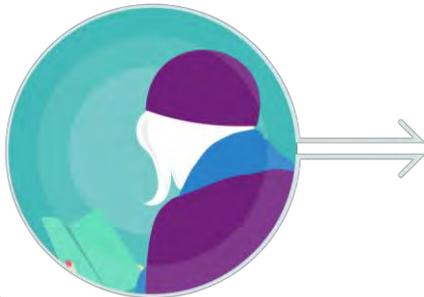
### Personalised follow-up plans

- Structured systems for follow-up alongside good communication avenues to ensure patients only attend follow-up as and when required

# Interventions in place for RA comorbidities

## Awareness & Prevention

Symptom identification



### Dedicated primary care coordinator

- Dedicated practice consultant to help educate PCPs in Oslo about the effects and impact of comorbidities

### Cardiology education

- Cardiologist specialising in rheumatology has designed a number of national and international initiatives to raise awareness of CVD risk and benefits of embedding screening into outpatient assessment

### Participation in writing national and local recommendations

- Dedicated rheumatologists working alongside Norwegian Society of Rheumatology to create recommendations / guidelines for RA and comorbidities

### Nurse congress attendance

- Annual attendance to congress to update knowledge and share insights

## Referral & Diagnosis

In secondary care



### Same-day screening

- Because there is a dedicated cardiologist in the department cardiovascular comorbidities, such as high blood pressure and hypercholesterolemia, are screened in new patients according to some pre-specified local recommendations

### Referral to specialists

- Rheumatologists use their internal network to refer patients to endocrinologists, infection specialists and psychiatrists on a case-by-case basis

### Preventive assessment of patients on biologics

- Nurses closely monitor these patients and ensure they receive vaccinations required to prevent progression or onset of infection

## Treatment & Management

Medical management

Non-medical management



### Preventive cardio-rheuma clinic

- First hospital to fully embed a cardiologist into the rheumatology clinic
- Cardiologist conducts screening, treatment and management of high-risk rheumatology patients
- T2T recommendations are followed for the reduction of lipid levels

### Osteoporosis specialist rheumatologist

- Dedicated specialist rheumatologist who focuses on osteoporosis care on an ad-hoc basis
- DEXA machine in the outpatient clinic

### Multidisciplinary teams for severe patients

- Rheumatologists meet with other specialist on an ad hoc basis to review treatments plans and assess complications

### On-site rehabilitation services

- Leading national rehabilitation centre that provides holistic care that help prevent and treat comorbidities (CVD, depression, osteoporosis & diabetes)

### Educational advice for patients

- Every patient has access to the learning and coping centre where they can receive personalised one-to-one sessions regarding the management of their disease and associated comorbidities

### Cardio-pulmonary exercise unit

- Development of an on-site medical activity centre – to help those patients with cardio/pulmonary comorbidities, helping to better integrate care and sustain activity following discharge

## Follow-up

Monitoring of chronic disease



### Longitudinal national and international cardiology studies

- Design and contribution to national and international research around CVD in patients with RA (NOCAR; SURF RA; ATACC-RA)

### Regular follow-up assessment of comorbidities

- Both the rheumatology nurse and rheumatologist assess lipid, cholesterol and blood pressure, bone densitometry and full blood tests at the follow-up appointment of high-risk patients

### Research into RA and mental health

- Studies and treatment are conducted around mental diseases effect on pain
- Education (documents and videos provided for HCPs, patients and PAGs)

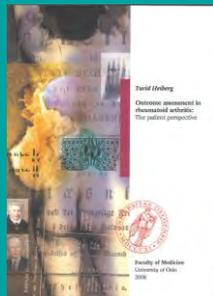
# These interventions have improved outcomes



EQ-5D-5L



Hand movement scores



Outcomes assessment in RA paper



How do you quantify the benefits in RA?

## Objective measures (KPIs):

- T2T goals
  - Remission rates
  - Ultrasound joint examination

## Clinical measures

- Composite scores: DAS28, SDAI, CDAI, ACR / EULAR Boolean remission criteria

## Most widely used PROMs:

- Global scales: VAS (global, joint pain & fatigue)
- Functional measures: MHAQ, HAQ
- SF-36 (physical functioning, physical role, bodily pain, general health, vitality, social functioning, emotional role, mental health)
- FACIT; EQ-5D, RAID

## Case study:

### National Advisory Unit on Rehabilitation in Rheumatology (NKRR)

#### Outcomes research dissemination for the benefits of rehabilitation in RA

- Website with a resource bank of most relevant recommendation and assessment tools
- They collect data from a variety of centres across Norway and create quality indicators for better management and outcomes for RA
- They use a patient panel to support the design of research projects, and this panel is also usually involved throughout the project including interpretation of research findings and publication of results

### The team at Diakonhjemmet routinely measures comorbidity outcomes on their patient management system:

#### Objective measures (KPIs):

- Continual screening of patients for comorbidities
  - CVD - cholesterol, lipid levels, blood samples
  - Additional screening and monitoring of high-risk patients

**“We help to create a network of centres to help and collaborate in bettering patient outcomes”**

- Rheumatologist



# How can care be improved?



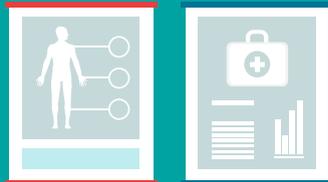
## What is next for the team at Diakonhjemmet Hospital?

### Overview: Research into comorbidities

- **Why?** Want to gain a further understanding of the effects and outcomes of medications on comorbidities and leverage findings and expertise to help develop recommendations/ guidelines around comorbidities
- **How?** Set up a number of protocols to assess the effects of medication and physical activities on comorbidity progression and effects

### Overview: Incorporation of more psychologists

- **Why?** To add a more comprehensive overview to multidisciplinary team discussions and understand the psychological aspect of pain. Attitudes to this in Norway in general will need to mature
- **How?** Training and education of more psychologists to become specialist within this field



## What advice would you give less specialised centres?

### Overview of advice: Promote patient education

- **Why?** To help patients manage their disease, greater understanding leads to more motivation to adherence to both medical and non-medical treatment protocols
- **How?** Learn from other centres how they have effectively educated their patients. Bring a peer group of patients in so that you can learn how they would prefer to learn and be educated and receive advice about how teaching materials can be tailored to their needs. Ensuring management buy-in motivates other doctors

### Overview of advice: Bio-psycho-social holistic approach to care

- **Why?** Holistic management of patients will ensure improved outcomes and design of a personalized treatment programme which best suits each patients bio-psycho-social needs
- **How?** Try have regular multidisciplinary team meetings, including rheumatologists, nurses, physiotherapists, occupational therapists, psychologists, social workers to ensure a comprehensive view of the patients' situation and development of management plans

### Overview of advice: Improve relationships with the wider treating community involved in the care of patients with RA

- **Why?** Educating and supporting the wider RA community about developments in practice and care can lead to better transition of patients between care settings and levels
- **How?** Ensuring PCPs are aware of how to effectively diagnose and write referral letters will ensure that patients are referred correctly to the hospital as needed, rather than mis-referrals which waste both patient and physician time. Ensuring that they also are aware of how to read and understand discharge letters which helps them to best treat the patient in their own community. In addition, collaborations with the patients local physiotherapist is essential to ensure longer term maintenance of physical rehabilitation once patients are discharged from hospital

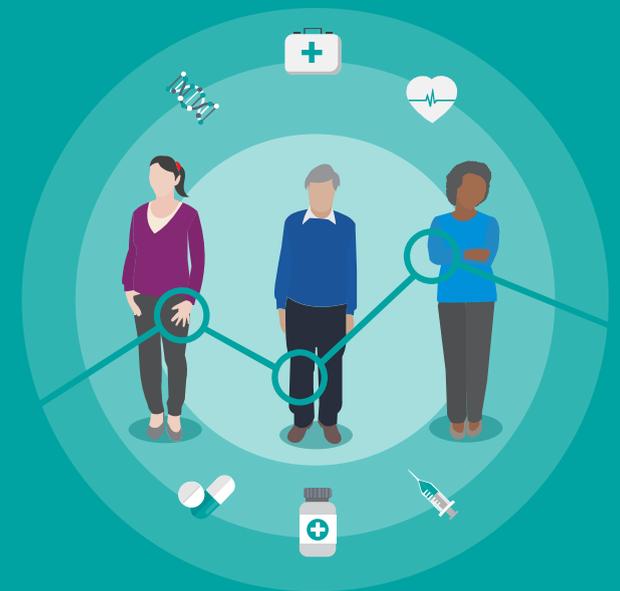


# Case studies

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# Case study 1

## Learning and coping centre

### Overview

- The hospital has created its own educational centre, called the 'learning and coping centre'
- This has been developed for a series of informative courses to teach patients and their families about the disease, diagnosis, treatment, medication and management
- Holistic education is offered to help patients deal with the everyday life functioning of the disease
- Specific courses are available for the management of pain and fatigue, drug interaction, life skills, including mindfulness-based course

Sources: (a) KPMG interviews with HCPs treating RA and associated comorbidities

### What is the rationale?



- Patients do not have long enough consultation sessions for the rheumatologists and nurses to fully educate the patients about the impact of the disease
- The hospital established an educational centre in 2003. A dedicated experienced rheumatology nurse is responsible for the teaching programs for the patients with rheumatic diseases and is supported by a multidisciplinary team when doing the educational courses
- The lead rheumatologist would prefer the patients to focus on positive health rather than the disease
- They provide an open forum of discussion to ensure patients have the opportunity to share their opinions and concerns in a safe place

### What are the key features of the interventions?



- There are a number of courses run by the centre which are open to all patients who see a rheumatologist or a health professional and the Dept. of Rheumatology at Diakonhjemmet Hospital
- These sessions are predominantly run in a group setting and family members are welcome to join
- Around 50% of patients with RA attend these courses

### Rheumaschool

- Runs over 2 days 6 times a year, with multidisciplinary teaching from rheumatologists, rheumatology nurses, physiotherapists, psychologists, social workers
- Sessions include: pedagogy, open question and answer session
- 'Expert patients' are involved and who attend all meetings to help educate the patients and answer questions from their perspective at a peer level
- 10-12 patients per course

### What are the key features of the intervention? (cont.)



### Pain management and fatigue

- 3h sessions available where patients and their families can talk about the disease and learn about coping skills to manage their pain
- There are 12 courses run over the year
- Some patients may come along to the centre with their rheumatology nurse as support

### Coping group course

- Specific peer support group session where patients can come and speak freely and openly in a group setting

### Vitality training course (mindfulness-based)

- To strengthen patients' quality of life and motivations
- Focus on health rather than being unwell, with a positive mental attitude to life

### Pharmacist education

- The pharmacist provides patient counselling around new treatments

### Patient videos

- 4 pharmacists, 2 rheumatologists and 2 patient representatives have developed a nationally accessible web-based video with specific education about treatment and medication using patient friendly language

### Environment

- The rheumatology nurse and everyone working in the centre do not wear medical clothes during their educational sessions in order to help make the patients feel comfortable, and so that they are not reminded of the hospital

### Patient feedback

- There are evaluation forms for the patients to help better tailor the education for their needs



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APPENDIX  
CENTRE REPORTS

## Learning and coping centre (contd.)

### What are the outcomes so far?



- Improved patient concordance to medication and treatment plans
- Greater motivation of patients to effectively participate<sup>(b)</sup>

### Benefits



#### Patient

- Greater understanding of disease and consequences for the patient and their family
- Patients feel supported with having holistic education in their language; and they appreciate the opportunity to discuss tough issues with peer patients
- Remote access to education from the pharmacist's videos that are understandable

#### Healthcare professionals

- Reduced burden on rheumatologists and rheumatology nurses within the clinic to have to provide holistic life management education

#### Wider RA community

- Learnings are shared at conference with other hospitals demonstrating the outcomes and benefits to patients

### Challenges



#### Patient attendance

- ~50% of patients with RA attend the sessions, increasing this would help to greatly benefit the patients and their families and help ensure rheumatologists can practice efficiently
- Patients are very busy because Oslo has a high level of employment (strong back-to-work programs for mothers)

#### Healthcare professional buy-in

- Other centres may not always believe that this is a necessary intervention and may prefer the rheumatology nurse or treating rheumatologists to have this role

### What's next?



#### Continual improvement

- The program is always evolving and continues to change (e.g. greater focus on breakout sessions, rather than patient reading and teaching). There is currently an education program running in Urdu, as many immigrants in the area are from Pakistan do not fully understand RA. Following the success of this, there is currently plans to run a program with several foreign languages to improve access to information for different groups of immigrants

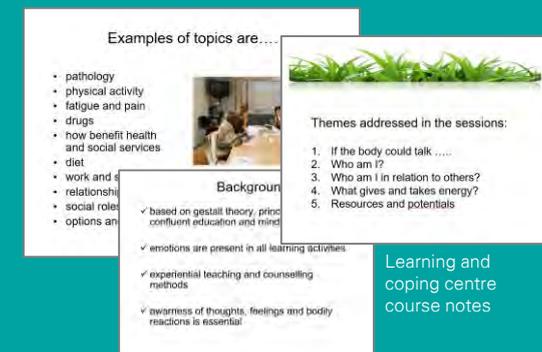


Peer-to-peer learning and group discussion is more important than the medical elements of the programme.

– Nurse (team at Diakonhjemmet)



Programme for the learning and coping centre



# Case study 2

## Dedicated primary care coordinator

### Overview

- Increasing awareness and education of the treating physicians involved in RA care both within the hospital and in the primary care community has great significance in increasing access to care by reducing delays in diagnosis, misdiagnosis, delays in referral and finding the right treatment for patients

Sources: (a) KPMG interviews with HCPs treating RA and associated comorbidities

### What is the rationale?



- There is often a delay in referral of patients, leading to a progression of joint swelling and pain. This can be due to lack of awareness of primary care physicians (PCPs) or unclear referral letters
- By increasing the awareness of PCPs, patients can be spotted at an earlier date and provided with treatment in a timely manner, as PCPs work a lot with preventive medicine

### What are the key features of the intervention?



#### Team

- One dedicated practice consultant in each of the three arms of the hospital (rheumatology, internal medicine and psychiatry) who works 1 day a week to improve the communication and collaboration between the hospital and PCPs
- There is one dedicated solely to rheumatology

#### Newsletter

- Distributed via email to a large number of PCPs several times a year, including information regarding training and educational sessions and updates regarding services and research findings

#### Collaboration contracting

- Agreement setting between the PCP and secondary care as to how to collaborate between the different care settings to ensure easy transition and referral

#### Rapid access to hospital

- There is an electronic referral system allowing appointments can be triaged and booked on the same day
- Direct line to Rheumatology department so new and early onset RA patients can be triaged rapidly (and patients with a disease flare)
- Telephone contact is encouraged when the PCP he/she has a patient with acute arthritis or a condition which is most likely new onset RA

### What are the key features of the intervention? (cont.)



#### Training

- A 15h course over 3 afternoons is organized yearly
  - 28 PCPs each time
  - Topics include pain and fatigue, early diagnosis and practical joint examination (with patients)
- Screening for comorbidities
  - Teaching of how to screen for all comorbidities involved with chronic inflammation such as CVD risk (cholesterol etc.), diabetes
  - PCPs can help with preventive medicine and are taught how best to triage these patients
  - PCPs can also learn by participating in the daily work of the department, especially the outpatient clinic
- On-the-job training
  - Connect PCPs with the local outpatient clinic so that they can gain training and accreditation points which enhance their family medicine training
- Referral letter writing
  - To ensure that the GPs write clear referral letters mapping out the patients diagnosis clearly to help with triaging of patients at the hospital and quicker diagnosis
- Discharge letters
  - The practice consultant helps to ensure that the rheumatologists discharge letters are understandable, teaching PCPs how best to understand these and maintain the right level of care for the patients



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APPENDIX  
CENTRE REPORTS

## Dedicated primary care coordinator (contd.)

### Benefits



#### Patient

- Smoother transition through the different levels of the care system
- Quicker diagnosis and access to treatment as PCPs have greater awareness of symptoms, how to best diagnose and screen for comorbidities

#### Healthcare professionals

- Correctly written referral letters sent through to the hospital, through direct online system. This helps to triage patients better, reduce misdiagnosis and the consequent time wasted for both patients and treating physicians
- PCPs are aware of the correct and proper treatment plans to follow from rheumatologists' discharge letters
- If PCPs learn how to screen and check patients for cholesterol treatment they can implement treatment at an earlier stage or will know how best to triage them into secondary care
- The PCPs gain accreditation credits for attending these specialist courses, which is a basic requirement to maintain their authorization as specialists in primary care medicine

#### Healthcare system

- Better integration and fluidity of patients, who get treated correctly and in a timely manner reducing burden on the healthcare system of flares and emergency appointments

### What are the outcomes so far?



- Decreased misdiagnosis from the PCPs
- Improved screening of comorbidities and quicker referral (same-day)
- Better patient outcomes

### Challenges



- Ensuring PCPs are interested and want to partake in the course and keep up to date with local developments in RA care

### What's next



#### Further enhance connection between care settings

- Increased collaboration will ensure smoother transition of patients between care settings and also enhance the opportunity for follow-up of patients who do not need specialized care
- Centres should reach out to local PCPs and ask them how best they can help them with referrals
- Credit systems to motivate PCPs to come to training and educational sessions

Sources: (a) KPMG interviews with HCPs treating RA and associated comorbidities



It is the hospital's job to reach out to the PCPs and ask them what they are missing and how best they can serve them to ensure better transition into secondary care

– Primary care coordinator



# Case study 3

## Preventive Cardio-Rheuma clinic

### Overview

- The hospital has a full-time cardiologist based within the department. This is the first cardiologist to be based and employed in a rheumatology department
- The role is designed to help assess patients for the common comorbidity of cardiovascular disease (CVD) as a preventive measure but also to ensure effective management of such patients

Sources: (a) KPMG interviews with HCPs treating RA and associated comorbidities (b) *Annals of the Rheumatic Diseases* 2014;73:62-68

### What is the rationale?



- Increased complications occur due to the inflammatory nature of the disease which leads to cardiovascular problems
- Patients suffering from RA have an increase risk of cardiovascular disease (e.g. myocardial infarction)<sup>(b)</sup>
- Therefore a more preventive care system needs to be put in place and maintained
- The cardiologist was working in department of internal medicine and conducted research into the frequency of CVD in RA and other inflammatory diseases, and the head of the department of rheumatology facilitated a move to have the cardiologist to work internally

### What are the key features?



#### Preventive Cardio-Rheuma clinic

##### Overview

- This clinic runs inside the rheumatology outpatient unit, which means that the cardiologist is fully integrated in the care of patients with RA
- This is the first clinic in the world to have an integrated cardiologist
- The clinic has registered more than 1,000 patients so far
- Consultation lasts approximately 60 mins

##### Key activities

- CV risk stratification and start of preventive medication
- High-risk patients are highlighted in their internal patient health record system, and are monitored more closely
- A clearly defined 6-step process is followed:

1. **Patients answer a questionnaire**
2. **Lab attended for blood tests (e.g. lipid levels)**
3. **Carotid ultrasonography**
4. **Echocardiography**
5. **BP**
6. **ECG**

##### Outputs

- **Outpatient summary report** (6 pages) is produced by the time the patient goes to see the rheumatologist
- **Prescription** (which can be held within the electronic health record (EHR) system which outlines the medical and non-medical requirements to both internal and external treating physicians
  - Standardised letter is already in the EHR system
- **Lifestyle advice** including diet and exercise, brochure with information of smoking cessation and reducing alcohol consumption

##### CVD care and monitoring

- This is predominantly within the rheumatology outpatient clinic
- Treat-to-target (T2T) recommendations are followed for lipid and blood pressure levels

##### Training

###### CVD risk and prevention

- Specialist rheumatology cardiologist travels across RA centres in Norway to educate health care personnel about the risk of CVD and enroll them in a national cardio-preventive project

###### Transfer of knowledge to HCPs

- 5-6 rheumatologists have come to the centre from other countries to learn about the Preventive Cardio-Rheuma clinic set-up (e.g. Denmark, Sweden, Finland, Portugal and US)



## Preventive Cardio-Rheuma clinic (contd.)

### What are the research activities undertaken?

The lead cardiologist has developed a number of national and international projects and studies. Four PHDs have emerged from the clinic

#### National studies

##### Norwegian Register

- Collection of outcomes data from patients with immunological diseases and CVD across the Norwegian population
- Combined with 6 other national registries to look at value hypotheses

##### NOCAR

- Study looking at 11 rheumatology outpatient clinics across Norway aiming to improve the cardiovascular risk assessment through embedding additional risk screening
- Clinics are already recording sex, gender, age, and smoking habits. This study demonstrates the benefits of adding an **additional assessment of blood pressure and lipid levels**, which can be done by any HCP, and may greatly improve CVD prevention. The whole process takes an additional 4-8 minutes to conduct and can be done firstly by either a rheumatology nurse or a secretary (e.g. ordering of tests)
- These data are entered into the EHR system to automatically calculate a composite score and be used to assess the risk of CVD
- This score is present for the rheumatologist when the patient comes into a consultation and can be fed back to patients with analysis and outcomes

#### Outcomes:

- 50% of patients received treatment for CVD
- 20% achieved lipid goals

### SURF of cardiovascular disease Risk Factor management in Rheumatoid Arthritis SURF-RA



ATACC-RA study


 NOCAR study  
paper

#### International studies

##### ATACC-RA

- A Transatlantic Consortium for Cardiovascular Disease in patients with RA. A study in 18 centres across 12 countries
- 5,000 patients with RA were followed across 5-7 years and developed approximately 500 CVD events
- Founded in 2013 in order to develop an RA specific CVD risk calculator. Currently 7-8 of these calculators developed for the general population have been shown to inaccurately predict CVD risk. Development of an RA specific CVD risk calculator has proven challenging

##### SURF-RA

- Survey of the cardiovascular risk factors in patients with RA
- This audit is being run in 40 centres across 24 countries. Centres are receiving a one page data collection sheet to be used in the outpatient setting
- The aim is to increase the awareness of the increased risk of cardiovascular disease in these patients, and of the need to record and control risk factors

## Preventive cardio-rheuma clinic (contd.)

### What are the benefits?



#### Patients

- Increased number of these high-risk patients receiving preventive cardiovascular treatment and adequate management
- Development of this novel role has led to early prevention but also increased diagnosis of CVD at an earlier stage

#### HCPs

- Increased awareness amongst HCPs across all disciplines (secretaries, rheumatology nurses, physicians, PCPs). This helps to remind them that there is an increased risk for CVD and that the effects can be reduced through early diagnosis and prevention
- The 6-step programme allows rheumatologists to be more focused on the control of the inflammatory activity during the consultation. All tests have already been conducted and results entered into the EHR, allowing the rheumatologist to focus on the patient himself ensuring correct and timely prescriptions of disease modifying therapies
- Control of the inflammatory activity is also important for reducing the risk of CVD

#### Wider healthcare system

- Reduced number of deaths and increased mortality due to CVD in patients with RA

### What are the challenges?



- RA is a chronic disease and the patients have to interact with many physicians throughout their treatment. They may potentially be adverse to having additional more specialists and doctors involved in their care
- It takes an additional ~8 minutes to fully assess for risk of CVD, which is highly applicable in a daily outpatient clinic/consultation since this time is divided between three HCPs
- Physicians are not necessarily aware of the importance and increased comorbidity risk in patients with RA
- PCPs are not well educated on the T2T goals required for patients with RA with CVD and therefore tend to refer into the centre as they believe specialist knowledge is required to adequately manage the patient

### Advice to other centres



- It takes an additional 8 minutes to fully assess for risk of CVD, so it is very easy to implement into this initiative and with great beneficial effects for the patient, physician and wider health care systems
- Participate in longitudinal studies



It's key to be integrated fully into the rheumatology department to ensure cohesion and collaboration of care with such an important and prominent comorbidity

- Cardiologist



# Case study 4

## Use of ultrasound in pain management

### Overview

- The hospital has a strong focus on the use of ultrasound in their outpatients clinic
- An ultrasound exam is conducted at most appointments for every patient, including diagnosis and follow-up
- Each patient will have an ultrasound examination as part of their assessment during their follow-up appointments



Pain catastrophizing paper written by head ultrasound rheumatologists<sup>(b)</sup>

Sources: (a) KPMG interviews with HCPs treating RA and associated comorbidities  
(b) Arthritis Care Res (Hoboken). 2018 May;70(5):703-712

### What is the rationale?



- Pain management is a major consideration in RA care since pain is the area of health where most patients would like to see improvement
- There are sometimes inconsistencies between PROMs and clinical measures. Ultrasound is used to help solve these clinical problems, giving a higher quality of examination and helping to assess the rationale for patients pain and evaluate the inflammatory activity
- The ultrasound machines are embedded and integrated into the day-to-day assessment of patients during the consultation
- 90% of rheumatologists use ultrasound during their clinical work in Norway (all clinical rheumatologists in our department)

### What are the key features?



### Resources

- The department has 17 ultrasound machines embedded into the department (the majority in the outpatient clinic) which helps to ensure patients are thoroughly assessed during consultations, rather than having to attend multiple consultations which can be inconvenient for both the patient and treating physicians

<b>Activities</b>	Diagnosis Follow-up appointments Consultation with cardiologists
<b>Timings / Duration</b>	During 30 min outpatient consultation
<b>Staff members involved</b>	Rheumatologists (in the future also for example physiotherapists and orthopedic surgeons)
<b>Type of consultation</b>	Outpatient (majority)

### What are the activities undertaken?



#### Ultrasound guided treatment

- This is conducted during the 30-minute outpatient consultation and is followed by real-time education around results
- They use ultrasound to help guide how they inject corticosteroids treatments into inflamed joints

#### Pain management

- The ultrasound helps to assess the location of inflammation and consequently required treatment for patients with RA
  - Helps to identify whether pain catastrophizing influences outcomes. The hospital has run a number of studies around this and pain catastrophizing has been shown to influence composite measures but not improvement in inflammatory activity assessed by objective measures including ultrasonography
  - Results are shown to the patient to help explain and validate findings

#### Training and education

- Junior members of the rheumatology team are taught how to use ultrasound from day one
- This is initially time consuming and a steep learning curve but this investment leads to better clinical examination
- Both junior and senior members of the team attend teaching sessions around the benefits of ultrasound; this is held for 45 minutes once a week
- Members of the team travel and take international courses to ensure they are fully updated with the developments within the field
- Transfer of knowledge between countries, with learnings from other international centres to learn about their practice

## Use of ultrasound in pain management (contd.)

### Benefits



- By having ultrasound machines embedded and integrated into the consultation patients do not have to attend multiple appointments which can lead to increased drop-out rates
- It produces evidence-based results for pain and swelling and is much faster than having an MRI, which may have a 2-month wait time
- Main issue for RA patients is pain management – this is why ultrasound is so key, to find out whether the pain is treatable (based on inflammation) or not
- The ARCTIC study did not indicate that monitoring US in a T2T approach gave any additional benefit. Thus, routine monitoring during T2T follow-up with US on a group level is not recommended

### Challenges



#### At the level of the Healthcare System

- Generally this method is not seen as a clinical measure, but as an imaging tool
- There needs to be more education around this to ensure it is integrated properly into the assessment of patients

### What are the outcomes so far?



- Improved assessment of inflammatory activity
- Improved diagnosis especially differentiation between inflammatory and non-inflammatory pain
- Better pain and fatigue management

### Tips to replicate this intervention



- “Believing in continuous improvement to be the best, means that your team will all have the basic wish to better and improve care. If you do not have this belief you will always do as if you have done” – Ultrasound specialist

### What else could be done?



- Integrating the ultrasound assessment for cardiovascular diseases (carotid arteries)
- Integrate specific pain management team to be into the care of patients



If you can afford an expensive treatment, you can afford an ultrasound machine. By using ultrasound machines as a preventive measure for treatment and analysis of the patient, you can save on cost of putting patients on expensive therapies

- Rheumatologist



# Case study 5

## National Unit for Rehabilitation for Rheumatic Patients with Special Needs (NBRR)

### Overview

- The hospital hosts the National Unit for Rehabilitation for Rheumatic Patient with Special Needs (NBRR)
- They receive patients from across the whole of Norway and provide their patients with a comprehensive rehabilitation programme using bio-psycho-social measures to ensure personalised and tailored short-term and long-term care

Sources: (a) KPMG interviews with HCPs treating RA and associated comorbidities

### What is the rationale?



- Specialized centre required to treat those patients with severe RA and related diseases. This centre is for complex patients who are in need of rehabilitation which cannot be managed in local hospitals or rehabilitation institutions
- The centre has developed an inpatient setting where patients can stay to receive a comprehensive rehabilitation programme, which is personalised directly to the patients' needs
- Started in 2000

### What are the key features of the intervention?



Patients are admitted to this service from across Norway, if they fulfill the following criteria:

1. Diagnosis of inflammatory rheumatic disease, medically treated according to current recommendations/guidelines by their local rheumatologists
2. Over 18 years old
3. Local and regional rehabilitation has been tested and/or considered insufficient
4. The need for interdisciplinary expertise in rheumatology and rehabilitation with simultaneous assessments from 6 different professional groups
5. Complex disease challenges (which include at least 3 of the following):
  - Pain and/or discomfort
  - Overuse of analgesics
  - Physical loss due to rheumatic disease
  - Psychological challenges such as anxiety and/or depression
  - Comorbid somatic disease
  - Social and activity related challenges (education, work economics, family and everyday life, leisure time)
  - Lack of offerings from their local health and social services

### Three stage rehabilitation program

#### 1<sup>st</sup> stay – Introduction to the programme

- 5-10 days at the centre
- Get to know the patients and gain an understanding of their context and the key challenges they are likely to face in daily life
- Patient's pain is mapped fully and assessment is made as to whether they need to come back for the secondary, longer stay

#### 2<sup>nd</sup> stay – Rehabilitation stage

- 14, 19 or 21 days at the centre
- Very tailored personalised plan defining short-term goals and prescription of activities
- Long-term goals are also set with the patient to help maintain their level of activity for when they are discharged

#### 3<sup>rd</sup> stay – Optional follow-up stay

- This is offered 6 months after the 2<sup>nd</sup> stay and ~60% of patients return
- Check-up for patient against their progress and helps to refocus patients in the direction that they need, resourcing them where needed for long-term benefit

<b>Frequency</b>	110 annual inpatient stays – available to patients across Norway
<b>Timings</b>	24/7
<b>No. of beds</b>	5 inpatient beds (single rooms)
<b>Staff members involved</b>	Full time Rheumatologist Nurses Physiotherapists Psychologist Occupational therapist Social worker

# National Unit for Rehabilitation for Rheumatic Patients with Special Needs (NBRR) (contd.)

## What are the key features of the intervention?



### Annual quality report self-review

- Each year the centre writes a quality report, assessing their practices and improvement areas, which they then disseminate to wider RA centres to learn from their best practices
- They have been accredited Commission on Accreditation of Rehabilitation Facilities (CARF) in 2013 & 2016

### Patient focus

- Booklet on how to improve patient care, with directing in how best to use patient-friendly language. This has been dispersed to departments all over Norway. The booklet entails cognitive behavioural therapy (CBT) or 'bio-psycho-social' methods which can be used to structure their everyday life
- Holistic approach to care where they have 2 multidisciplinary (MDT) team meetings a week to discuss the management of each patient and how they can better work together and with the patients to ensure they have the best care possible. Integrating factors such as finances, families and maintaining work
- The physicians assess the motivation of the patients to define clear objectives and goals that the patient wants to be able to achieve (e.g. be able to work independently). They then help define achievable practical small steps that each patient can take in order to reach these goals
- The unit also assess the patient home environment, including the local available rehabilitation services, to ensure that they are adequately supported once they are discharged and can maintain a high level of care

Sources: (a) KPMG interviews with HCPs treating RA and associated comorbidities

### Training and education

- The leaders of the centre give regular presentations at conferences and travelling around regional centres and other departments of rheumatology about fatigue and pain management and how physiotherapists and occupational therapists can better work with patients
- The unit then sends emails to regional hospitals and PCPs to raise awareness of the centre and its benefits
- Train local physiotherapists about the detailed requirements of the patients prior to them returning home, either over the phone or perhaps first-hand demonstrations within the centre
- Attendance to annual conferences where they give presentations to patient association groups (PAGs) about what they are doing in the centre
- Lectures and training on how to understand pain and communicate pain in a patient language

### Research focus

- The unit is currently running several research projects assessing the effects of rehabilitation services (physiotherapy and occupational therapy) on bettering patient outcomes

### Comorbidity focus

- About 70% of patients have between 2-4 comorbidities, with a high proportion having depression or anxiety
- The centre provides holistic and integrative measures such as mindfulness to manage mental health problems as well as sleep disturbances and pain syndromes

### Fatigue management

- They focus on fatigue and pain management and how best to ensure that they harness these problems
- Use the bio-psycho-social model and through multidisciplinary team discussion define a personalised plan

## What are the benefits?



### Patients

- Get access to long-term care that can improve their treatment outcomes and slow the progression of their disease
- Attend patient groups and spread the word of the benefits which results in more patients learning about the treatment options

### Rheumatologists

- Some rheumatologists have seen the benefits of using this centre by improving patient outcomes and therefore refer more patients

### Wider RA community

- The centre disseminates the findings across the community so that they can learn from their way of practice and refer patients

## What are the outcomes so far?



- 30-50% improvement in patients who come back for third-line stay
- Additional burden of depression or anxiety, which is common in patients with RA, is incorporated into the patients treatment and management through the holistic approach to care

# National Unit for Rehabilitation for Rheumatic Patients with Special Needs (NBRR) (contd.)

## Challenges

- National demands are requiring them to increase their volume to >100 patients per year; which is considered borderline based on the objective and the complexity of the patients
- They have to cater for all regional areas across Norway equally as a regulation
- There is periodically a waiting list for patients. However every patient who needs to be received gets a place
- Not all rheumatologists think that this care is necessary for their patients
- There is different awareness amongst the rheumatology communities. Most rheumatologists are busy in their day-to-day roles and do not always remember to refer patients for complex rehabilitation on a National level
- Patients who do not display severe symptoms remain on waiting lists at local physiotherapists until there is a vacancy
- The financial system of the health care may limit referrals since the budget of the local hospitals (or the regional health care) needs to cover the cost of treatment

Sources: (a) KPMG interviews with HCPs treating RA and associated comorbidities; (b) National Rehabilitation unit website; (c) <http://www.carf.org/home/>



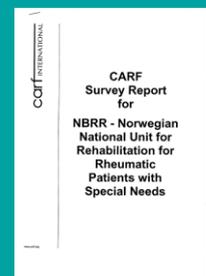
This program greatly impacts the patients' lives and can turn a very tricky situation into a good situation, especially for those individuals who have not yet reached working age. This initiative helps them to go back into normal life. It is a very big effort in the beginning but it will greatly benefit the patient and their family but also the wider community and society as a whole by increasing access to care and the right treatment

- Rheumatologist



National Treatment Services for Rheumatological Rehabilitation<sup>(b)</sup>

CARF Survey Report<sup>(c)</sup>



Overview of research projects running within the department<sup>(a)</sup>



These patients do not have the power to stand up for themselves so we have to do it for them

- Nurse



The patient's goals are the most important thing to understand, once we know this we can make this plan with the whole team

- Rheumatologist



# Case study 6

## Role of the rheumatology nurse

### Overview

- The rheumatology nurse plays an integral role to the functioning of the rheumatology department
- There are about 30 nurses who have large responsibilities for assessing, monitoring, treating and educating patients across the patient pathway

Sources: (a) KPMG interviews with HCPs treating RA and associated comorbidities

### What is the rationale?



- There are a large number of patients who are referred to the department who need a thorough assessment to ensure they receive high-quality care
- The role of the rheumatology nurse can help to supplement the care provided by the rheumatologist and other treating physicians ensuring that they can make the best use of their consultation times to address the needs of the patient
- In the inpatient ward nurses are needed in the afternoons and week-ends (nights are covered by collaboration with the unit of orthopaedic surgery)

### What are the key features?



#### Nurse hotline

- Patients have a direct line to the nurses in the out-patient clinic which they can call 9:30 – 11:30am on a week day
- 2-3 nurses answering a day, and the health secretaries answer any messages outside this time
- Patients feel they have constant access to care when they need it, making them feel more secure and cared for

#### Assessment

- The nurses are frequently in charge of the full assessment of the patient upon arrival at the consultation. This includes a joint assessment; bone densitometry; DAS and other composite measures; inputting PROMs to the electronic health record (EHR), as well as:
- Blood samples: these are crosschecked with patient-reported outcomes to assess severity of disease

### What are the key features? (cont.)



- Lipid and cholesterol levels supplemented by family history, smoking assessment etc.
- These are tested at each follow-up depending on risk severity - usually once yearly
- They are able to refer directly to in-house cardiologists if there is concern

#### T2T goals

- The nurse follows the recommendations set for T2T goals (new patients T2T goal is remission); if they are seeing acute patients the T2T goals are set by the rheumatologist in collaboration with the patient (shared decision making). The follow-up should be monthly after initiation of new DMARD therapy

#### Collaboration with PCPs

- Support the writing (and sometimes adapt rheumatologists) discharge notes to ensure they are understandable for PCPs

#### Comorbidity specialists

- They have had training and provide holistic management of patients with fatigue and fibromyalgia, as well as helping to screen for increased risks with patients on biologics

#### Education of patients

- Explanation around swelling of the joints, treatment, medication and impact of the disease
- Test results explanation and overview with their electronic health record (e.g. use of diagrams and graphs)

#### Training other general medicine nurses

- They attend the Norwegian nursing association conference, once per year in order to collaborate with a group of rheumatology nurses from across the country



CONTENTS



APPENDIX  
CENTRE REPORTS

# Role of the rheumatology nurse (contd.)

## Benefits

- The rheumatology nurses appreciate the close collaboration between team members, and being able to work closely with the rheumatologists which means they can learn consistently and have elevated roles within this centre
- The hotline means immediate access for the patient. The patients may know (or experience) that they can get key questions answered by rheumatology nurses in minutes and obtain rapid access to a rheumatologist if there is an emergency
- There is a strong emphasis on a multidisciplinary approach to care with rheumatology nurses helping support each other and their rheumatologist colleagues within the department

## What are the outcomes so far?

- Reduced burden on the rheumatologists so that they can spend more time with the patient rather than having to do a full assessment

## Challenges

- Patients have to be motivated to improve their symptoms, outcomes and their disease progression
- They need to be motivated to engage with and maintain their treatment and this can be difficult. Medication is the main barrier to concordance as the patients do not want to experience side effects and do not fully understand the way the medication works
- Having the time to fully assess patients and manage all the data collection and input into the electronic health systems

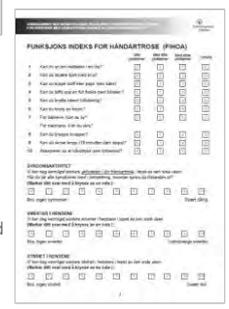
Paper on nurse-led telephone service<sup>(b)</sup>



PROMs assessing rehabilitation benefits<sup>(c,d)</sup>



FIHOA – functional index for hand movement<sup>(e)</sup>



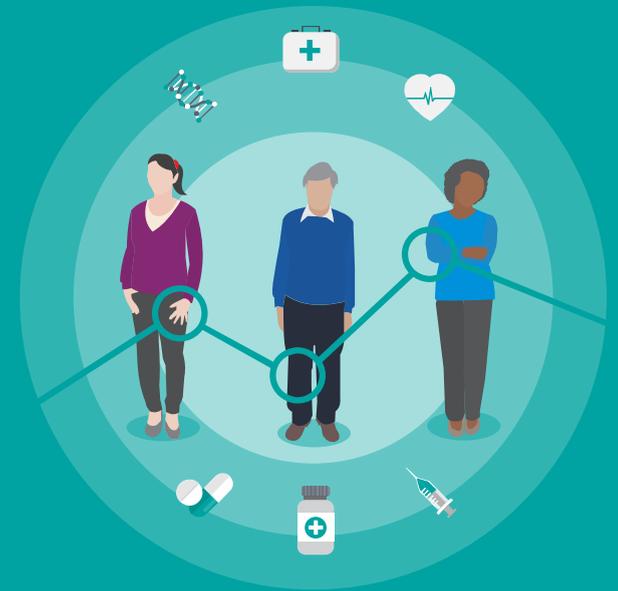
“We are very proud of the nurses in this team, they are highly experienced and are essential in making the patients feel safe and comfortable”  
- Rheumatologist





# Hospital de Santa Maria

Lisbon, Portugal



# Summary



## Context

- **Tertiary centre in Portugal** for rheumatic diseases and musculoskeletal disorders
- **Strongly integrated care across departments** ensures holistic care for the high volumes of patients seen at the hospital
- **Specialisation in management of associated comorbidities** running multiple clinics and joint MDT meetings within the hospital network to effectively assess risk of and treatment for a number of comorbid problems
- **Strong research focus** which is integrated into the day-to-day practices of the clinicians treatment of rheumatoid arthritis (RA) patients
- **Emphasis on continual improvement** is embedded within the team and has led to the development of dedicated areas that have improved quality of care and efficiency
- **Emphasis on education and training** with the hospital closely linked to the University of Lisbon providing both pre- and post-doctorate teaching for physicians, and education for the wider RA community
- **Strong relationship with the Portuguese Society of Rheumatology** with whom they have designed a national registry, and continue to collaborate with for other research activities



## Key strengths in the delivery of RA care

- **Systematic assessment and data collection** using an online national registry platform to register patients and record both clinical examination results and composite measures
- **Joint rheumatology and respiratory clinic** providing consultations to those patients with RA with more complex comorbidity-related issues requiring multidisciplinary consideration
- **Streamlining access for new patients** into the early arthritis clinic, ensuring rapid access for patients with suspected RA through a triaging system
- **Joint pregnancy clinic** with gynaecology and obstetrics dedicated to patients with RA providing pre-conception and pregnancy advice, treatment and care
- **Dedicated psychologist** who helps assess patients with, or suffering from associated psychological disorders
- **Investigations and procedures unit** contains dedicated resources for rheumatic patients, helping to improve quality and efficiency of patient examinations and procedures (e.g. joint injections)



## Key challenges faced in delivery of RA care

- High volumes of patients are referred from primary and secondary care across Portugal meaning Hospital de Santa Maria is oversubscribed
- Significant burden on rheumatologists because the treatment for RA is not well managed in the community, meaning patients remain in tertiary care for the duration of their chronic disease.
- Limited number of nurses and limited scope for enhanced roles for non-pharmacological healthcare practitioners, leads to increased burden for rheumatologists
- Limited funding leads to a number of issues relating to the capacity of the hospital
- Limited time and resources (personel and financial investment) means there are not enough hours are dedicated to clinical research
- Long waiting times for appointments, scans and procedures are due to demand regularly exceeding capacity. The hospital has developed a network of hospitals that enable patients to be referred on for discrete elements of their care e.g. investigations

# RA Portuguese healthcare system overview

## Portuguese healthcare system :



The Portuguese healthcare system is characterised by three co-existing and overlapping systems: the universal national health system (NHS), the health subsystems health insurance schemes; and private voluntary health insurance (VHI).

The delivery system consists of a network of public and private healthcare providers; each of them is connected to the Ministry of Health (MoH) and to patients in their own way.

**Public health service:** Portuguese NHS was established in 1979, and is a universal tax-financed system. It covers around 75% of the population:

- The MoH and its institutions concentrate on the planning and regulation activities of the health system
- The NHS is managed at regional level by the five regional health administrations (RHAs), each has a health administration board accountable to the Minister of Health and responsible for the strategic management of population health, control hospitals, management of primary care centres and implementation of national health policy objectives

**Health subsystem:** These subsystems are health insurance schemes for which membership is based on professional or occupational category. Approximately 16% of the population are covered by a health subsystem, these are made up of a number of public and private sector systems which are integrated into the ADSE (*Assistência à Doença dos Servidores do Estado*).

**Private insurance:** VHI began in 1978, and now has more than 2.7 million individuals ~25% of the population are covered by individual or group private health insurance. They mainly fulfil a supplementary role to the NHS rather than providing a local alternative to it, providing diagnostic, therapeutic and dental services, as well as some ambulatory consultations, rehabilitation and hospitalisation.

**Funding:** The RHAs play an essential role in the contracting of healthcare providers to work with the NHS. They are responsible, together with an independent public board the ACSS (Administração central do Sistema de saúde) who help to fulfill the duties of the MoH, to setting up (and paying for) contracts with the hospitals. They are also in charge of negotiating and signing Public-Private Partnership (PPPs) contracts.

**Hospitals:** All hospitals belonging to the NHS are under the jurisdiction of the MoH. Private sector hospitals, both not for profit and for profit, have their own management arrangements.

## Rheumatoid Arthritis in Portugal:



### Patients:

- Prevalence: 0.7% of the Portuguese population<sup>(b)</sup>

### Physicians:

- 200 rheumatologists in Portugal covering a population of 10.3 million<sup>(d)</sup>

### Guidelines:

#### RA:

- EULAR/ACR<sup>(d,e)</sup>
- National guidelines (e.g. Portuguese Society of Rheumatology<sup>(c,d)</sup>)
- Local guidelines (e.g. processo assistencial – local clinical care guideline developed to underpin quality accreditation)

#### Comorbidities:

- International EULAR/ACR guidelines

### PAGs/ Medical Societies:

- Portuguese Society of Rheumatology<sup>(d)</sup>
- Portuguese League against Rheumatic Diseases (LPCDR)<sup>(e)</sup>
- National Association of Patients with Rheumatoid Arthritis (ANDAR)<sup>(f)</sup>
- Portuguese Medical Association (Ordem dos Médicos): professional organisation for physicians.
- Two main unions: the National Medical Federation (Federação Nacional dos Médicos, FNAM) and the Independent Medical Union (Sindicato Independente dos Médicos, SIM)<sup>(a)</sup>

**Sources:** (a) Health Systems In Transition (b) Branco, Jaime C et al. "Prevalence of Rheumatic and Musculoskeletal Diseases and Their Impact on Health-Related Quality of Life, Physical Function and Mental Health in Portugal: Results from EpiReumaPt – a National Health Survey." *RMD Open* 2.1 (2016): e000166. *PMC*. Web. 4 July 2018. (c);KPMG interviews (d) <http://www.spreumatologia.pt/> (e) <http://www.lpcdr.org.pt/> (f) <http://www.andar-reuma.pt/>

# The rheumatology department

Hospital de Santa Maria is a large public hospital situated in the northern part of Lisbon

## The hospital



<b>Type</b>	Hospital de Santa Maria sits under the Centro Hospital Lisboa Norte EPE (CHLN) alongside Hospital Pulido Valente. It is a tertiary centre and university teaching hospital	<b>Locations</b>	North-western part of Lisbon (Western part of Portugal)
<b>Core services</b>	General hospital services with the following departments: vascular and endovascular surgery; medicine; surgery; children and family; obstetrics, gynaecology and reproductive medicine; neuroscience; oncology; complementary diagnostic measures; emergency intensive care; chest (cardio and respiratory); and otolaryngology	<b>Population served</b>	350,000 inhabitants in the north-western part of Lisbon <sup>(a)</sup> However they receive patients from across the country and further afield (e.g. from Portuguese-speaking countries such as Angola, Mozambique and South America)
<b>Size</b>	>1,350 doctors work at the CHLN; >6,300 employees ~40 doctors dedicated Rheumatology unit 1,000 beds	<b>Demographics</b>	Adult patients 84% female

## The rheumatology department



<b>Services</b>	The rheumatology and metabolic bone diseases department is led by Professor Doctor João Eurico Cabral da Fonseca. It has seven units dedicated to rheumatology: outpatient, inpatients, investigations and procedures department, day hospital, paediatric rheumatology department, metabolic bone diseases and clinical trials departments	<b>Collaborations</b>	Portuguese Society of Rheumatology to create Reuma.pt, a registry for rheumatic diseases, which can be accessed online by all rheumatologists across Portugal Biobank IMM collaborates with national and international research institutions to provide samples for studies The department collaborates in training activities organised by scientific societies. Promotion of medical school 'rheumatology series' lectures
<b>Teaching/ research scope</b>	The Department of Rheumatology runs an intense programme of research in several areas of rheumatology in close collaboration with the Research Unit in Rheumatology of the Institute of Molecular Medicine and the Faculty of Medicine of the University of Lisbon. It has specific interests in early arthritis and the affect of the environment around RA and its evolution (e.g. biological changes, synovial tissue examination, assessing bio- and epidemiological markers – early markers of disease prognosis and response to treatment <sup>(a)</sup> . Teaching: Pre-graduate training activity for medical students; postgraduate training; preceptorship programmes for trainees from European countries, and affiliated Portuguese-speaking countries (e.g. Brazil, Angola, Mozambique); internal development within the research team with weekly meetings to discuss topics, protocols of action, recommendations and research projects.	<b>Funding and Resources</b>	Entirely publically funded Clinical trials and research are funded by either public or private grants

# The rheumatology department (cont.)



## Overview of services

Service Division	Early Arthritis Clinic	Outpatient Care Unit	Inpatient Ward
Duration of stay	30 mins	30 mins	As long as required
Hours of availability	Monday to Friday 8:00 – 20:00	Monday to Friday 8:00 – 20:00	Monday to Friday 8:00 – 16:00
No. of staff available	2 rheumatologists for outpatient care, 2 rheumatologists providing ultrasound	4 rheumatologists at a time Nurses (rotational and unspecialised) 1 (dedicated) psychologist; 1 social worker (not exclusive to rheumatology); 1 nutritionist (not exclusive)	1 senior rheumatologist 1 consultant rheumatologist (rotates every month) and supports all other inpatient wards 1 trainee
Capacity (no. of beds/rooms)	Rooms – which are shared between therapy areas	40 rooms – which are shared between therapy areas	4 beds
No. of patients seen (per year)	Not available	30,000 consultations 2,000 patients with RA	100 patients
Patient type catered to	Early arthritis patients	Chronic patients or those in remission	Acute patients (e.g. complications or infections or investigations)
Services offered	Early diagnosis and treatment for patients with early arthritis. Fast track for treat-to-target (T2T) strategy and required complementary diagnosis tests, such as ultrasound	General RA consultation; initial suspected RA consultation; diet and nutrition; joint rheumatology clinic; pre-conception and pregnancy consultations (in conjunction with obstetrics); psychological consultation; MDT consultations with ophthalmology	Hospitalisation of rheumatic patients Support for rheumatic patients admitted to other services Post-discharge consultation
Specific tools	Reuma.pt Objective measures	Reuma.pt Objective measures	Hospital electronic medical record Objective measures

# The rheumatology department (cont.)



## Overview of services

Service Division	Investigations and Procedures Unit	Day Clinic	Clinical Trials Unit	Rehabilitation Centre
<b>Duration of stay</b>	For procedure	2-3h	Duration of trial	Ad hoc 20 sessions over 3 months
<b>Hours of availability</b>	Monday to Friday 8:00 – 20:00	Monday to Friday 8:00 – 20:00	Monday to Friday 8:00 – 16:00	Monday to Friday 8:00 – 20:00
<b>No. of staff available</b>	3 senior rheumatologists 2 trainee rheumatologists 1 rheumatology nurse	General nurses who specialise in infusions 1 rheumatologist who runs the ward	Study coordinator and study nurse (not exclusive to rheumatology)	None dedicated to rheumatology
<b>Capacity (no. of beds/rooms)</b>	4 rooms	18 chairs on the ward 4-5 chairs specifically for RA	2 offices 1 meeting room 1 study room (with adjacent nurse room) 3 clinical examination rooms	Not applicable
<b>No. of patients seen (per year)</b>	30,000 consultations	~400 patients	13 active clinical trials with 351 visits performed	Not available
<b>Patient type catered to</b>	Patients requiring technical procedures such as biopsies, ultrasound, bone densitometry etc.	Biologics patients Subcutaneous patients	Patients eligible for clinical trials	Those patients with severely progressed symptoms who have been diagnosed at a late stage (usually younger patients)
<b>Services offered</b>	Arthrocentesis; abdominal subcutaneous fat biopsy; biopsy salivary glands; ultrasound-guided synovial biopsy; capillaroscopy; periarticular infiltration; intra-articular infiltration; joint wash; mesotherapy; microscopy of polarised light; mini-arthroscopy; osteo-densitometry; ultrasound-guided diagnostic and therapeutic procedures	Decision-making on the initiation of biological therapies Consultation on monitoring the efficacy and safety of biological therapies Administration of intravenous therapies Teaching and administration of subcutaneous therapies Supportive transport is provided for those patients living far away	Collaboration in the development of the Clinical Research Centre Planning of investigator-initiated clinical trials Implementation of Phase I, II, III and IV multicentre clinical trials service Selection of clinical trial candidates Consultations and treatments associated with clinical trials Training including in clinical trials	Physiotherapy Occupational therapy Hydrotherapy Daily life activity sessions
<b>Specific tools</b>	2 ultrasound machines Bone densitometry Mini-arthroscopy of the knee	IV Reuma.pt	Biobank data Reuma.pt	Equipment to help to help re-train to perform every day activities, and aids to install in the patient's own home

# The team

## Core team profiles

- 18 specialist rheumatologists
- 10 trainee rheumatologists
- 1 rheumatology nurse
- 3 rheumatology researchers
- 2 service coordinators
- 2 social care workers
- 1 psychologist
- 2 study coordinators
- 3 operational assistant
- physiotherapists
- occupational therapists

## Affiliate team profiles

- Psychiatrist
- Psychologist
- Pulmonologist
- Ophthalmologist
- Cardiologist
- Endocrinologist / diabetologists
- Infectious diseases



## Key features of the care delivery team

- **Rheumatologists are the central** to the efficient diagnosis, treatment and management of patients with RA, they conduct a 30-minute appointment with each time they see a patient
- **Highly specialised team** with each rheumatologist having a different area of specialist interest (e.g. respiratory or cardiology)
- **Continuous improvement and learning** due to specialist knowledge which leads to increased knowledge-sharing as well as cover the broad bases of care needed especially with comorbidities
- **Integrated approach to care** with close relationships between the rheumatologists and other medical specialties leading to efficient referral between physicians when additional specialist knowledge is required (e.g. additional joint clinics with endocrinology and infectious diseases)
- **Strong emphasis on research** as many practices are integrated with the Faculty of Medicine. Collection of samples and inputting patient information into day-to-day working meaning that large amounts of data are collected and research undertaken

## Governance and processes

### Team meetings:

- Weekly 3-4h multidisciplinary team (MDT) meeting on Tuesdays where all HCPs and RA researchers convene to discuss, more complex cases; trainees present on developments in research

### Protocols:

- There are specific protocols aligned to local guidelines for every sub-specialty outpatient clinic

### Patient records:

- Internal electronic health record (EHR) system
- Physicians can use this to see records and book appointments with other physicians
- This is linked to the online national registry Reuma.pt

### Pharmacy:

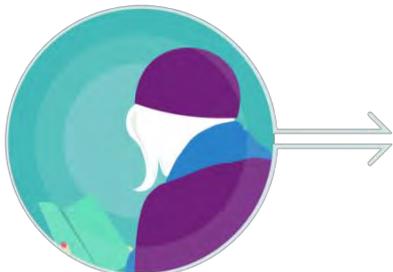
- Some drugs, e.g. biologics are not available in community pharmacy, and are provided by the hospital

Sources: (a) KPMG interviews with HCPs treating RA and associated comorbidities (b) [http://www.euro.who.int/\\_\\_data/assets/pdf\\_file/0007/337471/HiT-Portugal.pdf?ua=1](http://www.euro.who.int/__data/assets/pdf_file/0007/337471/HiT-Portugal.pdf?ua=1)

# Overview of interventions in place for RA

## Awareness & Prevention

Symptom identification



## Referral & Diagnosis

In secondary care



## Treatment & Management

Pharmacological management



Non-pharmacological management



## Follow-up

Monitoring of chronic disease/flare up



Interventions

### PCP shadowing

- 2 PCPs a month enrol in a programme to shadow a rheumatologist to learn best practice care in RA taking their learnings into the community to improve patient outcomes

### Awareness programmes

- The hospital has conducted studies to show the benefit of raising awareness of RA amongst the PCP and patient population

### Educational courses for the wider RA care team

- 1-2 day courses are available for all health care professionals (HCPs) such as PCPs / pharmacists, helping to increase the level of training and education on the symptoms and treatment of RA

### Rapid referral

- PCPs can refer patients from the community through an electronic referral system

### Preceptorship programmes-

- Receive training and gain experience in specialised management of RA

### Streamlining access for new patients

- Well developed triaging system created to help make a rapid assessment of the likelihood and severity of inflammatory arthritis, ensuring rapid access for those individuals with suspected RA to the early arthritis clinic
- Those with low likelihood of RA can be referred through the general rheumatology clinic less urgently

### Systematic assessment and data collection

- Reuma.pt is a nationwide online registry designed with the Portuguese Society of Rheumatology to capture clinical and composite score measures that assess disease activity and progression in the patient

### Investigations and procedures unit

- Dedicated unit for investigative procedures required in RA care (e.g. ultrasound, bone densitometry, biopsies) helping to improve quality and efficiency of services

### Role of the rheumatology nurse

- Only dedicated rheumatology nurse in the hospital who has a specialist role within the investigations and procedures

### Defined treatment pathway

- Clearly defined criteria to assign patients to required pathways for further management – helping to alleviate burden of increasing volume of referrals

### Role of ultrasound

- Ultrasound is integrated into both pharmacological management and research and helps to provide richer information on the development of patient's disease

### Joint rheuma-obstetrics clinic

- Weekly clinic for pre-conception and pregnant patients

### Dedicated clinical trials research wing

- Designated area for conducting clinical trials research – available to all departments

### Rehabilitation unit

- Physio- and occupational therapy services are available for patients demonstrating severe symptoms

### Patient education

- HCPs play an important role in educating patients in-person but also supplying supporting materials such as educational leaflets

### Biobank

- 5 dedicated research staff who integrate sample collection from clinical practice into the biobank for international research

### Group educational sessions with PAGs

- Collaboration with ANDAR to educate patients around self-management

### Telemedicine education

- Every fortnight the hospital holds educational sessions for colleagues in Portuguese-speaking countries

### Structured follow-up

- Patient disease activity is followed up according to T2T national guidelines (Portuguese Society of Rheumatology)

### Integrated follow-up programme

- Patients on biologics are followed up every 3 months by a rheumatologist in the day clinic, rather than having to have a separate appointment in outpatients

### Comprehensive EHR system

- Electronic system shares links across the hospital departments and with the primary care physicians (PCPs) in the community

### Emphasis on research to support clinical practice

- Ensuring comprehensive data collection and subsequent monitoring and follow-up into everyday clinical practice

### Community discharge

- Treating physicians tailor communication methods with PCPs when referring patients back into the community

# Interventions in place for RA comorbidities

## Awareness & Prevention

Symptom identification



## Referral & Diagnosis

In secondary care



## Treatment & Management

Pharmacological management

Non-pharmacological management



## Follow-up

Monitoring of chronic disease/flare up



Interventions

### Differentiated disciplines for rheumatologists

- Each rheumatologist within the department pursues an interest in a comorbidity relating to RA in both their clinical and research practice, helping to raise awareness and educate other HCPs about the potential of associated comorbidities

### Definitive referral procedure

- Regular MDT meetings are held to discuss patient cases and help to define the core care and treatment team to manage comorbid patients

### Comorbidity risk assessment

- T2T guidelines are followed in all patients to ensure early detection and diagnosis of potential comorbidities, and to enable adjustment to an appropriate target for all comorbidities

### Joint rheumatology and respiratory care

- Monthly combined clinic for patients with RA with suspected respiratory diseases
- Monthly MDT meeting to discuss complicated cases

### Rheuma-pulmonary hypertension clinics

- Weekly joint clinics and monthly MDTs are held with cardiologists to discuss treatment for patients with RA demonstrating symptoms or demonstrating a risk of suffering from pulmonary hypertension or other cardiac involvement

### Osteo-metabolic clinic

- Patients with RA are monitored for fractures according to their fracture risk, and as per local guidelines. Bone mineral densitometry (BMD) is situated within the rheumatology department and is well integrated into the treatment of patients with RA
- The protocol used in this clinic has received accreditation from the MoH

### Systematic assessment of comorbidities

- Assessment and data collection of comorbid factors for new patients via the national patient registry, Reuma.pt

### Dedicated psychologist

- Rheumatologist can refer patients to the resident psychologist who helps with patients with associated psychological disorders such as depression and anxiety

### Stomatologist supervision

- Patients on biologics are susceptible to having periodontitis and therefore are frequently evaluated in consultations with the stomatology team

### Joint rheuma-ophthalmology clinic

- Regular appointments available to assess corneal involvement in RA

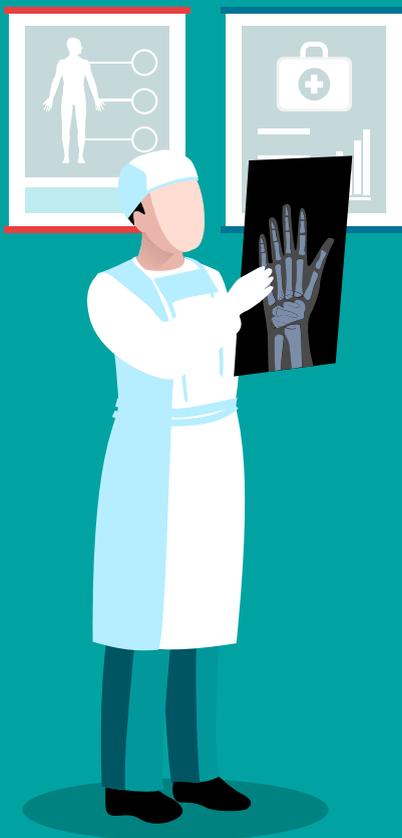
### Preventive vaccines programme

- Patients with increased risk of infection are enrolled into a vaccine programme

### Structured follow-up

- Patients are followed up for their associated comorbidity according to international guidelines (ACR/EULAR)
- This is also captured through the Reuma.pt system

# These interventions have improved outcomes



## How do you quantify the benefits in RA?

### Objective measures (KPIs):

- The department has an online system that was designed in partnership with the Portuguese Society of Rheumatology with the ultimate goal to register all rheumatic patients treated with biological agents in Portugal, Madeira and the Azores, ensuring effective monitoring of treatment indication, efficacy and safety
- T2T goals
  - CRP, extra-articular manifestations, erythrocyte sedimentation rate
  - Joint examination (number of tender and swollen joints)
  - Increased remission rates; decreased drop-out rates

### PROMs:

- Composite scores: DAS 28, SDAI, CDAI
- Global scales: VAS (global, joint pain & fatigue scores)
- Functional measures: MHAQ, HAQ, SF-36 (physical, bodily, general health, vitality, social function, mental), FACIT; EQ-5D-5L

### Centre routinely measures comorbidity indicators on their patient management system:

#### Objective measures (KPIs):

- CVD: cholesterol, lipid levels, blood pressure
- Respiratory: respiratory function tests, x-ray, CT
- Depression: PHQ-9
- Osteoporosis: DXA, x-rays

#### Department Quality Criteria:

- The department is currently leading an intervention with the Portuguese Society of Rheumatology to define a set of structural, process-related and outcomes quality criteria that will collectively describe a well-functioning rheumatology service. The criteria include:
  - **Structure.** Rheumatologists per population covered; rheumatology nurses per population covered; frequency of medical audit; access to medical equipment; existence of electronic medical record; availability of data across departments and health professionals
  - **Process.** % given educational materials regarding disease / treatment; % of diagnosed patients given written communication addressed to the PCP / other relevant health professionals
  - **Outcome.** Number of absent days from work per patient with RA per year; % of patients who have retired early due to illness; patient evaluation – survey including patient satisfaction and experience of care; general improvement in disease activity

**“The team here are motivated to do their best and aim for excellency. It can be exhausting but at times very rewarding”**  
 - Rheumatologist

# How can care be improved?



## What is next for the centre?

### Overview: Rescheduling strategy to increase capacity for new patients and reduce burden on rheumatologists

- **Why?** The department is operating above capacity and therefore cannot respond enough to support primary care needs, receiving 6-13 new patients a day. Senior rheumatologists are currently having to work overtime to ensure that patients are seen in a timely manner. This has an impact on effectiveness and quality of their work and clinical research as they lack time to administer and execute their studies
- **How?** The department are looking to refine their strategy in order to continue to receive this high number of new patients, but without letting it effect their day-to-day practice. They are looking to stream patients into categories to improve the appropriateness of cases seen by the early arthritis clinic and therefore the timeliness of diagnosis. RA will be treated at an earlier stage in more patients, remission achieved, and the patient transferred into the general rheumatology clinic

### Overview: Increased focus on research and investment in science

- **Why?** The hospital has always had a deep focus on research and integrating this with the department's clinical practice. Currently the rheumatologists are too busy working overtime and therefore do not have the appropriate capacity to conduct their own research studies. As a leading centre in Portugal they believe they have the responsibility of elevating and improving care through scientific aspects of rheumatology
- **How?** The department is changing its strategy to have more collaboration between the clinicians and the lab research teams, through encouraging the lab unit staff to help support the projects of trainee rheumatology clinicians in order to ensure that they can adequately meet their own motivations and expectations of completing their PhDs



## What advice would you give less specialised centres?

### Overview of advice: Invest in a comprehensive online platform allowing for robust, continual assessment of the patient

- **Why?** To ensure adequate and consistent assessment, management and treatment of patients across the patient journey. This will help maintain a high level of care but also ensure comprehensive collection of data which can be analysed over time assessing the progress and performance against certain treatments but also for use in future research
- **How?** Within Portugal, enroll patients using Reuma.pt. For other countries, perhaps work alongside a medical society to design an assessment and diagnostic online platform to facilitate adequate management and collection of data

### Overview of advice: Encourage collaboration within the team to ensure effective organisation of treatment

- **Why?** Encourage rheumatologists to pursue additional areas of clinical interest which help to increase knowledge-sharing and learning between attending physicians. This also widens the treatment possibilities for patients through encouraging scientific discussion and different opinions on patients and their management whilst formulating joint decisions on the management and treatment of patients. Rheumatologists are also motivated as they are able to pursue their specific interests
- **How?** By running specialist clinics you are able to help diversify your offering for patients and ensure that comorbidities are covered within the department, which will help to support the effective organisation and treatment of patients

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# Case study 1

## Systematic assessment and data collection

### Overview

- Reuma.pt is a collaboration with the Portuguese Society of Rheumatology to create an online national registry that helps to monitor patients treatment outcomes
- This online platform can be easily accessed across the hospital, but also from other Portuguese centres and even by patients in the home



Sources: (a) KPMG interviews with HCPs treating RA and associated comorbidities; (b) [http://reuma.pt/en\\_UK/Default](http://reuma.pt/en_UK/Default)



### What is the rationale?



- It can be difficult to locate and extract patient information and data as it is often captured on multiple different platforms and databases
- The Portuguese Society of Rheumatology collaborated with lead physicians in RA to develop a database which could be used for patients with RA within Portugal and further afield
- The ultimate goal is to register, monitor and assess all rheumatic patients treated with biological agents in mainland Portugal, Madeira and the Azores, ensuring effective monitoring of treatment indication, efficacy and safety<sup>(b)</sup>

### What are the key features of the intervention?



#### Overview

- This online platform was launched in 2008 specifically for RA and has since developed as a national registry for the other diseases
- It is used as a clinical record and is obligatory for all biologic patients
- ~50% of patients with RA at Hospital de Santa Maria are registered here

#### Measures

- Obligatory questions are highlighted in red and surround clinical aspects (e.g. swollen joints, CRP) and composite scores (DAS, SDAI, CDAI, HAQ)
- Optional questions surround quality of life, anxiety, SF36 and FACIT

Projectos Reuma.pt

Intitulação do projecto de investigação	Data de aprovação
Effectiveness, safety, quality of life, costs and persistence of treatment (comparing to reference treatment) in juvenile idiopathic arthritis patients - data from the Portuguese register	25-05-2010
Study of the representation of biologists in the treatment of different rheumatic diseases (performed by the patients and by society) (organization in Patient Reported Outcomes and economic impact) - (clinical case register)	18-06-2010
Validation of patient reported outcomes for patients with Rheumatoid Arthritis, Osteoarthritis, Ankylosing Spondylitis, Systemic Sclerosis, Sjogren's Syndrome, Myositis, and Dermatomyositis	14-05-2010
Validation of quality of life instruments (DAS, SDAI, CDAI, HAQ) in patients with RA, Psoriasis, Psoriasis arthritis, juvenile idiopathic arthritis, Sjogren's Syndrome, Myositis, and Dermatomyositis	14-05-2010
Validation of quality of life instruments (DAS, SDAI, CDAI, HAQ) in patients with RA, Psoriasis, Psoriasis arthritis, juvenile idiopathic arthritis, Sjogren's Syndrome, Myositis, and Dermatomyositis	14-05-2010
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Validation of quality of life instruments (DAS, SDAI, CDAI, HAQ) in patients with RA, Psoriasis, Psoriasis arthritis, juvenile idiopathic arthritis, Sjogren's Syndrome, Myositis, and Dermatomyositis	14-05-2010
Validation of quality of life instruments (DAS, SDAI, CDAI, HAQ) in patients with RA, Psoriasis, Psoriasis arthritis, juvenile idiopathic arthritis, Sjogren's Syndrome, Myositis, and Dermatomyositis	14-05-2010
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Validation of quality of life instruments (DAS, SDAI, CDAI, HAQ) in patients with RA, Psoriasis, Psoriasis arthritis, juvenile idiopathic arthritis, Sjogren's Syndrome, Myositis, and Dermatomyositis	14-05-2010

List of ongoing Reuma.pt studies<sup>(b)</sup>

- Comorbidities: there is a specific section assessing cardiovascular (CVD) risk factors (lipid/ cholesterol levels, family history) and pulmonary assessment (including X-ray results); additional vaccines (e.g. flu, pneumococcus); and periodontitis (stomatology)

#### Treatment efficacy

- The system creates visual graphs which can help both the physician and the patient understand and assess treatment outcomes
- T2T guidelines can be measured very efficiently with this

#### Outputs

- Longitudinal graphical and data that demonstrate the evolution of the patient's disease and can be shared in real time with the patients
- Optional composite scores are produced (e.g. ACR 20, 50, 70) which are of use in clinical trial data

#### Research

- All samples within the hospital's biobank are linked to the registry, helping to add to the body of information and research surrounding biomarkers
- The platform has a list of all the projects using the data

#### Accessibility

For the patient:

- Reuma.pt PROMs are accessible at home taking 10-15 mins to complete

For the physician:

- The information from Reuma.pt is easily transferable to the EHR
- The EHR is accessible to PCPs across Portugal and therefore patient information can be accessed for treatment in the community

## Systematic assessment and data collection (cont.)

### What are the outcomes so far?



- Faster assessment of disease activity in patient
- Data captured has and will continue to be used for research at this centre and further afield
- Outcomes data for biologics can help demonstrate efficacy and cost-effectiveness for reimbursement and funding

### Benefits



#### For the patient

- Automated reports from Reuma.pt can be shared with patients in real time, so they can see the outcomes of their treatment progress and disease progression through visual graphs and composite scores

#### For physicians

- Helps to educate patients around their disease and resolve any inconsistencies between assessed disease activity and PROM scores

#### In the hospital

- Consistent management of patient at least to a baseline measure which can be visualised over a selected time period and used to assess treatment outcomes
- Data records can be used in conjunction with biobank for research

#### In the community

- The platform is available across all centres in Portugal and is obligatory for all patients on biologics. This is an effective way of collecting national data for patients with RA

### Challenges



#### Patient

- The patient reported outcome measures (PROMs) within Reuma.pt are available for patients to access at home, however there is little uptake
- Only 50% of the patients in the hospital enrolled, as there is little time available to create profiles in the 30-min consultations

#### Healthcare professionals

- Having the capacity to input good quality data is difficult and often only the base level of information is input

### What's next



#### Data manager

- If they could obtain funding for a data manager, this role would be created to help relieve the burden on the rheumatologist and improve the database and the quality of the data available

#### Rheumatology nurse / enhanced role for other HCPs

- The involvement of a rheumatology nurse / other enhanced non-pharmacological HCP role could help with: assessment of patients; and input of PROMs and other data into the registry



This system ensures that all information is in your hands within minutes. We can see results and progress in real time

– Rheumatologist



Rheumatoid arthritis has many subjective aspects but this system with disease activity being composed of many elements means that assessment of patients can be decided objectively

– Rheumatologist



Sources: (a) KPMG interviews

# Case study 2

## Investigations and procedures unit

### Overview

- Dedicated investigations unit that receives high volumes of patients
- All resources are located in one department which helps to maximise and improve the efficiency and quality for the technical examinations of patients with RA
- The area is available to hold diagnostic procedures such as ultrasound, biopsies, bone density assessments, and treatments such as steroid injections



Sources: (a) KPMG interviews with HCPs treating RA and associated comorbidities



### What is the rationale?



- For a full assessment of patients with RA, invasive and non-invasive procedures are required to ensure accurate diagnoses and assess progress of disease
- Due to the high number of consultations per year the hospital has created a dedicated department to cater for the large volume of patients by streamlining activities to support the steady improvement of the quality of their procedures, while improving throughput and efficiency

### What are the key features of the intervention?



#### Overview

- The unit is situated a small walk away from the outpatient unit and consists of 4 consultation rooms

#### Facilities

- 2 ultrasound machines
- Bone densitometry machine
- Emergency car
- Disinfection room

#### Techniques

- Rheumatologists use the ultrasound machines to assess joint damage and swelling
  - High volume of ultrasound patients
  - Ultrasound-guided injections
- Bone densitometry machine
  - Dedicated technicians use the bone densitometry machine on those higher fracture risk patients
  - Patients with RA will have a bone density scan in accordance with their fracture risk and local (assistencial) guidelines

- Biopsies including ultrasound-guided
- Monthly meetings with a synovium-specialist pathologist to discuss complex cases where there is an unclear diagnosis

#### Dedicated rheumatology nurse

- Only nurse dedicated to a single specialty in the hospital, who has been assigned to help alleviate the burden on rheumatologists, and increase the capacity of the department
- Her role is to supervise the procedures within the investigations and procedures unit, organising clinical materials, quality control etc.
- She plays a large role in educating the patient about the procedures and has developed a number of educational materials with ANDAR
- Many of the patients over 60 have low literacy skills, so the rheumatology nurse also plays a role in educating these patients who cannot use the educational materials
- She raises awareness and advocates the role of rheumatology nurses in APPSRheuma (Portuguese Association of Rheumatological Health Professionals) and EULAR (for other medical professionals)

#### Teaching environment

- All trainees spend 6 months learning how to conduct procedures such as ultrasound screening and synovial biopsies and joint aspirations in the lab under the supervision of an experienced rheumatologist



Bone densitometry machine

## Investigations and procedures unit (cont.)

### Benefits



#### Patient

- The patient can come to the department for all procedures required which reduces the burden of multiple trips, especially for those patients who travel long distances

#### Healthcare professionals

- Trainees can learn on the job and receive 6-8 months training for ultrasound
- Due to the high volumes of scans performed, trainees quickly reach a proficiency to help to alleviate some of the burden for the rheumatologists who are working above capacity

#### Hospital

- Because all the procedures are located in and dedicated to one area, the arrangement encourages continual improvement with high volumes of patients being seen a day
- Care is regularly reviewed in order to maximise efficiency and quality



Educational pamphlets (b)



Educational pamphlets (c)

### Challenges



- The unit is open 10-12h a day but is still working over-capacity
- Patients who are illiterate take more time to educate and therefore need dedicated time with the nurse to learn about their disease. The rheumatology nurse usually holds one-to-one sessions to inform these patients about their treatment and how best they can manage their disease – which is important to achieve successful outcomes from treatment

### What's next



#### Increase number of rheumatology nurses

- There is a strong onus on the single dedicated rheumatology nurse to run and staff the department
- Increasing the numbers of dedicated rheumatology nurses will help to alleviate this burden and also perhaps increase the capacity of the unit to conduct more procedures through the year



My role is to help the patients feel comfortable. I help to educate the patients about each procedure and ensure that they are ready

– Rheumatology nurse



# Case study 3

## Joint rheuma-respiratory clinic

### Overview

- A joint rheumatology and respiratory assessment was started 2 years ago at Hospital de Santa Maria
- This has been led by a rheumatologist in order to cater for all rheumatological patients demonstrating elevated risk of symptoms for respiratory problems e.g. RA, diffuse connective tissue diseases e.g. scleroderma

### What is the rationale?



- Respiratory complications are of increased prevalence in patients suffering from RA (e.g. 7% of deaths in patients with RA are due to interstitial lung disease<sup>(b)</sup> (ILD))
- Therefore close monitoring of the chest of a patient with RA needs to be maintained
- There is sometimes a conflict between the goals of treatment for RA versus the treatment of the comorbidity. A multi-disciplinary approach helps to optimise management

### What are the key features?



### Overview

- A rheumatologist set up this clinic 2 years ago having developed a specialty in RA with respiratory complications
- The clinic runs monthly with both rheumatologist and respiratory physicians from Hospital de Santa Maria and the associated Hospital Pulido Valente

### Assessments

- Anytime there is a patient with RA with respiratory problems they have two physicians who will adequately assess the patients and determine treatment
  - Pattern; severity; disease overlap
- The physician's follow a specific protocol for a comprehensive assessment, including:
  - CT scan; respiratory function tests; 6-minute walk tests; chest x-rays

### Treatment

- The rheumatologists have to balance the joint profiles with organ health assessment to decide which drives what treatment takes priority as not all RA treatment can help control respiratory diseases and there are often conflicts in treatment efficacy between the two (e.g. anti-TNFs are not effective in treating ILD)

### Follow-up

- If a patient is showing signs but does not need treatment yet
- Follow-up every 6 months with all tests
- When stable, patients are monitored every 1-2 years

### Joint MDTs

- These meetings are held monthly within the respiratory clinic
- This time is mainly to discuss difficult cases and decide on the correct treatment regime
- Patients discussed are not just patients with RA with respiratory problems but also respiratory patients demonstrating possible RA symptoms
- There is a diverse representation within this MDT as each respiratory physician also has a different specialist interest (e.g. ILD or bronchoscopy biopsies) and therefore can leverage their specialist knowledge in conversations around complications that arise
- Research findings are also presented

### Training

- Trainee rheumatologists can shadow the lead, come to these sessions during their rotations, and can choose this as their sub-specialty

### Rheuma-respiratory MDT meetings

<b>Frequency</b>	First Tuesday of every month
<b>Timings / Duration</b>	3h
<b>Staff members involved</b>	Rheumatologists (x2) Respiratory physicians Radiologists Pathologists
<b>Patient profile</b>	Patient with RA with suspected pulmonary disease RA or other diffuse connective tissue diseases
<b>Discussion topics</b>	2 patients are discussed each session regarding the complications of their case

Sources: (a) KPMG interviews with HCPs treating RA and associated comorbidities; (b) Am J RespirCritCare Med 2011; 183: 372–378



## Joint rheuma-respiratory clinic (cont.)

### What are the outcomes so far?



- Increased regularity of screening amongst general rheumatologists
- Faster recognition of any risk and therefore reduced onset and progression of respiratory disease leading to better and improved patient outcomes
- Less severe cases as respiratory diseases are often caught at an earlier date, leading to less disease progression (e.g. less breathlessness and improved quality of life)

### Benefits



#### Patients

- Improved follow-up procedures and treatment choices

#### HCPs

- This has led to increased awareness of respiratory comorbidity in RA amongst all attending physicians and therefore they are more attuned to the possibility of this comorbidity arising
- Increased collaboration between attending teams. This fosters:
  - A culture of knowledge-sharing and continual learning between attending departments
  - Efficiency and quality of the referral pathway and access to care

### Challenges



- It can be difficult to find the best treatment for the patients when treatment for RA may worsen the symptoms of the respiratory disease
- A very comprehensive assessment is needed to ensure which medication and treatment is required for each patient. Different medications modify the various elements of RA to varying degrees. It is key that the physicians align on the right balance of medications and decide which element of disease requires the higher priority of treatment

### Advice to other centres



- Foster and develop close collaborations with colleagues from other specialties in order to gain a more holistic approach to care
- This can help raise awareness amongst all physicians in how to monitor and screen their patients more effectively to capture any associated comorbidity onset or progression



Our role at these meetings with respiratory specialists is to represent the patient and their needs to ensure they get the best care possible



- Rheumatologist with specialist interest in respiratory comorbidities



Sources: (a) KPMG interviews with HCPs treating RA and associated comorbidities

# Case study 4

## Dedicated psychologist

### Overview

- The rheumatology department has a dedicated psychologist situated within the outpatient clinic
- Patients are referred to the psychologist from rheumatologists when they demonstrate associated psychological problems

Sources: (a) KPMG interviews with HCPs treating RA and associated comorbidities



### What is the rationale?



- The prevalence of both depression and anxiety is increased amongst patients with RA
- This can be due to a variety of concurrent factors related to quality of life and pain management
- Specialist support is required for these patients, to cater for the emotional impact of the diseases on their quality of life and mental health
- The hospital has a dedicated psychologist who can assess patients and deliver psychotherapy

### What are the key features?



#### Overview

- Psychologist is specialised in generalised pain syndromes and most commonly deals with depression and anxiety

#### Referral

- The rheumatologists have a good relationship with the psychologist, whereby they can book their patients into a consultation with the psychologist on their online booking system

**No. of consultations** 50 consultations a month

**Frequency** Every week for 6 months to a year

**Timings / Duration** 30 – 50 mins

**Staff members involved** Psychologist

**Measures used** CBT

### What are the activities undertaken?



#### Patient profiles

- Two defined patient profiles at Hospital de Santa Maria
  - Early disease: helping them accept diagnosis
  - Long-term patients: reduced movement and ability due to joint damage
- Most patients suffer from: depression; some from fibromyalgia; and sometimes due to traumatic events

#### Assessment

- PROMs are usually compared against DAS28 scores as a benchmark, any differences highlighted can help to indicate and act as supportive evidence when patients seem demotivated and low
- Patients cannot always differentiate the mental health factors from the physical factors when assessing own quality of life. The assessment of PROMs is useful to help disaggregate the issues

#### Treatment

- Patients go to see the psychologists weekly but also can be seen on an ad hoc basis as needed, but this tends to be every 1-3 months
- Psychotherapy and cognitive behavioral therapy
  - Mainly teach patients effective coping mechanisms to help with their motivation around the disease, reducing apathy
- Referral to psychiatric department for severe cases (difficulty sleeping, poor appetite, isolated)
- Referral / communication back to rheumatologist where worsening of physical symptoms is detected

#### Output

- Written report
- Neurological tests to assess the effects of depression on cognitive performance

## Dedicated psychologist (cont.)

### Benefits



- On-call access to care for urgent referrals
- Both patients and families can access these services and have access to holistic care around their treatment
- Addressing concerns due to some of the key non-inflammatory causes of discomfort e.g. fibromyalgia
- Psychologist helps to educate the patients and their families about the disease

### Challenges



- Increased burden on the psychologists who has to cater for all rheumatology department patients
- Integration of holistic and comprehensive psychological services
- Chronic patients with RA can be challenging to treat, and may be resistant to attempts to change longstanding habits, attitudes and behaviours
- Patients often do not adhere to their medication due to other non-psychological factors, such as weight gain
- Lack of contact time with rheumatologists as they are busy which leaves them with limited opportunity to discuss difficult cases

### What are the outcomes so far?



- Patients with associated psychological symptoms are well managed
- Increased adherence to treatment

### Tips to replicate this intervention



- Adequate time to dedicate to the patients to ensure they feel understood and heard

### What else could be done?



- Increase the number of psychologists available on the ward
- Inclusion of the psychologist in multi-disciplinary discussions of more complex patients
- Increase communication between PCPs in order to help refer patients back for this care
- Enroll trainee psychologists to help relieve the burden



I have so much respect for rheumatology patients. We see them overcome the most amazing things

- Rheumatologist



Sources: (a) KPMG interviews with HCPs treating RA and associated comorbidities



# Case study 5

## Joint rheuma-obstetrics clinic

### Overview

- The hospital has created a dedicated clinic to manage rheumatological risks of conception and problems found in pregnancy in rheumatological patients
- The clinic is staffed by both rheumatologists and obstetricians
- This service is offered to all patients who have RA and are pregnant, or who are planning to conceive

Sources: (a) KPMG interviews with HCPs treating RA and associated comorbidities



### What is the rationale?



- Due to the nature of the disease, RA can impact and cause complications in pregnancy (chronic disease and pain)
- Additionally, the natural immunosuppression of pregnancy can lead to more complications or in other cases alleviate symptoms
- RA increases the risk of complications in pregnancy (e.g. intrauterine growth restriction, and pre-term delivery)
- RA treatments can also affect outcomes of the patient and their baby, impacting foetal development, while some are teratogenic
- Therefore, the hospital has created a clinic to manage the elevated risk in these patients

### What are the key features of the intervention?



### Overview

- The clinic caters to those with RA that are pregnant or are planning to conceive and is staffed by both rheumatologists and obstetricians
- There are no restrictions to access the clinic on catchment; the only restriction to access is that every patient must be placed under the care of the multi-disciplinary team at Hospital de Santa Maria, i.e. not under one or other specialty, while being jointly looked after at another centre

<b>Timings</b>	Every Thursday, 0800-1500
<b>No. of participants:</b>	Up to 3 rheumatologists, 4 obstetricians weekly
<b>Staff members involved</b>	Rheumatologists, obstetricians

### Education

- Education is provided on the risks relating to RA such as flares, certain medications and the importance of regular follow-up during pregnancy in high-risk patients

### Assessment

- Previous history and investigations are reviewed, and sometimes further blood tests and ultrasound scans may be requested
- Higher risk patients are followed up every 4 weeks in 1<sup>st</sup> trimester, every 3 weeks in 2<sup>nd</sup> trimester, and every 2 weeks/weekly in 3<sup>rd</sup> trimester
- Patients are also followed up 1 month after delivery

### Treatment

- All decision-making is shared with the patient on the basis of the latest available scientific evidence
- Procedures such as intra-articular, or periarticular corticosteroid infiltration (lower risk to mother and baby) can be done on the same day as clinic, but will have to wait up to a week for an ultrasound-guided procedure



## Joint rheuma-obstetrics clinic (cont.)

### Benefits



#### Patient

- Collaboration between rheumatologists and obstetricians enables higher quality clinical decision-making, taking into account multiple conflicting risks and avoiding e.g. ultra-cautious clinical approaches that result in poorer outcomes for the patient
- Patients feel comfortable and fully supported during pregnancy

#### HCPs

- Multi-disciplinary working enables sharing of knowledge around managing risk in patients that have cross-over obstetrics – rheumatological issues

### What are the outcomes so far?



- Reduction in patients with RA coming out of remission due to the disruption of treatment regimens, or disruption of pregnancy on the usual physiology of the patient
- Reduce in maternal and foetal complications including:
  - Secondary stillborn syndrome
  - Congenital heart block
  - Other comorbidities which can effect the foetus

### Challenges



- There is increasing demand, which is difficult to meet while maintaining jointly-staffed clinics, and maintaining level of education provided to patients
- Rheumatology nurses play a central role in education but are all obstetrics trained only. Thus the burden of educating on rheumatological issues is placed on the rheumatologist, placing increased pressures on the rheumatologist's patient-facing time



Sometimes doctors may stop all medication in pregnant patients with RA, resulting in deterioration and radiologic damage. Our joint clinic can make a critical difference to these patients

- Rheumatologist



We make sure our clinics are staffed with obstetricians and rheumatologists with experience in working across the two fields

- Rheumatologist



# Case study 6

## Emphasis on research to support clinical practice

### Overview

- Research is an important focus of rheumatology and metabolic bone diseases department at Hospital de Santa Maria
- The hospital is a university hospital and has a dedicated facility for research
- Research is well integrated into clinical practice within the department

Sources: (a) KPMG interviews with HCPs treating RA and associated comorbidities (b) Arthritis Care Res (Hoboken). 2018 May;70(5):703-712



### What is the rationale?



- Research is fundamental in developing and improving clinical practice
- In 2004 the hospital built a RA research unit, this has progressed to cover all diseases involved within rheumatology

### What are the key features?



### Overview

- The rheumatology department is closely linked to the Research Unit of Rheumatology of the Institute of Molecular Medicine and the Faculty of Medicine of the University of Lisbon

### Research unit

- There are 4 dedicated post-doctoral staff to rheumatology and 4 who split their time with clinical practice; they are supported by masters research students

### Biobank

- Started in 2012, part of a network of international biobanks
- It stores a wide variety of clinically annotated biological samples (20,000 RA samples already with >1,000 patients)
- In 2017 the biobank registered 16,757 samples donated voluntarily
- Aim is to foster biomedical research and find new biomarkers for pre-RA and help define a clearer approach to treatment for new therapeutics; in the future be more close to personalised medicine, and predict clinical outcomes from genetics
- Every month they can collect up to 1,000 patients' information
- Regular quality controls

### Differentiated specialities

- Each rheumatologist is encouraged to develop and pursue their own differentiated sub-specialty interest, with the aim of improving patient outcomes and share treatment knowledge

### Dedicated clinical trials unit

- The hospital has a dedicated wing for conducting clinical trials (both industry-initiated and investigator-initiated trials), which contains multiple examination rooms, meeting rooms and administrative rooms
- The aim is to enable busy departments to improve the capacity to conduct clinical trials through dedicated support staff - to help with administration and coordination

### Study coordinator

- There are two dedicated study coordinators situated in the clinical study unit, who are responsible for the management of studies from the recruitment of patients through collecting and recording of data, to process outcomes.

Examples include:

- Identification of patients for study purposes
- Enrolling and engaging patients so they have a good experience of their care
- Obtaining supply of medicines
- Samples collection and processing
- Relationships with biobank for additional samples
- Collection and recording of all data
- Financial management
- Assistant for the investigators
- Monthly 'newsletter' informing of studies in progress to help ensure recruitment is maximised across studies

## Emphasis on research to support clinical practice (cont.)

### Benefits



- Biobank samples are used for research not only within the hospital, but nationally and internationally
- The Reuma.pt is a national registry linked by patient to the biobank dataset
- The continual flow and access of information between clinical practice and research helps to create robust and current data for examination
- The clinical trials wing has enabled departments to have the capacity to run studies providing space for examinations and interrogations, as well as meetings and rooms for consultations and procedures in a hospital
- Potentially groundbreaking research which could lead to assessing the genetic determinants and these effects on treatment



DNA sequencer in the Biobank



Nurse observation room in the clinical study wing

### What are the outcomes so far?



- The biobank has 56 collections, 14,003 samples for RA alone; data has been used in 298 studies, including 40 in RA.
- The clinical study wing has run over 40 studies to date
- The clinical research lab has over 60 trials running with 100 patients involved (18 trials running for Rheumatology patients and 6 of these are dedicated to RA)

### Challenges



- Ensuring each rheumatologist has time to pursue their research interests, as physicians are currently overburdened with patient and therefore have limited time to conduct their research

### What else could be done?



- Reducing the burden on the clinicians through ensuring they have dedicated protected time for research
- Ensuring the non-clinical PhD lab scientists help the clinicians run their studies effectively in a timely manner

Research labs



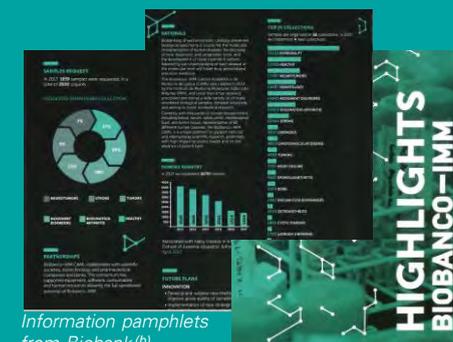
The best thing about working on a campus like this is the consistent and collaborative interest and focus on research

- Rheumatologist



We have a responsibility of elevating and improving the care and the scientific aspects of rheumatology for the whole community

- Rheumatologist



Information pamphlets from Biobank<sup>(b)</sup>

Sources: (a) KPMG interviews with HCPs treating RA and associated comorbidities; (b) Biobank IMM: highlights



# Hospital Universitario La Paz

Madrid, Spain



# Summary



## Context

- **Online communication systems** between primary care physicians (PCPs) and consultant rheumatologists for fast-track rapid referral and two-way conversations
  - Inbox monitored by rheumatology unit daily
- **Comprehensive Early Arthritis Clinic** initiates two-year period of monitoring for patients in the early phase of disease
  - Systematic data collection from point of referral enables research into whole disease lifecycle
  - Dedicated ultrasonography clinic for RA symptoms
- **Multidisciplinary patient care** facilitated by weekly whole-unit meetings to discuss patient treatment and a community-like feel of team dynamics
- **Routine consideration of common RA comorbidities** including interstitial lung disease and inflammatory osteoporosis
- **Addressing wider quality of life implications** with rehabilitation team, including mobility, self-care, pain/discomfort, usual activities, and anxiety and depression



## Key strengths in the delivery of RA care

- **A collaborative approach to patient care**, working closely across disciplines as an integrated unit to ensure all aspects of patient care are considered simultaneously
  - The combined rheumatology and respiratory clinic enables rapid treatment decision-making from simultaneous input of different expertise
  - Multidisciplinary meetings facilitate a whole-patient approach to treatment
- **Effective communication across whole patient pathway** between all care delivery teams
  - Direct online communication enables rapid and more-accurate referral by fast tracking patients in need of urgent care and providing rapid feedback to PCPs
- **Commitment to innovation in patient care** by taking on pioneering interventions to improve disease outcomes
  - Facilitation of clinical research through representation at weekly meetings ensures adoption of cutting-edge treatments
  - First-in-kind interventions such as combined clinics for RA & comorbidities and ultrasound screening for early-stage RA enabled by drive and willingness to innovate



## Key challenges faced in delivery of RA care

- A lack of resource to assess and treat mental health comorbidities of RA. Members of the rheumatology unit report inefficiencies when it comes to addressing depression, particularly long waiting times for psychologist/psychiatrist appointments
- Rolling out collaborative interventions across the primary care network faces challenges of slow uptake. A minority of 200 local PCPs have adopted the online communication software and typical attendance of online teaching workshops is around 30-40 PCPs. Challenges stem from lack of awareness and capacity of PCPs, and fewer resources to invest in engagement of PCPs on the hospital side

Sources: (a) KPMG interviews with HCPs treating RA and associated comorbidities

# RA Spanish healthcare system overview



## RA challenges in the Spanish healthcare system

- Limited coordination between the Autonomous Communities, which increases disparities in services and quality of care between the regions
- Increasing demand for social support services and benefits from the dependent population, and by carers. There are currently provided by relatives, meaning that there are very few public nursing and retirement homes<sup>(a)</sup>
- Despite having clinical practice guidelines on RA, there still exists a significant variability in RA management in Spain<sup>(b)</sup>

Sources: (a) <https://healthmanagement.org/c/hospital/issuearticle/overview-of-the-spanish-healthcare-system>; (b) <http://www.reumatologiaclinica.org/en/management-rheumatoid-arthritis-in-spain/articulo/S2173574312000822/>; (c) [https://www.researchgate.net/publication/270163394\\_Consensus\\_statement\\_on\\_a\\_framework\\_for\\_the\\_management\\_of\\_comorbidity\\_and\\_extra-articular\\_manifestations\\_in\\_rheumatoid\\_arthritis](https://www.researchgate.net/publication/270163394_Consensus_statement_on_a_framework_for_the_management_of_comorbidity_and_extra-articular_manifestations_in_rheumatoid_arthritis) [accessed June 25 2018]

## Spanish healthcare system overview:



### Background:

The Spanish National Healthcare System ("Instituto Nacional de la Salud"), founded on Spain's General Healthcare Act of 1986, guarantees universal coverage and free healthcare access to all Spanish nationals, regardless of economic situation or participation in the social security network

The National Health System has 2,914 health centres and 10,202 local clinics providing basic healthcare services to the local population<sup>(a)</sup>

There are three organisational levels:

1. *Central (Organizacion de la Administracion Central)*  
The Ministry of Health (Ministerio de Sanidad y Consumo): in charge of issuing health proposals, planning and implementing government health guidelines
2. *Autonomous Community (Organizacion Autonómica)*  
Each of Spain's 17 Autonomous Communities (Comunidades Autonomas) is responsible for offering integrated health services to the regional population
3. *Local (Areas de Salud)*  
The "areas de salud" are responsible for the unitary management of the health services offered at the level of the Autonomous Community. "Areas de salud" are subdivided into smaller units called "zonas basicas de salud"<sup>(a)</sup>

### Funding

The Spanish healthcare system is principally funded through taxation. The country's total healthcare expenditure, amounts to €88,828 million, which accounts for 8.5% of the GDP<sup>(a)</sup>

## Rheumatoid Arthritis in Spain:



### Patients:

- RA in Spain has a prevalence of 0.50% and an incidence of 0.08 to 0.20 cases/1,000 person-years<sup>(c)</sup>
- Prevalence of RA-associated comorbidities: metabolic: dyslipidaemia (46%) and diabetes (12%); cardiovascular: hypertension (41%), myocardial infarction (5%), and stroke (1%); psychiatric: depression (27%); pulmonary: asthma (5%) and chronic pulmonary obstructive disease (2%); hepatitis: hepatitis B (5%) and hepatitis C (1%); gastrointestinal: ulcers (3%); and cancers: basal cell carcinoma (3%), breast cancer (2%), uterine cancer (1%), colorectal cancer (1%), and cutaneous melanoma (1%)<sup>(c)</sup>

### Physicians:

A total of approximately 1150 rheumatologists in Spain:

- 8% of Spanish rheumatologists have private activity;
  - Around 20% exclusively private practice
  - 25% private practice shared with his or her public activity

### Guidelines:

RA

- SER, EULAR, ACR

Comorbidities:

- SER, EULAR, SORCOM<sup>(c)</sup>

### PAGs / Medical societies

- The Spanish Rheumatology Society / Sociedad Española de Reumatología (SER)

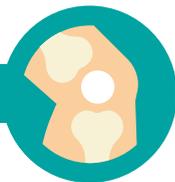
# The Rheumatology unit

La Paz University Hospital has a dedicated rheumatology unit

The hospital			
<b>Type</b>	Public, part of the autonomous community of Madrid <sup>(a)</sup>	<b>Locations</b>	North Madrid
<b>Core services</b>	Inpatient, outpatient, day hospital, maternity hospital, infant hospital	<b>Population served</b>	Serves the people of the municipalities of the area Norte, a population of ~750,000
<b>Size</b>	~50,000 admissions and ~220,000 outpatients annually	<b>Demographics</b>	Adult population only (children treated in paediatric hospital)



The Rheumatology unit			
<b>Services</b>	General rheumatology clinic Consultation (outpatient service) Combined rheumatology and respiratory clinic Inflammatory osteoporosis clinic Early Arthritis Clinic On-site ultrasonography and rehabilitation services Inpatient service Pain clinic Uveitis clinic	<b>Collaborations</b>	Research and development collaborations with local primary care centres (for example, rolling out the online direct communication systems)
<b>Funding and Resources</b>	Government funding is distributed via the autonomous community of Madrid, which is responsible for setting local restrictions and targets on prescription spending	<b>Teaching/ research scope</b>	All rheumatologists are actively engaged in clinical research, facilitated by a hospital clinical trial coordinator. The unit actively trains visiting ultrasonographers in RA applications through three-month training fellowships. Online PCP training workshops are hosted regularly.



Sources: (a) Hospital Universitario La Paz website

# The Rheumatology unit (cont.)

## Overview of Services



Service Division	Outpatient service	Ambulatory care service (Biologic Unit)	Inpatient service
<b>Duration of stay</b>	<ul style="list-style-type: none"> <li>— 30-minute initial consultation</li> <li>— 15-minute follow-up appointments</li> </ul>	<ul style="list-style-type: none"> <li>— Sufficient time for IV therapy (max 1 day)</li> </ul>	<ul style="list-style-type: none"> <li>— Typically 1-2 days</li> </ul>
<b>Hours of availability</b>	<ul style="list-style-type: none"> <li>— Morning clinic: 08:00-15:00</li> <li>— Afternoon clinic: 15:30-19:30</li> </ul>	<ul style="list-style-type: none"> <li>— Morning clinic: 08:00-15:00</li> <li>— Afternoon clinic: 15:30-19:30</li> </ul>	<ul style="list-style-type: none"> <li>— 24/7</li> </ul>
<b>Capacity (no. of beds/rooms)</b>	<ul style="list-style-type: none"> <li>— 7 consultation rooms in the hospital</li> <li>— 4 consultation rooms in speciality outpatient centres</li> </ul>	<ul style="list-style-type: none"> <li>— 3 beds, but more available if required</li> </ul>	<ul style="list-style-type: none"> <li>— 4 beds</li> </ul>
<b>No. of patients seen</b>	<ul style="list-style-type: none"> <li>— 27,000 patients seen in Rheumatology in 2015</li> </ul>	<ul style="list-style-type: none"> <li>— 4431 new patients per year</li> <li>— 21,698 follow-up patients</li> </ul>	<ul style="list-style-type: none"> <li>— 92 patients in 2017</li> </ul>
<b>Patient type catered to</b>	<ul style="list-style-type: none"> <li>— Patients with mild-moderate RA, including those in the early stages of disease progression</li> </ul>	<ul style="list-style-type: none"> <li>— Patients with moderate RA receiving infusion therapies (biologics and corticosteroids)</li> </ul>	<ul style="list-style-type: none"> <li>— Patients with severe RA or comorbidity-related symptoms (e.g. lung infections, fractured vertebrae) in need of intensive treatment and close monitoring</li> </ul>
<b>Services offered</b>	<ul style="list-style-type: none"> <li>— Multidisciplinary care of hospitalised patients is carried out throughout the rheumatology unit and wider hospital services as required</li> </ul>		
<b>Specific tools</b>	<ul style="list-style-type: none"> <li>— Medication explanation and review</li> <li>— Measuring DAS28 scores</li> <li>— Regular follow-up consultations provided by rheumatologist, respiratory physician, pharmacist, rehabilitation unit or rheumatology nurse, depending on patient pathology</li> <li>— Ultrasound, capillaroscopy and bone densitometry investigations as required</li> </ul>	<ul style="list-style-type: none"> <li>— Infusion therapies</li> <li>— Medication review</li> <li>— Serum analysis</li> </ul>	<ul style="list-style-type: none"> <li>— Higher intensity monitoring by inpatient doctor</li> <li>— As-required assessment and treatment by RA or comorbidity specialist</li> </ul>

# The team

## Core team profiles

- 14 rheumatologists
- 2 rheumatology nurses
- 1 rheumatology researcher
- 1 pharmacist
- 1 service coordinator
- 1 clinical trial coordinator



## Affiliate team profiles

- Respiratory specialist
- Ultrasonographers
- Rehabilitation doctors
- Occupational therapists
- Physiotherapists

## Key features of the care delivery team

- **Core rheumatology unit team** includes specialist rheumatologists working closely with a range of cross-disciplinary specialists: inflammatory osteoporosis, and respiratory in the context of RA comorbidity. Patients referred onto inpatient team as required
- **Rheumatology nurses** conduct initial and follow-up (as required) consultations with patients showing RA symptoms, effectively triaging patients prior to referral to the rheumatology unit.
- **Research representation** at multidisciplinary team meetings facilitates participation in clinical research
- **Rehabilitation team (OT, rehabilitation doctor)** integrated with the rheumatology unit via referral from rheumatologist to rehabilitation doctor. A rehabilitation plan (with possible onwards referral to occupational therapist, physiotherapist or psychologist) established from an initial consultation involving subjective and objective measures of functionality and discussion of patient's objectives
- **Dedicated rheumatology unit pharmacist** responsible for providing and keeping track of all RA prescriptions including specifically biologic treatments

## Governance and processes

### Team meetings:

- Weekly meeting with entire rheumatology team to present patients in need of treatment initiation or review
- Additional weekly meeting with core rheumatologists to discuss ongoing patient treatment

### Protocols:

- Rheumatology Unit adopts a 'Treat 2 Target' strategy to control biologics prescription costs, tapering treatment dosage with symptom improvement
- Resulting cost reductions have led to changes in Community of Madrid guidelines for prescriptions

### Patient records:

- Electronic hospital-wide system for all patient data enables rapid referral and facilitates research efforts
- All patient data (fracture risk, metabolic analysis, DAS28 score, etc.) entered into electronic database

### Pharmacy:

- One specialised pharmacist responsible for all RA prescriptions
- Rheumatologists responsible for medication decisions
- Community of Madrid guidelines dictate target cost of treatment per patient per year

Sources: (a) KPMG interviews with HCPs treating RA and associated comorbidities (b) [http://www.euro.who.int/\\_\\_data/assets/pdf\\_file/0008/378620/hit-spain-eng.pdf?ua=1](http://www.euro.who.int/__data/assets/pdf_file/0008/378620/hit-spain-eng.pdf?ua=1)

# Overview of interventions in place for RA

## Awareness & Prevention

Symptom identification



## Referral & Diagnosis

In secondary care



## Treatment & Management

Pharmacological management

Non-pharmacological management



## Follow-up

Monitoring of chronic disease/flare up



### Web-based PCP training

- Rheumatology unit runs online education sessions for local PCPs

### Direct communication channel between PCPs and rheumatologists

- Electronic messaging software allows rapid direct communication between PCPs and RA team to fast-track patients with suspected RA
- Immediate feedback provided by specialists positively impacts the referrer's own learning

### Online rapid referral software for primary care practitioners

- Solicitud de Cita en Atención Especializada (SCAE) rapid referral online form monitored daily by consultant rheumatologist to fast-track patients. Appointments in 14 days rather than 55 days (standard referral)

### Dedicated ultrasound screening clinic

- Specialist RA ultrasonography clinic facilitates differential diagnosis, picking up early signs of RA to reduce uncertainty before criteria met
- Clinic integrated smoothly with early arthritis clinic and wider rheumatology unit via online communication system

### Early arthritis clinic

- For patients in early stages of disease (onset >1yr, for a total of 2 years), with clinics held three times per week.
- Dedicated early-stage clinic reduces burden on rheumatology unit, enabling more attentive patient care across the disease lifecycle

### Multidisciplinary weekly meetings

- Entire rheumatology unit (x14 rheumatologists), including clinical research representative (x1) meet weekly to present patient cases. Resulting treatment decisions consider evidence, comorbidities, demographic, circumstances and European League Against Rheumatism (EULAR) guidelines
- Additional weekly meetings to review biologic treatment performance (x 6 specialists)

### Rehabilitation services

- Rheumatologist referral to rehabilitation doctor providing advice on symptom management and referral to occupational therapists or physiotherapists when required
- Focus on empowering patient by educating in self-management of symptoms and severity judgement

### Mobile application for treatment and lifestyle management

- A mobile app is currently in development to remind patients to take medication, perform tests, attend appointments, and to recommend evidence-based lifestyle tips to ease symptoms and improve quality of life

### Direct communication channel between PCPs and rheumatologists

- Electronic messaging software allows PCPs to fast-track patients experiencing flare-ups/ in crisis

### Direct patient access for follow-up appointments

- Patients with RA provided with direct line to unit for rapid scheduling (within around one week) of follow-up appointments if required

### Online monitoring and data capture

- Data from patients collected electronically and maintained on hospital system to facilitate referrals and research

### Regular biologic treatment monitoring appointments

- Patients receiving intravenous and subcutaneous biologic treatment monitored through appointments every 1-2 months and 3 months, respectively. Treatment adjusted if necessary
- Follow-up with pharmacist every 3-4 months to track treatment adherence and side-effects

Sources: (a) KPMG interviews with HCPs treating RA and associated comorbidities

# Overview of interventions in place for RA comorbidities

## Awareness & Prevention

Symptom  
identification



## Referral & Diagnosis

In secondary care



## Treatment & Management

Pharmacological  
management



Non-pharmacological  
management



## Follow-up

Monitoring of chronic  
disease/flare up



### Comorbidity specialists present at weekly rheumatology unit meetings

- The multidisciplinary meetings facilitate greater awareness of comorbidities amongst rheumatologists
- Treatment decisions take implications of comorbidities into account

### Systematic inflammatory osteoporosis screening

- All patients in early arthritis clinic and others starting biologic treatment screened for comorbid inflammatory osteoporosis (IO) markers
- Patients screening positively (early or established RA) seen by consultant rheumatologist with a special interest in IO

### Effective communication between specialties

- Internal online referral and communication system enables rapid referral from rheumatology to other specialties and vice versa

### Combined rheumatology and respiratory clinic

- Pioneering approach involving combined treatment decision-making for patients with RA and comorbid interstitial lung disease (ILD)
- Weekly clinics with both rheumatology and respiratory physicians present for patients with RA with ILD
- Enables more timely diagnostics and decision-making on therapeutic management

### PCP whole-patient approach to monitoring comorbidities in RA

- Depression, diabetes, cardiovascular disease and other key comorbidities of patients with RA monitored by PCP
- Referral to specialist consultant if necessary through online direct communication

### Rehabilitation services

- Wider lifestyle consequences of RA comorbidities are addressed if required by rehabilitation doctor
- Services address impact of RA on mental health, involving tips and signposting to facilitate improvements in quality of life, and referral onto psychologist/psychiatrist if required

### Bone fracture risk monitoring in patients with early-stage and established RA

- All patients in the early arthritis clinic undergo systematic bone fracture risk screening (bone densitometry and metabolic analysis) throughout a two-year period following RA symptom onset
- Data collected used to evaluate progression of risk from RA onset to later stages, with the aim of reducing the number of fractures in patients with RA
- Bone fracture risk screening / monitoring for patients with established RA as needed

Sources: (a) KPMG interviews with HCPs treating RA and associated comorbidities

# These interventions have improved outcomes



How do you quantify the benefits in RA and associated comorbidity care?

**Objective measures (KPIs):**

- DAS 28
- Ultrasound measurements
- Capillaroscopy measurements
- Dexterity and strength evaluation

**PROMs:**

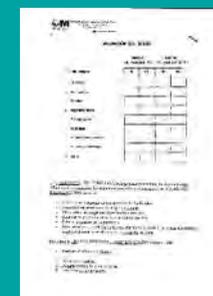
- Barthel scale (measuring performance in daily activities)
- Lawton And Brody Instrumental Activities Of Daily Living (IADL) Scale

**Centre routinely measures comorbidity outcomes by:** *Pain evaluation form*

- Objective measures:
  - Bone densitometry
  - Metabolic analysis

**PROMs:**

- Pain evaluation form



*Dexterity and strength evaluation form*



How have these interventions improved patient outcomes?

**RA**

- Benefits: earlier, more reliable diagnosis, improvements in movement, strength and ability to perform daily activities
- Quantitative output: early diagnosis in 10-15% patients

**Comorbidities**

- Integrated care approach of the rheumatology unit facilitates rapid treatment decisions to tackle comorbidities alongside RA
- High comorbidity awareness amongst rheumatologists due to multidisciplinary meetings facilitates detection and consideration

**“Our measures reduce uncertainty, enabling us to make better decisions”**

- Ultrasonographer

Sources: (a) KPMG interviews with HCPs treating RA and associated comorbidities

# How can care be improved?



## What is next for the centre?

### Overview:

Members of the La Paz rheumatology unit are acutely aware of current limitations in mental healthcare systems, stressing the need for improved mental health care for patients with RA. Currently, psychologists and psychiatrists have limited availability, and there is no protocol for integration of mental health services with RA care. The rheumatology unit aims to improve access to mental health treatment for patients with RA.

- **Why?** Recent research conducted within the unit revealed that depression was the most prevalent RA comorbidity, in line with wider reports across Europe. Poor mental health can have a negative impact on physical health outcomes<sup>(a)</sup>
- **How?** Plans are still in the early stages of development, but possibilities include systematic screening of patients with RA for depression using self-report questionnaires, and psychiatrist or psychologist representation at weekly unit-wide multi-disciplinary team meetings



## What advice would you give less specialised centres?

**Overview of advice:** Take a whole-patient approach when deciding upon treatment for RA

- **Why?** By considering comorbidities alongside RA symptoms, treatment decisions can be based on what's best for the patient overall, providing the greatest opportunity for improved quality of life
- **How?** Multidisciplinary representation at collaborative treatment decision meetings, combined clinics, and means of maintaining direct and regular communication between team members and external units

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# Case study 1

## Online direct communication systems

### Overview

- Two years ago, the rheumatology unit set up two online communication channels with primary care practitioners: a rapid referral form and a two-way messaging system
- Both streams are checked daily by a member of the rheumatology team, who can then act accordingly by:
  - Answering PCPs questions
  - Requesting more information
  - Conducting over-the-phone patient triage
  - Making an appointment with the relevant specialist

Sources: (a) KPMG interviews with HCPs treating RA and associated comorbidities

### What is the rationale?



- The traditional referral route to the rheumatology unit is associated with a mean appointment wait of 55 days
- The objective was to enable a rapid referral route allowing more urgent cases to be fast-tracked
- In addition, direct communication between PCPs and rheumatologists was set up to enable a two-way discussion of patients in need of urgent care, particularly useful if PCP has questions for rheumatologist

### What are the key features of the intervention?



- PCPs can directly contact the rheumatology unit via two systems:
- **1) SCAE (Solicitud de Cita en Atención Especializada) Fast track rapid referral online form**
  - PCP fills out online form detailing symptom profile and various risk and severity factors
  - Submitted forms are reviewed daily by a rheumatologist, who are then in a position to make a decision on best course of action
- **2) Online messaging portal**
  - PCP sends online message directly to the rheumatologist, who is then able to reply
  - Inbox is checked daily
  - If necessary, rheumatologist can ask for more information or answer PCP's questions

The screenshot shows a web form for 'Solicitud de Cita en Atención Especializada (SCAE)'. The form is titled 'Datos de la Solicitud' and contains several input fields and dropdown menus. The fields include: 'Nº Identificador', 'Fecha Solicitud Desde', 'Fecha Solicitud Hasta', 'Estado Solicitud' (dropdown), 'SubEstado Solicitud' (dropdown), 'Edad desde', 'CIAS', 'Paciente', 'Hospital Ref.', 'Centro Pet.', 'Servicio' (dropdown), 'Prestación' (dropdown), and 'Edad hasta'. There are also buttons for 'PDF', 'Excel', 'Buscar', and 'Limpiar'.

### The SCAE rapid referral online form

### What are the outcomes so far?



- Patients experiencing severe symptoms are seen in 10-14 days rather than 55 days
- PCPs express high satisfaction with the ease of communication

## Online direct communication systems (cont.)

### Benefits



- Rapid referral and shorter wait times for patients in urgent need of an appointment
- Two-way communication allows filtering of patients, as PCPs can find out before referring a patient whether or not RA is likely
- Improved education and increased awareness in PCP community through direct communication with RA specialists

### Challenges



- PCP education and adherence. 200 PCPs refer patients to La Paz, but only a subset of practices have adopted this communication system
- To address this challenge, La Paz representatives run practice-based training sessions to educate PCPs in using the system – an on-going intervention



The direct electronic communication is the aspect of the unit that makes communication easier. Not all specialists are good at this.

– General Practitioner



Sources: (a) KPMG interviews with HCPs treating RA and associated comorbidities



# Case study 2

## Comprehensive Early Arthritis Clinic

### Overview

- Patients who first experienced the onset of symptoms within the last 12 months are referred to the Early Arthritis Clinic
- Clinic provides regular appointments and thorough care for a targeted cohort of patients
- Thorough screening of symptoms takes place at the initial evaluation, including measurement of RA diagnostic criteria. Ultrasonography and bone densitometry / metabolic analysis
- Patients are treated through the Early Arthritis Clinic for the first two years of disease development, after which they are referred onto the regular rheumatology clinic

Sources: (a) KPMG interviews with HCPs treating RA and associated comorbidities

### What is the rationale?

- The Early Arthritis Clinic (EAC) was set up to address the need for early referral and intervention, presenting the opportunity to delay disease progression and improve longer term outcomes
- Close monitoring of patients in the early stages of arthritis diseases enables appropriate treatment and research into disease progression

### What is the patient journey?

#### 1 Referral

- Patients are referred to the Early Arthritis Clinic (EAC) through a number of routes:
  - From the PCP (fast-track or regular referral) via a rheumatology nurse (only when approved by rheumatologist)
  - From the Emergency Unit (EU; only when approved by rheumatologist)
  - From the rheumatology unit (RU)
- Direct electronic communication between PCP and rheumatologist during initial referral effectively triages patients, filtering out referrals with low likelihoods of RA

### What is the patient journey (cont.)?

#### 2 Initial evaluation

- Tests (X-rays, lab tests, serology) are ordered by the rheumatology nurse and conducted before the initial consultation
- An initial consultation is conducted following receipt of test results by an experienced rheumatologist, who diagnoses patient and discusses treatment options
- Routine ultrasonography screening enables the detection of disease markers in early stage patients

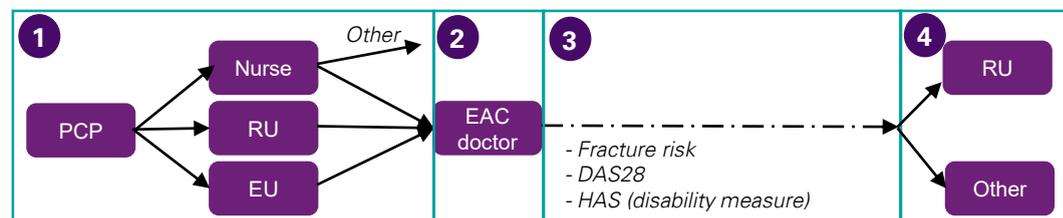
#### 3 Monitoring

- Patients are systematically followed for the two years, with appointments every three months or more frequently if required
- Fracture risk (via the inflammatory osteoporosis clinic), DAS scores and disability (HAS) scores are systematically monitored throughout the two years, at a frequency depending on disease severity

#### 4 Onwards referral

- After two years, patients with RA are referred onto the RU

### Early Arthritis Clinic: Patient Journey



## Comprehensive Early Arthritis Clinic (cont.)

### Benefits



#### Benefits to the team

- Systematic collection of bone densitometry data has led to publication of research into fracture risk progression with RA<sup>(b)</sup>, contributing to development of treatment guidelines
- A dedicated clinic for patients only in early stages of RA takes the burden off the rheumatology unit
- Early triage step means fewer downstream appointments for suspected RA

#### Benefits to patients

- Routine ultrasonography screening enables detection of disease markers in the early stages and therefore earlier diagnosis and treatment; evidence suggests patients with RA treated show greater improvement in disease scores (DAS28) than those treated later<sup>(b)</sup>
- Less crowded clinics mean that patients can be adequately monitored without long waiting times for appointments

### Tips to replicate this intervention



#### Ensure smooth communication

- Set up direct communication with the wider rheumatology unit teams and comorbidity or screening specialists throughout the period of EAC care
- This will both smooth referral onto onwards care and hasten treatment decisions

#### Filter patients prior to admission

- Perform triage prior to initial consultation in the early clinic e.g. with rheumatology nurses
- This will reduce patient numbers and therefore improve waiting times and relieve pressure to see high volumes of patient in the EAC

### What are the key features?



#### Team:

Two core rheumatologists

#### Clinic frequency:

One full clinic and two half clinics per week

#### Patients:

Typically 13-15 receiving ongoing treatment at any one time, (figure includes all patients with any kind of peripheral arthritis)

**Sources:** (a) KPMG interviews with HCPs treating RA and associated comorbidities; (b) Effectiveness of a clinical practice intervention in early rheumatoid arthritis, Accessed from: <https://onlinelibrary.wiley.com/doi/full/10.1002/acr.20682>

# Case study 3

## Combined clinic for comorbid ILD

### Overview

- The combined clinic was set up 10 years ago as part of the rheumatology unit
- During patient consultations, both a respiratory and rheumatology specialist are present, enabling collaborative and efficient clinical decision-making<sup>(a)</sup>

**Sources:** (a) KPMG interviews with HCPs treating RA and associated comorbidities (b) Pulmonary manifestations of collagen diseases Available from: <https://www.ncbi.nlm.nih.gov/pubmed/23683373>

### What is the rationale?



- The combined clinic was set up 10 years ago following observations of a high level of morbidity in patients with RA with interstitial lung disease (ILD)<sup>(b)</sup>
- It was considered that the best approach would be a single clinic to address the complexities of managing RA with concurrent ILD, as this approach would enable joint decision making with respect to treatment

### What are the key features?



**Clinic Frequency** One day per week

**Number of patients** Around 20 patients during each clinic

**Staff members involved** A consultant rheumatologist and respiratory physician

**Referral** Most referrals come from a rheumatology consultation or from a respiratory physician, with occasional referrals from dermatology. However, there has been a shift towards direct referrals from primary care if patients present with both lung problems and RA symptoms

### What are the activities undertaken?



- Patients referred onto the combined RA/ILD clinic undergo a consultation with both specialists
- Treatment decisions are made collaboratively, taking ILD and RA progression, as well as wider patient context, into account
- Patients continue to be seen by both specialists throughout their treatment, typically alternating between appointments with the respiratory physician and rheumatologist
- Any required treatment changes are coordinated between the two specialists, via a hand-in-hand decision-taking approach



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## Combined clinic for comorbid ILD (cont.)

### Benefits



#### Benefits to patients

- More timely diagnostic and treatment-related decisions – treatment decisions that usually take up to two weeks due to to-and-fro communication between specialists can be achieved in a single consultation
- Improved quality of care due to combining of expertise

#### Benefits to the clinicians

- Enhanced awareness of recent developments in the respective disease areas – for both of which diagnostics and treatments are evolving
- More efficient decision-making processes save time for clinicians running the combined clinic, as well as wider rheumatology and respiratory units

### Challenges



- As the first and one of the only existing combined clinics for RA and comorbid ILD, patients are being referred from across Spain. This may present a capacity challenge as there is only one clinic per week
- Primary pathology may be hard to identify in patients presenting with both RA and ILD
- Treatment decisions depend on accurate patient recall of the order of onset and precise nature of symptoms
- In the short-term this approach is not cost-effective; however, improvement in patient treatment could reap financial benefits in the long term

### Tips to replicate this intervention



- Communication and coordination between the clinicians is key in the post-consultation phase, particularly if the patient is not stable



Fundamentally, the combined clinic represents a paradigm change – we are now treating the whole patient, not just individual diseases.

- Respiratory specialist



Sources: (a) KPMG interviews with HCPs treating RA and associated comorbidities (b) The impact of a jointly staffed clinic on the diagnosis of lung involvement and connective tissue diseases. Available from: <https://academic.oup.com/rheumatology/article/50/3/434/1790081>

# Case study 4

## Systematic inflammatory osteoporosis screening

### Overview

- A rheumatologist with a specialism in inflammatory osteoporosis (IO) set up a clinic for the routine screening and monitoring of this common comorbidity of RA
- The clinic sits within the metabolic unit, and has a strong focus on data collection for research
- Patients undergo a baseline evaluation before being referred onto inflammatory osteoporosis specialist for a thorough consultation
- Systematic monitoring of Early Arthritis Clinic patients and those receiving biologic treatment helps to track fracture risk, with the end goal of reducing fracture rates in RA

**Sources:** (a) KPMG interviews with HCPs treating RA and associated comorbidities  
(b) Pulmonary manifestations of collagen diseases Available from:  
<https://www.ncbi.nlm.nih.gov/pubmed/23683373>

### What is the rationale?



- It was noted that many patients with RA reported joint difficulties, so nine years ago a specialist inflammatory osteoporosis (IO) clinic was set up to screen for and treat this comorbidity
- The goal is to reduce fracture risk in patients with RA, with a particular focus on disease progression

### What are the key features of the intervention?



#### 1 Baseline evaluation

- All patients in the Early Arthritis Clinic, all patients with RA starting biologics treatment, and any other patients from the rheumatology unit or elsewhere in the hospital displaying symptoms complete a full evaluation
- This involves evaluation of fracture risk, involving historical clinical information, risk factors, metabolic analysis, and x-rays of dorsal and lumbar spine (bone densitometry)

#### 2 Referral

- Patients at risk of fracture are then referred onto IO clinic for a consultation with the specialist to discuss treatment and follow-up

#### 3 Systematic monitoring

- All patients in the Early Arthritis Clinic and all patients with RA starting biologics treatment undergo systematic monitoring of fracture risk

### What are the key features of the intervention (cont.)?



<b>Date clinic established</b>	2009
<b>Number of patients</b>	Around 30 patients are seen per week (~6 new patients and 24 follow ups)
<b>Staff members involved</b>	1 inflammatory osteoporosis specialist (rheumatologist), 4 specialists in the metabolic unit
<b>Referral</b>	Referrals from the Early Arthritis Clinic, all patients starting biologic treatment from the rheumatology unit, and patients elsewhere in the hospital displaying symptoms

### Benefits



#### Systematic attention to this comorbidity

- Inflammatory osteoporosis is better managed in-general, towards the goal of reduced osteoporotic fractures in patients with RA

#### Establishment of new guidelines

- All data collected from systematic monitoring is analysed, and the results are used to develop guidelines for the treatment of patients with risk of osteoporotic fracture – e.g. the use of corticoids



# Karolinska University Hospital

Stockholm, Sweden



# Summary



## Context

The Karolinska University Hospital and Academic Specialist Centre **provide specialised rheumatology care** for the population of Stockholm .

**The Division of Rheumatology at Karolinska carries out extensive basic science and translational research in rheumatic inflammatory diseases.** The strategy is to take advantage of unique and large patient groups followed up over time via the Swedish Rheumatology Quality Register

**The Division has extensive international networks,** where typically members from 10-15 nations are active in clinical and research groups

**Key research groups** include work on rheumatoid arthritis, SLE and myositis

**The Karolinska Hospital will deliver more highly specialised services in future** while more care will shift to out-of-hospital settings

As part of this shift the recently opened **Academic Specialist Centre** – a collaboration between Stockholm Health Care Services and Karolinska Institutet - **will provide more of the specialist arthritis care in the community**

The Academic Specialist Centre aims to integrate **innovative models of care with early access to research**, with a strong emphasis on **patient-centred, technology-enabled care**

**Note:** 1. A collaboration between Stockholm Health Care Services and Karolinska Institutet  
**Sources:** (a) KPMG interviews with HCPs treating RA and associated comorbidities



## Key strengths in the delivery of RA care

**Systematic data capture on patients with rheumatic diseases** – the Karolinska Hospital leads the operation of the Swedish Rheumatological Quality Register (SRQ) - a comprehensive, high-coverage, high-quality disease register

**Standardisation of assessment** – because of high adherence to the voluntary register of all RA patients onto SRQ, and the integration between the electronic health record and the registry, there is a strong basis for consistent assessment and monitoring of RA, informed by evidence-based research. The integration of registry data with day-to-day practice is also optimised to support timely and data-driven clinical decisions

**Timely diagnosis and treatment of early arthritis.** The majority of patients with new onset RA achieve remission within 12 months of being seen at early RA clinic at the Karolinska Hospital

**Close collaboration with patient groups.** The Academic Specialist Centre hosts a Patient Council to provide critical feedback on the quality of current care, and input into service improvement. In both centres, there is a great emphasis on patient experience and organising care around the real-life needs of the patient

**The Rheumatology Units have developed e-health tools to enable self-management.** The Academic Specialist Centre has developed e-services with the aim of developing improved access to care and strengthening the ability of the patient to take greater control in managing their RA



## Key challenges faced in delivery of RA care

Primary and secondary care providers in Sweden in general are not so integrated. Timely diagnosis of RA depends on early detection by primary care physicians. Specialist rheumatologists need to raise and maintain awareness through education, and providing direct and informative feedback on referrals to the rheumatology department

There is less emphasis on the integration of mental and physical healthcare provision. There may be a significant cohort of patients with lower severity mental health issues e.g. mild depression; or perhaps complex social issues, who would benefit from a multi-disciplinary approach e.g. including psychological / psychiatric input to manage both physical and mental health problems Both the Karolinska Hospital and the Academic Specialist Centre would benefit from having more rheumatologists with training in ultrasound – to maintain standards of clinical assessment in the early arthritis clinic

The Patient Council and other patient representatives depend on the dedication of unpaid volunteers. These representatives will need to be kept appropriately engaged and motivated in order to successfully achieve the objectives of collaboration

# RA Swedish healthcare system overview



## RA challenges in Swedish healthcare system

- Complaints about functionality and user-friendliness of the national health information exchange platform, due to disparate EHR systems across counties
- Low number of hospital beds (2.3 acute care beds per 1,000 population, compared to an EU average of 4.2<sup>(a)</sup>), which is mostly a function of shift of healthcare provision from hospital to more community-based settings

## Swedish healthcare system overview:



**Public health service:** The government is responsible for providing universal healthcare to the population, giving equal access to healthcare regardless of demographics. The healthcare system is decentralised, with the central government dictating overall health policy, and local decision-making devolved to county councils

**Private insurance:** ~6%<sup>(c)</sup> of the population has private healthcare insurance. ~70% of these insurance policies are employment-based and provide policyholders primarily with faster access to outpatient (ambulatory) visits and elective surgery

**Funding:** Health care expenditure represented 11%<sup>(b)</sup> of GDP in 2015 – third highest in the EU. Public expenditure accounts for 84%<sup>(b)</sup> of the total funding (mainly general tax revenue raised by county councils and some national tax revenue). Municipalities fund elderly care, home care and social care, while the county councils are responsible for primary, psychiatric and specialist health care. Benefit packages are not defined and direct user charges (flat-rate payments) are levied for primary and specialist care, which are set by the county councils, leading to variation across the country

**Hospitals:** There is a mix of publicly and privately owned health care facilities, but they are all publicly funded - there are seven university hospitals providing highly specialised care, 70 hospitals at the county council level (two-thirds of which provide 24/7 acute care) and six private hospitals (three of which are not-for-profit<sup>(d)</sup>). There has been a consistent effort across Sweden to move services from hospital to community settings, including for example, the Academic Specialist Centre

**EHR:** decentralised organisation of healthcare results in different EHR systems being used and a national Health Information Exchange (HIE) platform has been implemented to facilitate single-point connectivity. Updated national eHealth Vision – 2020 aims to provide all residents (>16years of age) with access to all health-related information documented in county-funded health<sup>(d)</sup>

## Rheumatoid arthritis in Sweden:



### Patients:

- Prevalence: 0.77%<sup>(d)</sup> (overall)
- Overall prevalence is higher in women (1.11%) compared to men (0.43%)<sup>(d)</sup>

### Physicians:

- Approximately 250-300 rheumatologists covering 10.0 million people<sup>(e)</sup>
- 16%<sup>(b)</sup> of all physicians work across 1,200 primary care practices – with an average of four GPs per practice. However there is no formal gatekeeping function

— Guidelines:

### RA:

- The European League Against Rheumatism (EULAR)
- National guidelines set up by the Swedish National Board of Health and Welfare
- Guidelines by the Swedish Rheumatological Society

### Comorbidities:

- International EULAR guidelines (and Swedish rheumatology association recommendations)

### PAGs / Medical Societies:

- Swedish Rheumatism Association (Svenska Reumatikerförbundet)
- Swedish Rheumatological Society (Svensk Reumatologisk Förening)

Sources: (a) State of Health in the EU – Sweden, OECD, 2017; (b) Insurance in Sweden, Svensk Försäkring, 2018; (c) The Swedish Health Care System, Commonwealth Fund, 2018; (d) How Sweden is giving all citizens access to their electronic health records, Future Health Index, 2017; (e) Nationwide prevalence of rheumatoid arthritis and penetration of disease-modifying drugs in Sweden, ARTIS Study Group, 2010; (f) KPMG interviews with HCPs treating RA and associated comorbidities

# The Rheumatology care settings

Karolinska University Hospital is a major teaching hospital with a strong focus on academic research, on which it collaborates with the Karolinska Institutet. It provides emergency and elective specialist care across its two sites to the people of Stockholm and beyond. The Academic Specialist Centre provides specialist rheumatology care in the community setting as part of a collaboration between the Karolinska Institutet and Stockholm County Council.

Karolinska Hospital			The Academic Specialist Centre		
<b>Type</b>	Major academic tertiary and secondary centre	<b>Locations</b>	Solna (North); and Huddinge (South)	<b>Type</b>	Community-based specialist centre
<b>Core services</b>		<b>Population served</b>	2.3 million in Stockholm County	<b>Core services</b>	Three specialist healthcare units covering rheumatology, neurology, and diabetes
<b>Size</b>	1,340 inpatient beds 15,000 staff			<b>Locations</b>	Solna
The Karolinska Hospital Rheumatology unit			The Academic Specialist Centre Rheumatology unit		
<b>Services</b>	Covers: inflammatory arthritis including rheumatoid and other systemic inflammatory diseases such as SLE, Scleroderma, myositis and vasculitis; and rarer inflammatory diseases including Behçet's	<b>Collaborations</b>	Working with extensive international and national networks including Project 4D Arthritis; SRQ, Epidemiological Investigation of RA (EIRA)	<b>Services</b>	Community services covering three specialties – rheumatology, neurological disorders, diabetes
<b>Funding and Resources</b>	Run by Stockholm County Council and is publicly funded. Funding for research comes from both public and private sources	<b>Teaching / research scope</b>	Vast majority of patients are included as part of research projects Research groups include: RA; cellular immunology; translational research; experimental rheumatology; paediatric rheumatology; and anti-rheumatic therapies	<b>Funding and Resources</b>	Run by Stockholm County Council and is publicly funded. Funding for research comes from both public and private sources
				<b>Collaborations</b>	Is a collaboration between Karolinska Institutet and Stockholm Health Care services to provide more specialist care in the community
				<b>Teaching / research scope</b>	RA; PsA; back pain; Patients at risk of RA; Early arthritis including epidemiological examination; drug therapies in RA: patient self-management including technological innovation; biobanking

# The Rheumatology care services



Service Division	Karolinska University Hospital			Academic Specialist Centre	
	Outpatient service	Ambulatory Care	Inpatient service	Outpatient service	Ambulatory care
<b>Duration of stay</b>	20-minute appointment with rheumatologist, 10 minute for follow-up appointments	<1 Day	Variable	20-minute appointment with rheumatologist, 10 minute for follow-up appointments	<1 Day
<b>Hours of availability</b>	08:00 – 17:00	08:00 – 17:00	24/7	08:00 – 17:00	08:00 – 17:00
<b>Patient type catered to</b>	All RA patients	Patients with DMARD-resistant RA	Systemically unwell RA patients	All RA patients	Patients with DMARD-resistant RA
<b>Services offered</b>	<ul style="list-style-type: none"> <li>— Early arthritis clinic</li> <li>— General rheumatology clinic (including later phase RA patients)</li> <li>— Physiotherapy, occupational therapy</li> <li>— Patient education</li> </ul>	<ul style="list-style-type: none"> <li>— Intravenous biologics administration</li> </ul>	<ul style="list-style-type: none"> <li>— Daily inpatient rheumatology review</li> <li>— Rapid comorbidity review (usually within 24 hours) – e.g. cardiology, psychiatry, diabetology, pulmonology</li> <li>— Physiotherapy, occupational therapy</li> </ul>	<ul style="list-style-type: none"> <li>— Early arthritis clinic</li> <li>— General rheumatology clinic (including later phase RA patients)</li> <li>— Physiotherapy, occupational therapy</li> <li>— Patient education</li> <li>— Psychology</li> </ul>	<ul style="list-style-type: none"> <li>— Intravenous biologics administration</li> </ul>

# The team



## Core team profiles

### Karolinska Hospital

- >50 rheumatologists (full-time and part-time)
- Rheumatology nurses
- Rheumatology researchers
- Pharmacists
- Service coordinator
- Comorbidity coordinators
- Physiotherapists
- Social assistants
- Psychologists
- Dieticians
- Occupational therapists
- Orthopedists
- Podiatrists

### Academic Specialist Centre

- 12 rheumatologists (full-time and part-time)
- 10 nurses
- 3 assistant nurses
- 2 physiotherapists
- 1 occupational therapist
- 1 research coordinator

## Key features of the care delivery team

- **Strong emphasis on research** Both the Hospital and the Academic Specialist Centre are focused on translating research quickly into improvements in clinical care. The Karolinska University Hospital has a strong track record in research and has a particular focus on RA.
- Key areas of research currently being pursued include identification and management of patients at-risk of RA; pain in inflammatory disease; and investigating multi-morbidity in RA
- **Robust and user-friendly clinical information system.** HCPs benefit from an information system that captures a comprehensive set of useful clinical and non-clinical patient information, and presents it in a visually accessible way. HCPs are therefore able to make high-quality and efficient clinical decisions, and explain them easily to their patients.
- **Enabling patients' involvement in service improvement.** The Academic Specialist Centre's Patient Council provides a forum for patient representatives to provide direct input into the way care is delivered, with a particular focus on patient experience.

## Governance and processes

### Team meetings:

- Weekly working group meetings for operational management issues
- Patient Council input to Academic Specialist Centre is an integrated part of operational decision-making

### Protocols:

- Local protocols are based on EULAR and Swedish Rheumatology guidelines e.g. on management of RA; early arthritis; comorbidities; and use of biologics

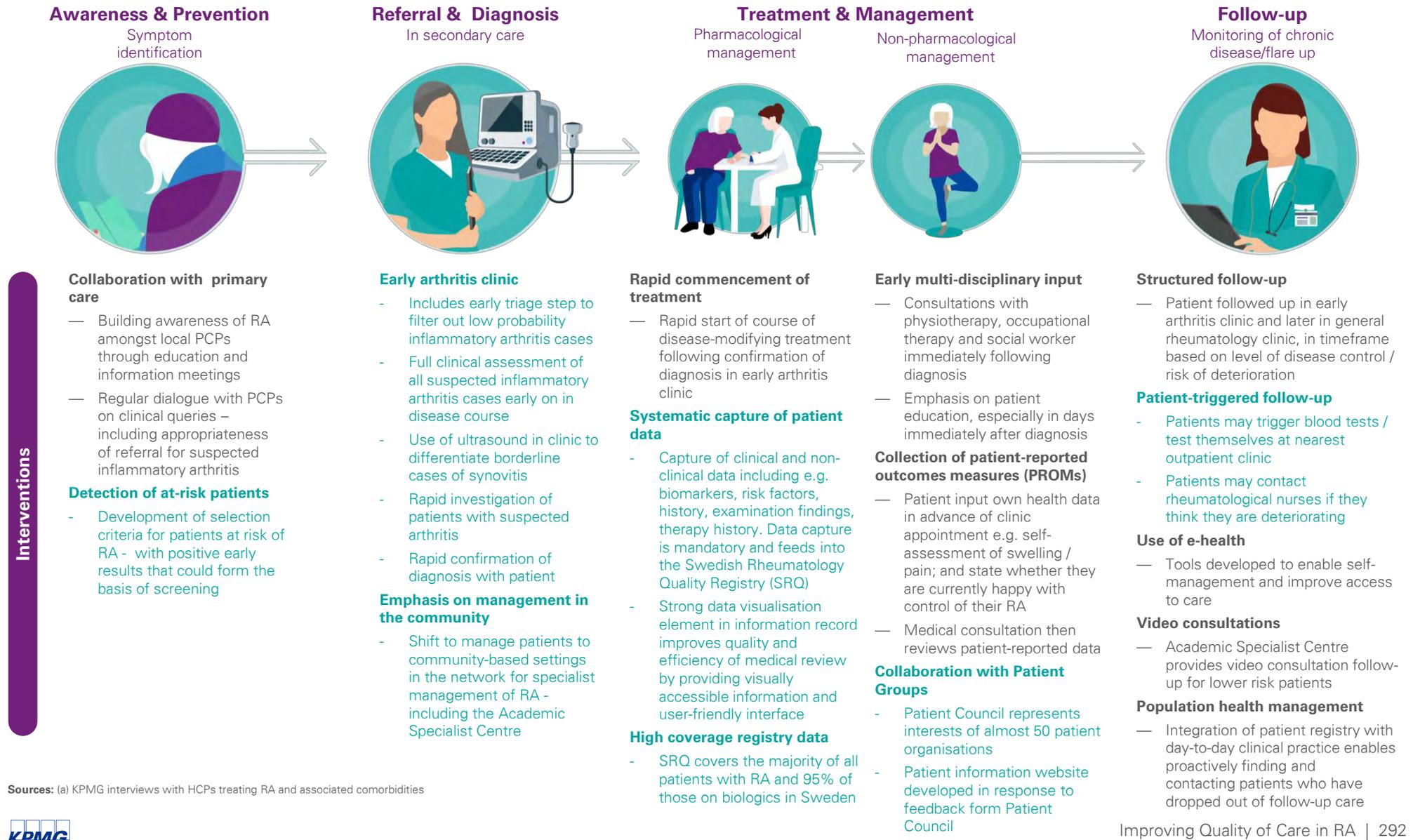
### Patient records:

- Information is captured on a dedicated system for rheumatology that fully integrates with the SRQ national registry
- The information system enables longitudinal monitoring of patients at an individual or grouped level

### Pharmacy

Sources: (a) KPMG interviews with HCPs treating RA and associated comorbidities

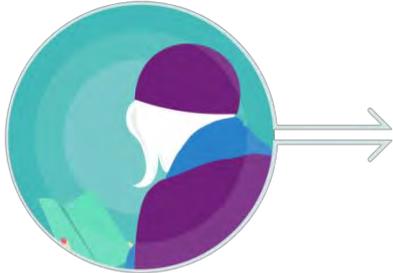
# Overview of interventions in place for RA



# Overview of interventions in place for RA comorbidities

## Awareness & Prevention

Symptom identification



## Referral & Diagnosis

In secondary care



## Treatment & Management

Pharmacological management



Non-pharmacological management



## Follow-up

Monitoring of chronic disease/flare up



Interventions

### Comorbidity and lifestyle factor screening

- Early identification of comorbidities following diagnosis
- Proactive searching for comorbidities and lifestyle factors that influence RA and comorbidity outcomes

### Comorbidity research programme

- Detection of key associations e.g. with TB in patients on biologics
- This has resulted in the formation of a screening programme
- Evidence to back up more targeted early management of CVD risk

### High coverage registry data

- High-quality, high coverage national registries in many other diseases allow for linkage of data between RA and other diseases for clinical and research purposes – made possible through a unique patient identifier across registry databases. For example, linkage of RA biologics registry with TB registry allowed detection of increased incidence of TB in patient on anti-TNF therapies and led to TB screening programme

### Systematic capture of patient data

- Capture of clinical and non-clinical data includes modules for comorbidities including CVD, osteoporosis, diabetes, lung disease

### Collaboration with psychologist

- To manage mental health issues in RA e.g. around depression, fatigue

### Collaboration on pain management

- Collaboration with pain specialists including psychological input to manage residual pain following flares

### Emphasis on lifestyle and environment modification

- Communication to the patient of increased risk of certain lifestyle behaviours in producing poor health outcomes in RA and associated comorbidities e.g. cardiovascular disease, diabetes, depression and lung disease:
  - Explanation of risk via visual tools
  - This approach is incorporated in the Swedish Society for Rheumatology (SRF) guidelines

### Enhanced role for physiotherapy

- Physiotherapy plays a key role in pain management through encouraging and coaching on physical activity, and in providing education on self-management

### CVD screening

- Screening for presence of CVD / risk of CVD at 6 months
- Referral to lifestyle modification courses e.g. smoking cessation, exercise programme

### Collaboration with PCPs

- Ongoing management / prevention of diabetes / CVD / depression handed over to PCP
- Checks with PCP on patient progress relating to comorbidity management

Sources: (a) KPMG interviews with HCPs treating RA and associated comorbidities

# These interventions have improved outcomes



How do you quantify the benefits in RA?

**Objective measures (KPIs):**

- DAS 28, CRP, ESR

**PROs:**

- HAQ, EQ-5D, SF-36, Pain-VAS

**Centre routinely measures comorbidity outcomes by:**

- Objective measures:
  - 5-year cardiovascular risk, FRAX

**PROs:**

- PHQ-9, NYHA heart failure classification



How have these interventions improved patient outcomes?

**RA**

- Benefit: Fewer patients are now seen with structural damage. Quantitative output: Median DAS 28 score at 12 months following diagnosis = 2.4  
i.e. the majority of newly diagnosed cases of RA achieve remission within 12 months.

**Comorbidities**

- Very small number of patients seen with interstitial lung disease – likely due to early treatment of inflammation

**“Collaboration with primary care is good. Patients are detected and referred early here compared to other countries. Once with us, patients are also diagnosed and treated early, and followed up tightly.”**

- Rheumatologist

Sources: (a) KPMG interviews with HCPs treating RA and associated comorbidities

# How can care be improved?



## What is next for the centre?

### At-risk patients and prevention

- **Overview:** The next frontier for the Karolinska Hospital is the identification of patients at risk of developing RA and prevention of RA
- **How?** The Hospital is currently actively investigating the whether risk of RA can be predicted through detection of biomarkers e.g. ACPA antibody, and other factors e.g. family history or lifestyle. The Swedish Rheumatology Quality Registry is a rich source of data to start investigating and following up patients, and will help to differentiate the impact of various genetic and environmental factors. Already trials have begun on the effectiveness of various therapies at preventing RA in selected at-risk populations

### Investigating neuropsychological manifestations of RA

- **Overview:** The Karolinska Hospital would like to better manage some of the neurological and psychological complications of RA e.g. around pain, depression and fatigue
- **How?** The Hospital is currently actively pursuing research into mechanisms of inflammation and their neurological and psychological sequelae. With a greater understanding of the dynamics between inflammatory and psychological factors there will be opportunities to adapt the model of care to target opportunities to reduce the impact of RA on patient physical and mental well-being.

### Spreading responsibilities across RA care team

- **Overview:** There may be opportunities for spreading responsibilities across the MDT – for other healthcare disciplines to take on some of the role of physicians - in order to optimise use of human resources
- **How?** There is an evolution of roles in progress for example in spondyloarthritis, with physiotherapists taking on some of the appointments usually led by doctors, and are usually able to spend more time and give more education and advice. In RA, rheumatology nurse maybe best placed to take on an expanded role given the regularity of touchpoints each patient has with rheumatology nurses as part of current standard care.



## What advice would you give less specialised centres?

### Overview of advice: Registries should aim to include all patients sent through rheumatology clinic

- **Why?** Following up these patients over time and linking to other disease registries may help to understand the natural history of disease e.g. development of early RA and comorbidities
- **How?** HCPs will need to make registering of patients part of the management of patient flow through their clinics.

### Overview of advice: Ultrasound can be a useful adjunct investigation in diagnosis and monitoring of RA

- **Why?** Ultrasound can help to confirm synovitis where difficult to detect on physical examination
- **How?** Strong expertise in joint ultrasound is recommended to improve accuracy sufficiently that use of this imaging modality can be beneficial

# Case studies

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# Case study 1

## Swedish Rheumatology Quality Registry (SRQ)

### Overview

- Nationwide quality registry coordinated by the Karolinska Hospital
- Systematically captures clinical and non-clinical data relating to patients with rheumatic diseases
- Full coverage of RA patients on biologics, and very high coverage (>90%) of all RA patients
- Voluntary data collection with high credibility and adherence enables consistency of assessment and measurement according to best practice
- SRQ and its linkage to other disease registries provides rich source of data that can be used for rheumatological studies, including longitudinal surveillance and linkage to other registries for registration of comorbidities

Sources: (a) KPMG interviews with HCPs treating RA and associated comorbidities (b) [www.srq.nu](http://www.srq.nu); (c) Askling J, Fored M, Brandt L, et al. Risk and case characteristics of tuberculosis in rheumatoid arthritis associated with tumor necrosis factor antagonists in Sweden. *Arthritis & Rheumatism* (2005)

### What is the rationale?



- The objective is to continually improve the quality of patient care including assessment, treatment, and follow-up of rheumatology patients<sup>(b)</sup>
- The registry provides a real-time view of health data – input by both clinicians and patients as part of care
- The data captured includes all relevant clinical and non-clinical data to RA, enabling clinicians to make better data-driven clinical decisions
- The registry also provides a basis for broad programmes of research across diseases and specialties as patients can be followed up over time, data is reliable, and data can be linked with other disease registries and data sources e.g. biobanks

### What are the key features of the intervention?

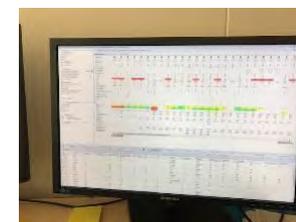


- Systematically captures clinical and non-clinical data relevant to patients
- Mandatory collection of data as a condition of being a provider of rheumatological care
- Full coverage of patients with RA on biologics, and very high coverage (>90%) of all patients with RA
- Different modules for different rheumatological diseases and their variants / associations
- Automated production of outputs / reports e.g. letters to PCP or to the patient

### What are the key features of the intervention? (cont.)



- One-screen full overview of patient clinical data including defined clinical findings, investigation results, disease scores, medication history, adverse effects and red-amber-green (RAG) rating of current disease status



*One-screen digital overview of patient information*

- Automated triggers ‘nudge’ clinicians as a reminder to take action – where clinically appropriate
- Yearly meeting run by the Karolinska Hospital on behalf of Swedish Society of Rheumatology – presenting results of registry-based research, and resulting updates on the evidence-based national guidelines

### What are the outcomes so far?



- SRQ has been granted Certification Level 1, the highest level for a national disease registry in Sweden
- Both patients and clinicians have been very satisfied with use of the registry
- The registry has been the source of many original research publications over the period of its operation by epidemiological and rheumatological investigators
- It has recently provided evidence for implementation of a TB screening programme for patients on biologics<sup>(c)</sup>

## Case study 1 (cont.)

### Benefits



- Voluntary data collection with high credibility and adherences enables consistency of assessment and measurement according to best practice
- User-friendly visualisation of clinical data allows rheumatologists and other HCPs to make higher quality data-driven (and evidence-based) clinical decisions in less time, freeing up clinical staff to undertake other clinical tasks / see more patients
- Information and some analysis (e.g. of trend in disease activity) can be reflected back to the patient immediately, improving the quality of doctor-patient communication
- Linkage to other disease registries and to biobank data provides a rich source of data that can be used as the basis of further research on e.g. comorbidities; previously undiscovered associations and links; and response to therapies (where bias can be discounted)
- Significant pieces of research that have used the registry data include papers on: infection rates in patients from 5 different national registries<sup>(c)</sup>; and trends in mortality following new-onset RA<sup>(d)</sup>
- Because data is captured systematically and uniformly across all rheumatological care in Sweden, there is potential for detection of unexplained variation across regions

### Challenges



- It would be a significant programme of work on a national scale to implement a registry with similar coverage and quality
- To adapt physician / HCP behaviour to consistently and reliably capture this comprehensive set of clinical data requires dedicated resources e.g. in terms of time and people
- Maintenance of the registry also requires dedicated resource around quality coordination, education and extraction of data from the registry and compiling statistics. Use of the data needs to be overseen through strict governance processes e.g. research ethics board; or information governance.



The registry is a key instrument for us in daily practice

– Rheumatologist



Sources: (a) KPMG interviews with HCPs treating RA and associated comorbidities; (b) [www.srg.nu](http://www.srg.nu); (c) Yamanaka H, Askling J, Berglind N, et al. Infection rates in patients from five rheumatoid arthritis (RA) registries: contextualising an RA clinical trial programme. *RMD Open*. 2017 (d) Holmqvist M, Ljung L, Askling J. Mortality following new-onset Rheumatoid Arthritis: has modern Rheumatology had an impact? *Ann Rheum Dis*. 2018

# Case study 2

## Early arthritis clinic

### Overview

- Rapid process of referral to treatment for all suspected cases of inflammatory arthritis
- Screening (triage), investigations including imaging, confirmation of diagnosis and patient education all take place within the same week
- Proven strong outcomes including majority reaching remission within 3 months and maintaining remission for first 12 months
- Success underpinned by expertise in ultrasound and raising awareness amongst PCPs

Sources: (a) KPMG interviews with HCPs treating RA and associated comorbidities

### What is the rationale?



- The objective is to detect, see, investigate, diagnose and treat RA as early as possible in the disease lifecycle, as per international Treat-to-Target guidelines
- Early diagnosis and treatment of RA slows accumulation of damage and makes more likely for a patient to live a normal life free of disability
- Before the clinic was started, the process for assessment, investigation and diagnosis was more drawn out, leading to delays in diagnosis and treatment and greater incidence of structural joint damage in patients with RA

### What are the key features of the intervention?



<b>Frequency</b>	Weekly
<b>Timings</b>	<p><b>Monday</b> – Triage / screening, diagnostic tests including ultrasound</p> <p><b>Tuesday</b> – Follow-up medical consultation (half to Solna, half to Huddinge) including investigation results</p> <p>Start treatment (methotrexate) same day if no contraindication</p> <p><b>Wednesday / Thursday</b> - Follow-up with rheumatology nurse/ other HCP for further education</p>

### Staff members involved

<b>Members of the core MDT</b>	Rheumatologist, rheumatology nurse, physiotherapist, occupational therapist
<b>Others</b>	Social worker

### What are the key features of the intervention? (cont.)



- There are a total of 5 scheduled visits to the rheumatology clinic in the first 12 months following diagnosis
- Scheduled follow-up appointments in first year at 3, 6, and 9 months as a default programme. If patients are found to have higher disease activity, they will be followed up in 1 month. Patients may return for follow-up outside of this schedule if deterioration, and can trigger this themselves by calling into a helpline run by nursing staff
- At 6 months a rheumatology nurse conducts cardiovascular disease screening. Those found to have elevated cardiovascular risk are referred to their primary care practitioner. They may also be referred to the smoking cessation service

### Which guidelines are used?



- EULAR recommendations for management of early arthritis (2016)<sup>(a)</sup>

## Case study 2 (cont.)

### What are the outcomes so far<sup>(b)</sup>?



#### Timeliness of care

- Median time from presentation in primary care to diagnosis is **25 days**
- Median time between referral and first visit is **17 days**

#### Clinical outcomes

- The majority of patients achieve remission by 3 months, and maintain remission status for first year:

Time from first assessment at EAC (months)	Median DAS 28 score (clinical remission is defined as $\leq 2.6$ )
0	5.2
3	2.6
6	2.6
:	
12	2.4

#### Clinical outcomes (cont.)

- Median time from first symptom to diagnosis is 121 days
- Fewer patients have joint erosion or structural damage compared to before operation of early arthritis clinic

#### Medication penetration

- Proportion of patients with DMARDs after 3 months is 95.2%
- Proportion of patients with biologics in first 12 months 20.3%

:

### Benefits



#### Benefits to patients

- Early treatment at a stage of the RA disease process when it is most responsive to current therapies
- Prevention of inflammation-induced structural damage of joints. Earlier commencement of disease-modifying treatments prevents or slows accumulation of structural damage / erosions to joints

#### Benefits to the Rheumatology team

- Early screening of patients allows improved prioritisation of cases according to urgency, i.e., seeing inflammatory arthritis earlier versus other types of case
- High-quality training for trainee rheumatologists on use of ultrasound to detect synovitis -through high-volume clinics with integrated ultrasound investigation
- Increased levels of identification of patients for clinical studies early in their disease – at a point in the disease process that is currently a great focus for research, because of the potential responsiveness to treatment and opportunity to prevent damage over the longer term

Sources: (a) KPMG interviews with HCPs treating RA and associated comorbidities; (b) Karolinska Hospital data

## Case study 2 (cont.)

### Challenges



- Use of ultrasound at screening visit to differentiate synovitis requires rheumatologist with significant expertise – without the required level there is the risk of a high level of false-positives and false-negatives
- One critical component that is more difficult to influence is the awareness of PCPs of inflammatory arthritis, and the opportunity to refer all suspected cases to the early arthritis clinic. Collaboration with PCPs and regular education over a sustained period has been key to improving referral rates and reducing delays in diagnosis

### Tips to replicate this intervention



- Centralisation of screening to create higher volume centres improves quality of the clinic, with greater standardisation of care, better outcomes for patients, and improved training experiences for trainee rheumatologists
- Raise awareness of inflammatory arthritis amongst PCPs through education sessions and dialogue with PCPs through the referral process
- Inclusion of the triage step early in the flow through the clinic, helps to quickly filter out non-inflammatory arthritis, avoiding unnecessary investigations and disutility of care for many patients

### Other recommendations



- The next step for this clinic will be to follow up in a more systematic way the impact of early arthritis on medium to long-term outcomes
- The early arthritis clinic may benefit from greater input from the multi-disciplinary team, particularly physiotherapy and occupational therapy



We are now seeing less and less patients with structural damage. We treat inflammation as early as we can.

- Rheumatologist



# Case study 3

## Patient Council (Academic Specialist Centre)

### Overview

- The Patient Council is a representative body for over 50 patient organisations across the 3 specialties covered by the centre
- The Council meets regularly to provide input on improving all aspects of care in which the patient has an interest from quality of clinical care through to patient experience



Academic Specialist Centre reception and greeting area

Sources: (a) KPMG interviews with HCPs treating RA and associated comorbidities



### What is the rationale?



- Listening to patients can help healthcare professionals (HCPs) involved in RA care to identify previously unidentified needs and to develop solutions to meet those needs
- By engaging patient representatives in a regular forum there is an effective, streamlined process for ensuring appropriate input from patients on managing care
- Patient input can be relevant for redesigning services, making improvements to the patient environment, and for developing communications for patients

### What are the key features?



#### Patient Council

- The Patient Council provides a representative body for patients in all matters relating to the centre's services across the three specialties covered (rheumatology, diabetes, neurology)
- It currently comprises 17 members collectively representing over 50 patient organisations including local associations, district associations, national federations and youth associations
- Input from the Patient Council is an important component of the centre's decision-making process around service operations

### What are the activities undertaken?



#### Key focus areas

- The centre is particularly focused on developing the following areas, which require critical input from patient representatives:
  - Moving to more patient-centred models of care
  - Digitisation of services including e-health tools
  - Collaborative opportunities with the Centre

#### Key elements

The Patient Council is hosted by the Academic Specialist Centre:

- The Centre helps to develop the agenda, while Council members create the content and conduct the discussions themselves
- They provides views on areas requiring improvement and how the centre might better meet needs of patients
- It meets 6-weekly, and is followed by a rheumatology-specific meeting

#### Patient representatives also:

- Participate in centre planning days
- Participate in development of patient information
- Provide input into staff training e.g. talk to students about their experiences
- Organise information evenings and community-building / social events for patients
- Talk with patients about their care experience and report back to the centre



CONTENTS



APPENDIX  
CENTRE REPORTS

## Case study 3 (cont.)

### What are the outcomes so far?



- The centre's website was fundamentally developed through several rounds of engagement with the Patient Council
- Patient representatives have helped to provide a useful intermediary when collecting survey data – patients were more forthcoming with honest feedback when not talking to a healthcare professional

### Benefits



#### Benefits to patients

- Patient services are developed or improved with greater consideration of the needs of the patient
- Experience of care is a higher priority for the team delivering care, which improves patient feeling about their care, and can help to improve clinical outcomes

#### Benefits to the Rheumatology team

- The team is able to benefit from more direct communication and feedback regarding new additions or changes in care

### Challenges



- The Patient Council relies on the involvement of unpaid volunteers. Clearly the success of the Patient Council partially depends on the degree to which it feels engaged by the centre, and whether the centre gives it the opportunity to make a real impact
- There is a risk that patients who become regular contributors become 'too professional' i.e. they become more focused on their relationship with the centre organisation versus providing the authentic real-life perspective provided by patients

### Tips to replicate this intervention

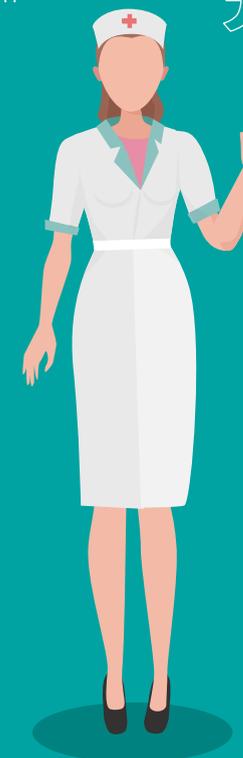


- Give patient representatives the voice, tools and resources necessary to make a strong impact
- Engagement is a two-way activity. Centres need to listen to patients, and also provide feedback on their suggestions and the decisions made on changes to care



At the Patient Council, we discuss everything from the colour of the walls to big changes in the way care is delivered

- Patient Council liaison



Sources: (a) KPMG interviews with HCPs treating RA and associated comorbidities

# Case study 4

## Use of e-health tools (Academic Specialist Centre)

### Overview

- Digitisation of care is a key focus area for the centre, with the aim of providing care tailored around the needs of patients with RA and others with chronic disease
- Patients increasingly expect to be able to access healthcare in the same way they consume non-health products and services online
- The e-services use the national online platform 1177 as a platform, while tailoring to specific patient needs by disease including RA



Patient-reported data input station

Sources: (a) KPMG interviews with HCPs treating RA and associated comorbidities; (b) www.1177.se



### What is the rationale?



- The aim is to develop improved access to care and strengthen the ability of the patient to take greater control in managing their disease
- A significant proportion of care does not require in-person consultation
- Patients have increasingly high expectations around using their electronic devices to access care and information remotely - as they would non-health products and services

### What are the key features of the intervention?<sup>(b)</sup>



- The centre deploys dedicated resources to develop and implement new e-health solutions and digital tools
- The existing national online platform for information / e-services 1177.se is the main basis for many of the e-health solutions. It provides information, advice, and a 24/7 telephone helpline to patients



1177.se education video still

### What are the key features of the intervention?



#### Key interventions

The centre has begun to integrate a number of e-health interventions into its services:

- Video consultations can be provided in place of in-person consultations through the 'Always Open' app. Video consultation may be appropriate for a significant proportion of follow-up appointments e.g. to confirm disease is well controlled and no further action is required
- Patients can access their medical record and input their patient-reported outcomes data remotely
- Patients can also inform the HCP in advance of an appointment what they would like to get out of the consultation e.g. what questions and concerns; whether they would like a new prescription

The e-health tool also provides prompts to the patient for the types of questions that they may want to ask / cover in the consultation

- Prescriptions can be renewed without seeing a HCP
- Patients can book, cancel and rebook appointments
- They may also notify the rheumatology team if they think they need to be seen sooner than their next scheduled appointment



## Case study 4 (cont.)

### Benefits



#### Benefits to patients

- By providing access to their own medical data in their own time, patients can gain a more solid understanding of their disease
- Giving the opportunity in advance for the patient to share what they would like to cover in their consultation helps to make sure all questions / concerns are addressed
- Video consultation can be much more convenient and less costly for the patient especially if they are travelling far or from somewhere with fewer transport links
- Patients are still able to ask for face-to-face consultations or a telephone call – helping to maintain patient choice

#### Benefits to the Rheumatology team

- Information from the patient on what they would like to achieve from a consultation can help to make the appointment more effective and efficient by allowing the HCP to be more focused and take less time

### Challenges



- Many patients require additional encouragement to do their own 'homework' e.g. input their patient-reported outcome data
- Patient data between centres is not currently linked – meaning patients may experience duplication in care and other issues caused by lack of communication between healthcare providers
- Telehealth consultations currently benefit from currently having equal reimbursement as face-to-face consultations – without this aspect there could be a financial disincentive for healthcare providers to deliver telehealth – e.g. if they are less well reimbursed than face-to-face appointments
- To effectively integrate e-health tools requires dedicated resource – who are able to: liaise with patient representatives to understand need; gain buy-in from HCPs around the implications for their day-to-day practice; and to provide time and effort to overcome practical challenges of implementation



E-services are aimed at empowering patients to manage their own disease

– E-services Lead



Sources: (a) KPMG interviews with HCPs treating RA and associated comorbidities (b) [www.1177.se](http://www.1177.se)

# Case study 5

## Comorbidity research programme

### Overview

- Key research programme for the Karolinska Hospital
- Strong emphasis on use of registry data to identify trends, and more definitively demonstrate associations with RA
- Key associations detected include higher cardiovascular risk early in the disease course of RA; and increased risk of TB in patients treated with anti-TNF treatments

**Sources:** (a) KPMG interviews with HCPs treating RA and associated comorbidities ; (b) Mantel A, Holmqvist M, Nyberg F, et al. Risk factors for the rapid increase in risk of acute coronary events in patients with new-onset rheumatoid arthritis: a nested case-control study. *Arthritis Rheum.* 2015; (c) Liao K, Gunnarsson M, Källberg H, et al. A specific association exists between type 1 diabetes and anti-CCP positive rheumatoid arthritis. *Arthritis Rheum.* 2009; (d) Askling J, Fored C, Brandt L et al. Risk and case characteristics of tuberculosis in rheumatoid arthritis associated with tumor necrosis factor antagonists in Sweden. *Arthritis Rheum.* 2005; (e) Arkema E, Jonsson J, Baecklund E et al.: Are patients with rheumatoid arthritis still at an increased risk of tuberculosis and what is the role of biological treatments? *Ann Rheum Dis.* 2014; (f) Reynisdottir G., Karimi R., Joshua V. Structural Changes and Antibody Enrichment in the Lungs Are Early Features of Anti-Citrullinated Protein Antibody-Positive Rheumatoid Arthritis. *Arthritis Rheum.* 2013

### What is the rationale?



- The relationships between RA and its comorbidities are not fully understood
- There are strong associations between RA and some comorbidities but it is not completely clear in all whether there is causation; shared pathological processes; or presence of common risk factors
- The natural course of development of comorbidities in RA is also not always clear
- By conducting research into evolution of comorbidities there will be opportunities to discover ways of reducing the impact of some key causes of mortality and morbidity in RA

### What are the key features of the intervention?



- The Karolinska Hospital is conducting a research programme to understand associations of RA
- The objective is to identify the associations, when they occur, and the consequences
- With access to the SRQ registry it is possible to link with national registries for CVD, cancer, birth defects etc. via each patient's unique personal identification code
- Once an association is identified (e.g. complication of RA in smokers) then a well-matched cohort of patients without the variable in question (e.g. smoking history) is identified to demonstrate the association is related to the variable

### What are the outcomes so far?



- The Karolinska Hospital has led research looking at risk factors for heart attacks / unstable angina in RA, demonstrating that the risk is most elevated in the first year following onset<sup>(a)</sup>. This has led to modification of the national guidelines to more actively manage cardiovascular disease early on in the course of the disease
- At an early stage of the life of SRQ, researchers at the department spotted increased risk of TB in patients treated with anti-TNF biological treatments<sup>(d)</sup>, which resulted in the implementation of a TB screening programme that has mitigated the risk<sup>(e)</sup>
- The Hospital has also demonstrated an association between rheumatoid and type 1 diabetes
- The research programme has also produced a study that demonstrated that presence of ACPA during early phases of RA is associated with abnormalities in the part of the lung tissues involved in gas transfer<sup>(e)</sup>

## Case study 5 (cont.)

### Benefits



- Biomarkers have been identified that could help in assessing risk of deterioration e.g. ACPA

#### Benefits to patients

- Cardiovascular risk is addressed during the period when the risk is greatest, reducing the likelihood of debilitating and potentially life-threatening cardiovascular events such as stroke, heart attacks(b)
- Incidence of TB has reduced significantly since the implementation of screening in patients on anti-TNF agents(e)

#### Benefits to the rheumatology team

- Management strategies for cardiovascular risk can now be more targeted – emphasising early treatment of cardiovascular risk factors

### Challenges



- It can be challenging to apply results from epidemiological studies - e.g. on identifying risk factors for comorbidities - in another population because the target population may have different characteristics and confounding factors to the study population



National guidelines on management of comorbidities in RA have been changed as direct result of our work

– Rheumatologist



**Sources:** (a) KPMG interviews with HCPs treating RA and associated comorbidities; (b) Mantel A, Holmqvist M, Nyberg F, et al. Risk factors for the rapid increase in risk of acute coronary events in patients with new-onset rheumatoid arthritis: a nested case-control study. *Arthritis Rheum.* 2015 (c) Liao K, Gunnarsson M, Källberg H, et al. A specific association exists between type 1 diabetes and anti-CCP positive rheumatoid arthritis. *Arthritis Rheum.* 2009; (d) Askling J, Fored C, Brandt L et al. Risk and case characteristics of tuberculosis in rheumatoid arthritis associated with tumor necrosis factor antagonists in Sweden. *Arthritis Rheum.* 2005; (e) Arkema E, Jonsson J, Baecklund E et al.: Are patients with rheumatoid arthritis still at an increased risk of tuberculosis and what is the role of biological treatments? *Ann Rheum Dis.* 2014; (f) Reynisdottir G., Karimi R., Joshua V. Structural Changes and Antibody Enrichment in the Lungs Are Early Features of Anti Citrullinated Protein Antibody Positive Rheumatoid Arthritis. *Arthritis Rheum.* 2013

# Case study 6

## At-risk patients research programme

### Overview

- Prevention of RA is key future objective for rheumatologists in general
- Currently there is pioneering work looking predictors for developing RA including genetic and environmental factors, and biomarkers
- The Karolinska Hospital has recently found that patients with musculoskeletal symptoms and positive ACPA are at high risk of developing RA in the near future

**Sources:** (a) KPMG interviews with HCPs treating RA and associated comorbidities; (b) [www.eirasweden.se](http://www.eirasweden.se); (c) Klareskog L, Malmström, Lundberg K et al. Smoking, citrullination and genetic variability in the immunopathogenesis of rheumatoid arthritis. *Seminars in Immunology*. 2011; (d) Hensvold A, Kisten Y, Hansson M et al. ACPA-Positive Risk-RA Subject without Subclinical Arthritis Are in High Risk for Later Arthritis Onset, Especially Carriers of HLA-SE Risk-Gene [abstract]. *Arthritis Rheum*. 2018; (e) Kisten Y, Rezaei H, Klint E et al. Tenosynovitis Detected By Ultrasound Predicts Arthritis Onset in Individuals at Risk of Developing Rheumatoid Arthritis. [abstract] *Arthritis Rheum* 2018



### What is the rationale?



- Detection of at-risk patients raises the possibility of prevention of RA or delaying the onset of RA
- Currently there are no ways of screening for RA, nor any practical prevention strategies
- As per the early RA paradigm, the earlier the treatment the lower the accumulation of joint damage over time

### What are the key features?



- The Karolinska Hospital is part of an international collaboration including teams from the Netherlands, Austria, Switzerland and UK focusing on patients at risk of developing RA
- The collaboration is looking at how to identify, classify and treat patients at risk of RA
- Currently still in the research phase, but there are indications of an opportunity to proactively identify and treat at-risk patients i.e. prevent development of RA
- Known associations of RA present potential targets for research into predictors for RA
- The presence of a comprehensive and high-coverage registry for RA enables longer term epidemiological follow-up studies
- The Karolinska Hospital is also leading a research intervention looking at factors leading to RA: Epidemiological Investigation of Rheumatoid Arthritis (EIRA).
- EIRA examines genetic and environmental factors associated with RA e.g. smoking, alcohol, work environment/chemicals, diet, patient's perception, socioeconomic status, weight<sup>(b)(c)</sup>

### What are the outcomes so far?



- The Karolinska Hospital is currently running the Risk-RA programme of studies to investigate the prediction of future onset RA in patients referred from primary care with musculoskeletal symptoms and positive anti-citrullinated protein antibody (ACPA). Those without arthritis on clinical and ultrasound examination were included in the prospective programme and monitored by a multi-disciplinary team
- Within 27 months (median 8 months), 41% had clinical / ultrasound-detected arthritis
- A significant difference in occurrence of a HLA-SE risk-gene was detected in subjects developing arthritis (86%) versus not developing (56%)<sup>(d)</sup>
- The increased relative risk of developing arthritis in those with tenosynovitis was 3.0 (95% CI 1.8-4.8). Therefore tenosynovitis detected by ultrasound is highly predictive of rapid arthritis onset in ACPA positive subjects with musculoskeletal symptoms<sup>(e)</sup>



## Case study 6 (cont.)

### Benefits



#### Benefits to patients

- The study performed at this centre on predictors of RA presents an opportunity to institute an effective screening programme
- The screening programme will enable earlier detection of RA for a proportion of patients, and could be adapted to include preventive treatments as the research develops in this area
- The benefit to the patient will be either full prevention of RA or reduced inflammation leading to less joint destruction over time

#### Benefits to the rheumatology team

- The screening programme could be relatively straightforward to implement given there were just three inclusion criteria – musculoskeletal symptoms; presence of ACPA antibody; and no clinical or ultrasound-detected arthritis

### Challenges



- It can be intrinsically challenging (especially when conducting retrospective studies) to identify causality relationships between different risk factors, which can make it difficult to translate to improvements in treatment / prevention strategy
- There is a trade-off in development of screening programmes – the wider the target population, the greater the resources required to implement, and the greater potential for negative consequences e.g. from treating false positives, or simply the impact of being investigated for a chronic illness. The study described here suggests a well-targeted screening programme is possible, with 40% of patients going on to be diagnosed with RA



We may have found an approach to detecting heightened risk of RA that could result in a significantly earlier diagnosis for some patients

- Rheumatologist



It is important to investigate further the environmental and lifestyle factors that are at play in the development of RA

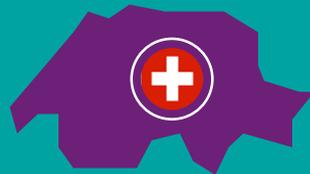
- Rheumatologist





# Geneva University Hospitals

Geneva, Switzerland



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APPENDIX  
CENTRE REPORTS

# Summary



## Context

- **High educational standards for HCPs in Switzerland** whereby most rheumatologists will have spent roughly 8-10 years in postgraduate training prior to full specialization, there are monthly and annual continuing medical education (CME) meetings and conference attendance is prioritised
- **High accessibility to timely care for patients with RA** due to the high density of rheumatologists in Geneva and availability of diagnostic investigations
- **Tertiary referral centre** supporting community rheumatologists, where the majority of patients with RA are seen in Switzerland
- **Hospital based rheumatologists have a direct influence on generalist care** through a professional network and CME interventions
- **Personalised patient care** using patient specific data in order to tailor services to patient needs
- **Strong research focus** within the department, running various projects assessing the genetics, epidemiology, therapeutic effects and biological construction of rheumatoid arthritis (RA)



## Key strengths in the delivery of RA care

- **Defined role of the rheumatologist in comorbidity care** which includes screening, detection, prevention of infections, referral to appropriate comorbidity HCP or generalist, treatment of RA, treatment of severe cardiovascular comorbidities, osteoporosis and depression and annual follow-up
- **Collaboration with generalists** including community rheumatologists through clear communication and shared systems. Generalists provide centralisation of referral and management of all other RA-associated comorbidities
- **Nurse-led patient care** including administration of medications, blood tests, therapeutic education and informal counselling
- **Standardised data capture and reporting** through Swiss Clinical Quality management in Rheumatic Diseases (SCQM) system which captures comprehensive RA and comorbidity data and the EPR system across public hospital and primary care physician (PCP) settings
- **Patient empowerment** through multiple services designed to increase patient autonomy including; auto-injection techniques and mobile applications for self-tracking and monitoring of disease progression

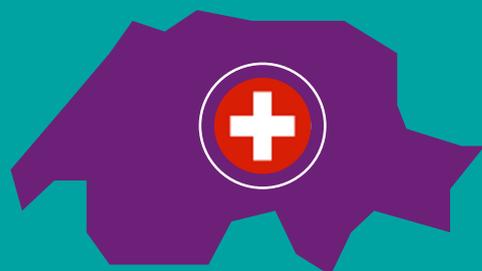


## Key challenges faced in delivery of RA care

- Highly specialised rheumatologists may require additional generalist training to better support comorbidity care
- National recommendation to shorten consultation times for all medical practitioners and specialists to 20 minutes <sup>(b)</sup>
- Increasing burden of administrative tasks
- Restricted reimbursement for nurse-led care
- Difficulty in tracking and monitoring medication compliance

Sources: (a) KPMG interviews with HCPs treating RA and associated comorbidities; (b) <https://www.bag.admin.ch/bag/fr/home/aktuell/news/news-09-01-20182.html>

# RA Swiss healthcare system overview



## RA challenges in Swiss healthcare system

- Reimbursement is not offered for additional roles of the rheumatology nurse in RA care. This acts as a barrier to supplementary care delivery for patients with RA

**Notes:** 1. Most patients with RA are seen in private practice

**Sources:** (a) [https://www.expatica.com/ch/healthcare/Getting-healthcare-in-Switzerland\\_103130.html#Overview](https://www.expatica.com/ch/healthcare/Getting-healthcare-in-Switzerland_103130.html#Overview); (b) <http://international.commonwealthfund.org/countries/switzerland/>; (c) <https://www.bfs.admin.ch/bfs/en/home.html>; (d) <https://www.sqcm.ch/>; (e) <http://www.sonar-group.ch/>; (f) Smolen et al. (2017) EULAR recommendations for the management of rheumatoid arthritis with synthetic and biological disease-modifying antirheumatic drugs: 2016 update; (g) <http://www.chu-rouen.fr/page/publisher/societe-suisse-de-rhumatologie-societe-suisse-de-medecine-physique-et-readaptation>; (h) <http://www.laligue.ch/>; (i) <http://www.arthritis.ch>

## Swiss healthcare system overview:



### Responsibilities:

- Duties and responsibilities in the Swiss healthcare system are divided among the federal, cantonal, and municipal levels of government
- It is a highly decentralized system, with the cantons playing a critical role. Each of the 26 cantons has its own constitution and is responsible for licensing providers, coordinating hospital services, and subsidizing institutions and individual premiums
- The municipalities, in turn, are responsible mainly for long-term care and social support services for vulnerable groups

### Quality assurance

- The federal government plays an important role in ensuring the quality and safety of pharmaceuticals and medical devices; overseeing public health interventions; and promoting research and training
- Local quality interventions, often at the provider level, include the development of clinical pathways, medical peer groups, and consensus guidelines

### Funding:

- Following introduction of the Federal Health Insurance Law in 1996, the Swiss federal government regulates the financing of the healthcare system, which comes from three main streams:

1. Direct financing for healthcare providers through tax-financed budgets for the Swiss Confederation, cantons, and municipalities. The largest portion of this spending is given as cantonal subsidies to hospitals providing inpatient acute care
2. Mandatory health insurance (MHI) premiums – government then provides income-based subsidies
3. Social insurance contributions from health-related coverage of accident insurance, old-age insurance, disability insurance, and military insurance

### Privately financed insurance

- Residents are legally required to purchase MHI within three months of arrival in Switzerland, this ensures universal coverage. There are virtually no uninsured residents<sup>(b)</sup>

## Rheumatoid Arthritis in Switzerland:



### Patients:

- 25,000 – 84,000 (0.3-1 % of population)<sup>(c)</sup>
- All patients should be included in the national registry - Swiss Clinical Quality management in Rheumatic Diseases (SCQM)<sup>(d)</sup>

### Physicians:

- 40 private rheumatologists in Geneva<sup>1</sup>

### Guidelines:

#### RA

- Swiss Clinical Quality management in Rheumatic Diseases (SCQM)<sup>(d)</sup>
- Swiss Sonography in Arthritis and Rheumatism (SONAR)<sup>(e)</sup>
- EULAR/ACR<sup>(f)</sup>
- Société suisse de Rhumatologie (Swiss Rheumatology Society) – national Swiss guidelines<sup>(g)</sup>

#### Comorbidities

- Société suisse de Rhumatologie<sup>(g)</sup> (for comorbidities)

### PAGs/ Medical societies:

- League Against Rheumatism – Cantonal patients with RA group<sup>(h)</sup>
- Association Suisse des Polyarthritiques (ASP) – National patients with RA group<sup>(i)</sup>

# The Rheumatology Unit

## Geneva University Hospitals

### The Hospital



<b>Type</b>	Part of HUG (Hôpitaux Universitaires de Genève / Geneva University Hospitals) which comprises 8 hospitals in the Canton of Geneva <sup>(a)</sup>	<b>Locations</b>	8 hospitals throughout the Canton of Geneva
<b>Core services</b>	Emergency critical care services, private services, medical and specialty consultations, intensive care, blood transfusion, research, academic centre closely linked to the Faculty of Medicine of Geneva (UNIGE - University of Geneva), <sup>(b)</sup> 7 centres of excellence, including Rheumatology (centre for Musculoskeletal and Sports Medicine) <sup>(c)</sup> . The centre is a leader of medical imaging and home to the first PET-MRI scanner <sup>(d)</sup>	<b>Population served</b>	Very small population of Geneva ~ 195,000 people <sup>(e)</sup>
<b>Size</b>	<ul style="list-style-type: none"> <li>– 8 hospitals</li> <li>– 40 outpatient clinics</li> <li>– 1,781 beds <sup>(a)</sup></li> </ul>	<b>Demographics</b>	<ul style="list-style-type: none"> <li>– Well-educated</li> <li>– 80% of the patient population have private healthcare insurance</li> </ul>

### The Rheumatology Unit



<b>Services</b>	Services on offer include genetics, laboratory and pathology, rheumatology laboratory, ambulatory consultation service, outpatient consultation service consisting of diagnosis, treatment and follow-up; multidisciplinary back consultation, musculoskeletal and ultrasound consultation <sup>(f)</sup>	<b>Collaborations</b>	Links to the following societies: Swiss Rheumatology Society, Rheuma-Suisse, Institute of Arthritis Research (iAR), Geneva rheumatologists Group, Geneva Medical Association, Swiss Cohorts of Patients With Inflammatory Rheumatism, Swiss Clinical Quality Management (SCQM) in Rheumatic Diseases, Association Suisse des Polyarthritiques, Swiss Ankylosing Spondylitis Association
<b>Funding and Resources</b>	The research projects are supported by various foundations, such as the Swiss National Scientific Research Fund, the Rheumasearch Foundation, the Reuter Foundation, the Schmidheiny Foundation, and the Institute of arthritis Research <sup>(f)</sup>	<b>Teaching/ research scope</b>	The department's current research areas are: 'Mechanisms of inflammation in rheumatic diseases', 'The role of autophagy in immune responses', and various epidemiological, therapeutic and biological projects on SCQM; a project researching family members of patients with RA through the "Arthritis Checkup" study determining the usefulness of blood markers and genetic and environmental factors to predict the risk of developing RA <sup>(f)</sup>

**Sources:** (a) <https://www.worldhealthsummit.org/m8-alliance/members/geneva-university-hospitals.html> (b) <http://www.swisshealth.ch/en/patienten/spitaeler/HUG.php> (c) <https://www.hug-ge.ch/en/> (d) KPMG interviews (e) <http://population.city/switzerland/geneve/> (f) <https://www.hug-ge.ch/rhumatologie>

# The Rheumatology Unit (cont.)



## Overview of Rheumatology services

Service Division	Outpatient	Ambulatory / Inpatient care
Duration of stay	20 – 30 minutes	
Capacity (no. of beds/rooms)		2- 4 beds
No. of patients seen	5,000 across entire rheumatology department (~10% are patients with RA)	300 patients with RA per year
Patient type catered to	<ul style="list-style-type: none"> <li>– Outpatients are given a referral consultation by their PCP or community rheumatologist <sup>(b)</sup></li> <li>– All patients with RA receive structured follow-up at varying frequencies according to their disease severity</li> </ul>	<ul style="list-style-type: none"> <li>– Usually patients with severe RA</li> <li>– Patients can self-refer or be referred by a physician</li> </ul>
Services offered	<ul style="list-style-type: none"> <li>– Consultation review wherein the following areas are addressed: <ul style="list-style-type: none"> <li>– Diagnosis</li> <li>– Radiological investigations i.e. Echography, X-rays</li> <li>– Treatment (including vaccinations administered by the rheumatologist)</li> <li>– Follow-up (including monitoring of comorbidities, assessment of disease activity using DAS 28, inflammatory markers and a structural damage test every 6 months)</li> </ul> </li> <li>– Rheumatology nurse review of the patient for blood tests +/- subcutaneous and intravenous injections</li> </ul>	<ul style="list-style-type: none"> <li>– Inpatient ambulatory assessment which covers <ul style="list-style-type: none"> <li>– Diagnosis</li> <li>– Radiological investigations i.e. Echography, X-rays, MRIs</li> <li>– Treatment i.e. administering of infusion therapies</li> </ul> </li> </ul>

Sources: (a) KPMG interviews with HCPs treating RA and associated comorbidities

# The team

## Core team profiles

- 10 rheumatologists
- 4 rheumatology nurses
- 2 rheumatology researchers
- 1 service coordinator
- 1 physiotherapist
- 1 occupational therapist

## Affiliate team profiles

- Psychiatrist
  - Neurologist
  - Dietician
  - Endocrinologist
- 
- Central PCP (can be private or hospital-based) and coordinates referral to the following specialists:
    - Cardiologist (via PCP)
    - Orthopaedic surgeon (via PCP)



## Key features of the care delivery team

- **Highly educated rheumatologists** who have spent roughly 8-10 years in postgraduate training prior to full specialization
- **Highest density of rheumatologists in Europe** reside in Geneva <sup>(a)</sup>
- **Highly personable HCPs** who are open to ad hoc and out-of-hours patient contact, with a clear emphasis on the importance of accessibility to care advice for patients

## Governance and processes

### Team meetings:

- 2-3 weekly team meetings (include case study discussions, journal clubs and radiology meetings)
- Monthly meetings with private community rheumatologists (CME, 2 case presentations, 1 guest speaker)
- Bi-annual half day meeting with private rheumatologists and PCPs (CME)

### Protocols:

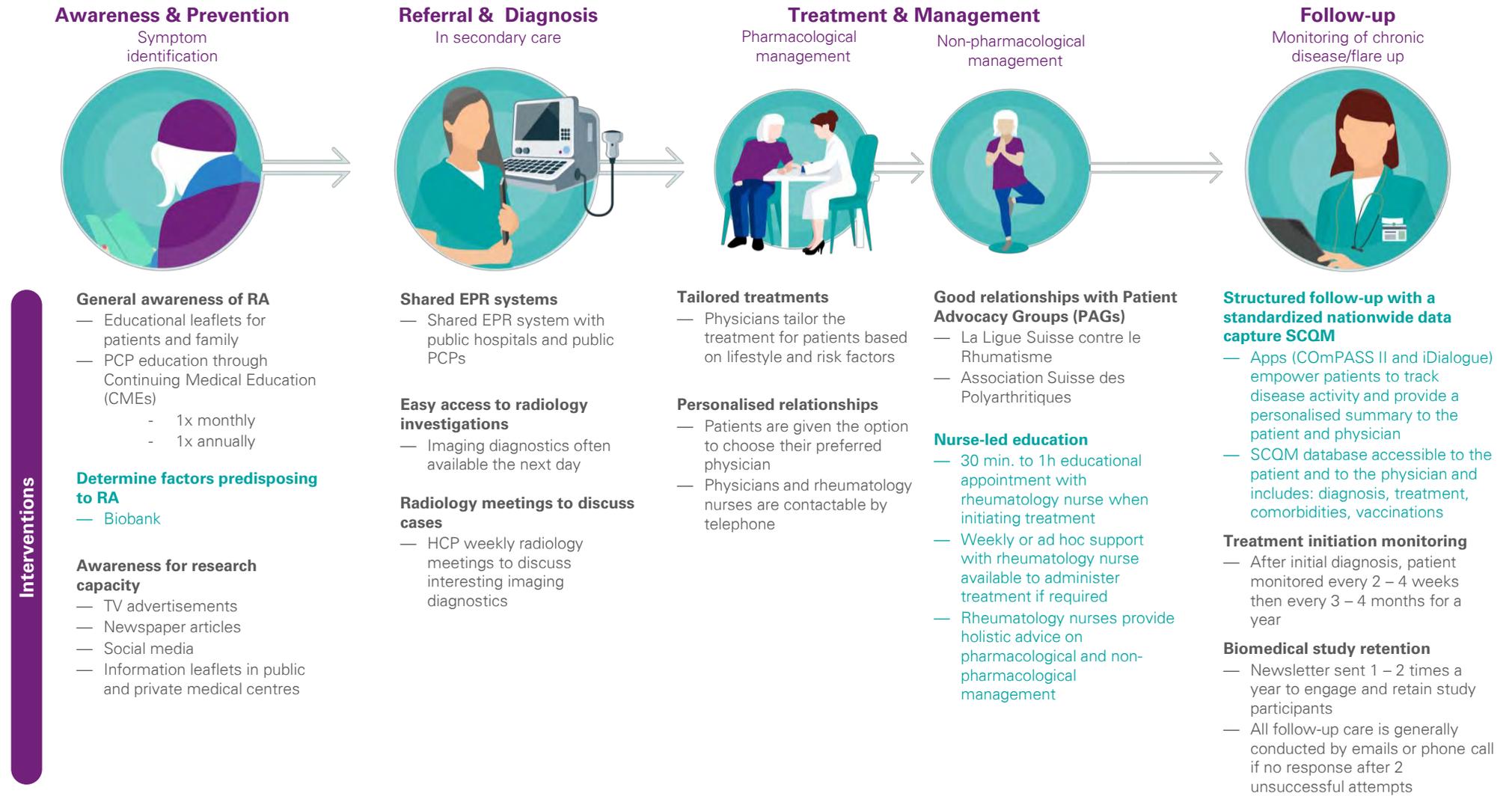
- Société suisse de Rhumatologie (Swiss Rheumatology Society) – national Swiss guidelines <sup>(b)</sup>
- No centre-specific guidelines in use

### Patient records:

- EPR in use across the University Hospital
- Swiss Clinical Quality Management (SCQM)

Sources: (a) KPMG interviews with HCPs treating RA and associated comorbidities (b) <http://www.chu-rouen.fr/page/publisher/societe-suisse-de-rhumatologie--societe-suisse-de-medecine-physique-et-readaptation>

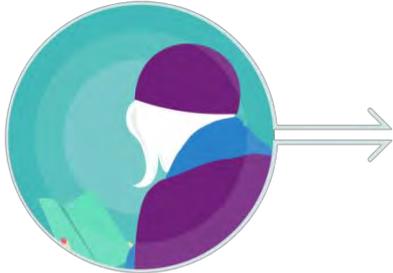
# Overview of interventions in place for RA



# Overview of interventions in place for RA comorbidities

## Awareness & Prevention

Symptom identification



## Referral & Diagnosis

In secondary care



## Treatment & Management

Pharmacological management

Non-pharmacological management



## Follow-up

Monitoring of chronic disease/flare up



Interventions

### Screening

- Physician refers to EULAR comorbidity check-list
- Physician conducts annual check up where they screen for lipids, blood pressure, depression and record all information in SCQM

### Prevention

- Physician prevents infections via vaccination injections at the centre: yearly for influenza vaccination and ad hoc for other vaccinations

### PCP as central point of contact

- Strong communication and collaboration with PCPs for comorbidity diagnosis and referral, in particular for orthopaedics and cardiology
- Specific criteria for communicating desired management plan

### Strong links with University Hospital specialists

- Strong links with University Hospital specialists and easy referral mechanisms for:
  - Psychiatrists
  - Neurologists
  - Physiotherapists
  - Occupational therapists
  - Dietician/Endocrinologist

### Knowledge sharing

- Ad hoc attendance to interstitial lung disease and systemic disease MDTs at the University Hospital
- Rheumatologists share information

### Radiological guidance

- Ultrasound guided injections for joint pain
- Ultrasound guided assessment of disease activity to aid treatment tapering

### Lifestyle advice

- Refer to specialty hospital services for Lifestyle factors:
  - Smoking cessation
  - Endocrinologist
  - Physiotherapist if needed

### RA OP consultation

- Check PCP has actioned items comorbidities and re-check comorbidity risk factors
- rheumatologists carries out preventive procedures at each check-up and re-screen

### Structured follow-up with a standardized nationwide data capture SCQM

- SCQM database accessible to the patient and to the physician and includes: diagnosis, treatment, comorbidities and vaccinations.
- Comorbidities and comorbidity risk factors can be monitored and tracked at each visit

Sources: (a) KPMG interviews with HCPs treating RA and associated comorbidities

# These interventions have improved outcomes



How do you quantify the benefits in RA?

**Objective measures (KPIs):**

- DAS 28
- Radiological imaging: Echography

**PROMs:**

- HAQ-DI questionnaire
- Pain VAS

**Centre routinely measures comorbidity outcomes by: <sup>(b)</sup>**

- Objective measures:
  - Clinical data, lab, medication, adverse event report, radiological disease progression via X-ray, ultrasound (echography) scan data (optional), biosamples (optional)

**PROMs:**

- HAQ, SF12, EuroQoL, Socioeconomic questionnaire



How have these interventions improved patient outcomes?

**RA**

- Benefit: greater patient engagement and reduced dropout rate, increased awareness of RA in the wider community
- Quantitative output: high uptake rate of first degree family members to the Biobank study<sup>(a)</sup>

**Comorbidities**

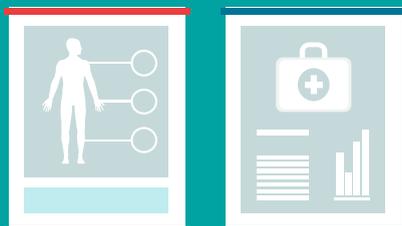
- Benefit: better management of metabolic diseases in particular<sup>(a)</sup>
- Quantitative output: higher rate of early diagnosis of comorbidities<sup>(a)</sup>

**“Patients are more invested in their care”**

- Rheumatologist

Sources: (a) KPMG interviews with HCPs treating RA and associated comorbidities (b) <https://www.scqm.ch/en/aerzte/scqm-datenbank/>

# How can care be improved?



## How can care be improved?

**Overview:** More education for PCPs on RA comorbidity management e.g. key examination techniques and checking for red-flags

- **Why?** To enable early and more frequent detection of RA associated comorbidities and to identify disease progression
- **How?** Repeated engagement with community physicians through CME meetings and through correspondence

## What is next for the centre?

**Overview:** Consultation times will be shortened to 20 minutes

- **Why?** This is due to the legislation imposed by the Swiss Federal Office for Public Health (Office fédéral de la santé publique – OFSP) according to TARMED (tarifs des médecins) <sup>(b)</sup>
- **How?** The centre have not yet devised an implementation plan for this legislative change and will address this throughout the course of the year



## What advice would you give less specialised centres?

**Overview of advice:** Having standardised patient records and unified communication systems between HCPs is vital

- **Why?** To minimize gaps in care and to lessen the administrative burden of duplicative tasks
- **How?** Through the use of EPR systems and accessible patient databases e.g. SCQM

**Sources:** (a) KPMG interviews with HCPs treating RA and associated comorbidities; (b) <https://www.bag.admin.ch/bag/fr/home/aktuell/news/news-09-01-20182.html>

# Case studies

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# Case study 1

## Swiss Clinical Quality management in Rheumatic Diseases (SCQM)

### Overview

- The SCQM foundation operates a medical registry for inflammatory rheumatic diseases. It is in use across public and private primary, secondary and tertiary healthcare settings, simultaneously operating as a research platform for long-term studies. Data on the following diseases are collected in the SCQM register throughout Switzerland:
  - Rheumatoid arthritis
  - Spondyloarthritis
  - Psoriatic arthritis <sup>(a)</sup>

**Note:** 1. For further details on Biobank, please see case study 2, 'Biobank'  
**Sources:** (a) <https://www.scqm.ch>; (b) KPMG interviews with HCPs treating RA and associated comorbidities

### What is the rationale?



- To support the rheumatologist in the quality management of the treatment of rheumatological disease<sup>(a)</sup>
- To enable longitudinal tracking and monitoring of disease and improve RA care through research<sup>(b)</sup>

### What are the key features of the intervention?



#### SCQM

- SCQM can be accessed in all healthcare settings throughout Switzerland
- In practice, it is used more in secondary and tertiary care where there is less time pressure with consultations<sup>(b)</sup>
- Geneva University Hospitals (HUG) are a key proponent in the use of SCQM within their consultations
- ~80% of the rheumatology patient population at HUG have their data captured in the register
- ~50% of all patients with data in the register are followed up by community rheumatology practitioners
- There are 2 apps available for both patients and HCPs to use (*COMPASS II* and *iDailog*) which feed data into the database

#### Biobank

- The establishment of SCQM has enabled the formation of a parallel study called Biobank which is currently ongoing
- Biobank is a study which aims to determine the usefulness of blood markers, genetic and environmental factors to predict the risk of developing RA<sup>1</sup>

### What are the key features of the intervention?



**Frequency** The 'best-practice' expectation is that the register is filled in at every visit, however at a minimum data is captured from every patient with RA at least once a year

**Timings** Takes 45 minutes – 1 hour to complete

**No. of participants:** ~80% of all rheumatology patients have their data captured in the register

#### Staff members involved

**Members of the core MDT** Rheumatologists

**Other Practitioners** Community rheumatologists

#### Data captured

- Presenting complaint
  - Diagnosis
- Past medical history and social history
  - Comorbidity screening questionnaire
  - Quality of life questionnaire
- Medication history
  - Current therapy regimen
  - Any medication changes and the reason for changes (e.g. side effects)
- Infection history
  - Any previous infections and vaccination history
- Family history
  - Any first degree family members who are willing to partake in the subsidiary Biobank study<sup>1</sup>

## Swiss Clinical Quality management in Rheumatic Diseases (SCQM) (cont.)

### What are the outcomes so far?



#### Standardised reporting across healthcare settings

- Data captured on RA and comorbidities can be accessed by both community and hospital practitioners

#### Ongoing research studies

- SCQM has enabled multiple research studies using the data captured. In particular, patients have been identified for genetic testing along with their first degree family members<sup>1</sup>
- The use of both apps has also enabled two more studies, one looking at patient outcomes where both the patient and the HCP can see the input date, and the other where the HCP is blinded

COmPASS II	iDialog monthly
Recording disease activity by means of Rapid 3	Recording disease activity by - RADA1 (with RA)
Compliance	DMARDS compliance
Steroid intake (mg/day/last 7 days)	Steroid intake (mg/day/last 7 days)
Effect of the weather (Recording the postcode of the patient's whereabouts)	NSAR intake (brand, dosage, interval)
Work incapacity	Data collecting frequency: 1 per month with reminder
Data collecting frequency: 1 per week with reminder	

Features of the Apps used with SCQM: COmPASS II and iDialog

**Note:** 1. For further details on Biobank, please see case study 2

**Sources:** (a) KPMG interviews with HCPs treating RA and associated comorbidities



### Benefits



- SCQM ensures comorbidities are screened for and “not forgotten”, leading to timely and effective detection of comorbidities
- It is accessible by all HCPs involved in RA care and ensures effective sharing of patient records when used in all healthcare settings
- It serves as a patient database which can be used in current and future RA research projects

### Challenges



- Retention is a challenge whereby some patients have started to use the apps and have not maintained usage, reporting that they find consistent monitoring difficult as it is a constant reminder of the disease and its effects
- Community practitioners use the SCQM register far less than hospital practitioners due to the remuneration and time constraints in private practice; they are not always reimbursed for the extra time taken to fill in the register. In practice, hospital rheumatologists will often take the extra time to enter patient data into SCQM each time they encounter a predominantly private patient



The aim is to have all rheumatology patients on the database and then this will help to unify care records

– Rheumatologist



# Case study 2

## A project on family members of patients with RA called "Arthritis Checkup" using *Biobank*

### Overview

- Biobank is a longitudinal cohort study which originated as an offshoot of the SCQM register in 2011
- Blood samples are taken from patients with RA and their first degree family members for the analysis of serological blood markers and DNA in order to assess for predisposing factors to RA
- Patients and relatives are then tracked and monitored within Biobank for 5 years

Sources: (a) KPMG interviews with HCPs treating RA and associated comorbidities

### What is the rationale?



- To determine the usefulness of blood markers and genetic and environmental factors to predict the risk of developing RA
- The goal is to enable early diagnosis and treatment of RA

### What are the key features of the intervention?



<b>Frequency</b>	Ongoing through ad hoc referrals of patients with RA on the SCQM register and their first-degree relatives
<b>Timings</b>	Blood samples are taken and a monitoring questionnaire is filled in annually for high risk patients. Blood samples are taken once every 5 years for low risk patients
<b>Location</b>	It is conducted throughout a research network of 3 RA centres in Switzerland which have a secure transportation system for frozen samples. The laboratory at HUG is the main centre for analysis
<b>Participants</b>	Patients with RA and their first degree family members
<b>Staff members involved</b>	
<b>Members of the core MDT</b>	Research nurses rheumatologists
<b>Other practitioners</b>	Laboratory technicians

### What are the key features of the intervention?



#### Recruitment

- Enquiring at each outpatient consultation. Patients with RA are asked if they have any first degree family members who would be willing to partake in the study
- Dissemination of leaflets in RA centres throughout Geneva
- Advertisement on TV and in local newspapers
- Use of social media via the 'Arthritis Checkup' Facebook page

#### Visit

- Information video and documents
- Questionnaire
  - This is filled in at the initial visit and annually thereafter. It is used to assess medical and lifestyle factors
  - Outputs from the questionnaire, together with blood markers, help to identify patients as high risk or low risk

High risk patients  
~20%

Annual monitoring questionnaire requested via email with telephone chaser if no response

- Annual check up
- Blood test
- DAS28
- Radiological investigations

Low risk patients  
~80%

Annual monitoring questionnaire requested via email

- Five yearly check up
- Blood test
- DAS28
- Radiological investigations

#### Retention

- A newsletter is sent out annually with the latest findings and publications. This is done in order
- to keep patients engaged with the study

## "Arthritis Checkup" using Biobank (cont.)

What are the outcomes so far?



### Early identification of RA

- There have been instances of early diagnosis and referral to a rheumatologist

### Reporting of findings in CME meetings with community rheumatologists

- Rheumatologists involved in Biobank at HUG present their findings at local CME meetings with community practitioners

Benefits



- Patients are more involved in their care by participating in this study
- The involvement of first degree relatives means there is increased awareness amongst family members of RA
- This study has encouraged screening and early diagnosis of RA

Sources: (a) KPMG interviews with HCPs treating RA and associated comorbidities

Challenges



- Recruitment can sometimes be difficult as the process relies on patients asking their family members
- Loss to follow-up is an issue, and often only comes to light when the annual check-ups are due

“

Biobank will allow more personalised care, tailored to patients' individual biological patterns which should have a positive impact on Quality of Life

- Nurse

”



“

What's exciting is that the future of RA care will be founded on this research

- Nurse

”



# Case study 3

## Nurse-led education

### Overview

- The rheumatology nurses provide one-to-one educational support to the patient to:
  - Ensure understanding of disease and prescribed treatment
  - Ensure awareness of comorbidities and the impact on overall health
  - Empower patients to self-administer treatments at home
  - Answer and alleviate any questions or concerns concerning RA care, overall health, lifestyle and quality of life
- The rheumatology nurses tailor their educational training to each patient depending on the patient's prescribed treatment, lifestyle and cultural beliefs
- Rheumatology nurses develop a trusted relationship with patients, providing clinical, social and moral support whenever it is needed

Sources: (a) KPMG interviews with HCPs treating RA and associated comorbidities

### What is the rationale?



- The rheumatology nurse educational patient training is intended to help a person diagnosed with RA to acquire or maintain the knowledge and skills required to either manage their own care, or be know how to seek support to administer treatment
- The goal of the education is to facilitate understanding and to empower the patients to adhere to treatment, autonomously if possible and desired

### What are the key features of the intervention?



<b>Frequency</b>	Ad hoc – some patients see the rheumatology nurses once a week, others every 3 to 4 weeks depending on their personal preference and on the requirements of their condition
<b>Timings/Duration</b>	30 minutes – 1 hour per consultation
<b>Staff members involved</b>	3 rheumatology nurses
<b>Type of consultation</b>	Individual sessions are provided by one rheumatology nurse in a face-to-face meeting. Sessions take place in a room where patients can be seen with their family members. Follow-up questions / concerns are answered by the rheumatology nurse via telephone if required

### What are the activities undertaken?



Nurse-led education is carried out when a new RA treatment is prescribed by a rheumatologist for 30 minutes to 1 hour. This is followed by ad hoc education as and when it is requested by the patient

### Topics covered

- Knowledge of the disease
- Pharmacological and non-pharmacological treatments and adherence
- Pain management and management of flares
- How to seek support and discuss the disease with family and friends
- Quality of life, particularly the impact on personal and professional life
- Leisure time and hobbies
- Day-to-day life

### Outputs

- The rheumatology nurse will provide the patient with information booklets and other support materials to the patient following the educational training

## Nurse-led education (cont.)

### What are the outcomes so far?



- Patients are well educated on their RA care, including the implications of their condition, how to administer treatment, and which comorbidities to follow-up with their PCPs
- Patients have a strong support network within the centre and have a strong relationship with the nurses

### Benefits



#### Benefits to patients

- Trusted communication channel where patients are more comfortable discussing questions or concerns than in their check-up with the physician

#### Benefits to the Rheumatology team

- Improved patient acceptance of condition
- Improved understanding of patient circumstances for the entire RA care team
- Improved patient retention in care
- Improved patient adherence to treatment

### Challenges



- Administrative burden of care means that rheumatology nurses are spending less time with patients than before
- Personnel capacity constraints means that rheumatology nurses often have limited availability and time to spend with the patients. However the strong support network amongst the nurses in the rheumatology clinic allows them to balance their administrative workload amongst each other so that patients always come first

### Tips to replicate this intervention



- Establish dedicated rheumatology nurses with clear roles and responsibility to educate the patient on the requirements of their condition and act as a support network
- Ensure rheumatology nurses are aware of the right language to facilitate trust with the patients to build and encourage a positive supporting environment
- Ensure rheumatology nurses and rheumatologists have good levels of communication to share learnings on patients' quality of life
- Training provided to rheumatology nurses regarding patient education



We are a listening ear for the patients and have a very close relationship with them, we don't only talk about their medical treatment. We also listen to all aspects of their lives, from daily troubles to children and grandchildren – we try to be there for them in any way that we can

- Rheumatology nurse



Sources: (a) KPMG interviews with HCPs treating RA and associated comorbidities





# Leeds Teaching Hospitals

Leeds, United Kingdom



# Summary



## Context

- **Innovative centre**  
Chapel Allerton Hospital is driven by the goal to continually improve patient outcomes. The team are committed to innovation in their service provision model. This is with the aim of providing a service which is dynamic and responsive and maintains a patient focus
- **Shared expertise**  
All team members share the care of patients and are equally as open to sharing their expertise through case discussion. This is done informally on a daily basis as well as through regular formalised meetings
- **‘One city, one Trust’**  
The centre provides a breadth and variety of rheumatological expertise borne of the fact that it operates within a singular Trust (an organisational unit providing healthcare) serving the local population of Leeds and greater Yorkshire (5.4 million people). This is a rarity, given that cities of a similar scale in the UK often have more than one operational NHS Trust, resulting in many other centres specialising in fewer subspecialties
- **Strong teaching ethic**  
The centre provides region-wide teaching based centrally at the unit, catering to HCPs throughout the locality. There is also a focus on regular internal teaching as well as on patient education



## Key strengths in the delivery of RA care

- The centre is skilled at **translating research into clinical practice**. Awareness is raised among staff and patients e.g. through the placement of research synopsis posters in outpatient clinics to encourage in-consultation referrals to ongoing research programmes. The interweaving of research and clinical practice is fundamental as one improves the other
- **Early diagnosis** is “woven into the DNA” of the centre and is part of the “raison d’être” of the rheumatology unit. Professor Paul Emery, one of the leading clinicians at the centre, was a pioneer of early and aggressive intervention in RA treatment, improving patient outcomes nationally
- There is a **remission service** in place at the centre, underpinned by ongoing research evaluation
- **Rapid access to radiological imaging** is a key feature of the centre’s services. The unit employs ultrasound as a useful adjunct in clinic consultations to address the limitations of clinical examination
- **Good workforce balance** of medical expertise and nursing and wider AHP expertise, especially with the embedment of clinical nurse specialists (CNSs). The centre employs the treat-to-target (T2T) guidelines which lends itself well to providing a nurse-delivered service; but with clinical oversight to tailor to individual patients appropriately



## Key challenges faced in delivery of RA care

- There is a **lack of clarity as to how newer drugs fit in to the care pathway** and whether or not the pool of access should be widened to accommodate them. Given the fact that the cheapest option is not always the best option for patients, there is a need to exercise clinical judgement, autonomy and ethics in these decisions
- The health technology assessment (HTA) body NICE<sup>1</sup> has recently published **guidance which has taken a prescriptive stance** on biologics and ultrasound use in the management of RA. As a result, HCPs feel that there is a limited remit for exercising clinical acumen on a case-by-case basis
- There is **constrained capacity of HCPs to provide patient care**. There has been a 6-7% increase of referrals year on year to rheumatology departments in the UK, without a matching increase in the level of medical or CNS resource

**Notes:** 1. National Institute for Health and Clinical Excellence. 2. For example, NICE guidance indicates a maximum of 3 biologics per Trust for the treatment of RA, and in an agreed sequence. However, due to settlements with CCGs, the centre is able to use 4 in any order so long as there is clinical justification for doing so

**Sources:** (a) KPMG interviews with HCPs treating RA and associated comorbidities

# RA in the United Kingdom: Healthcare system overview



## RA challenges in the UK healthcare system:

- Recent NICE guidelines on RA management explicitly advise against the use of ultrasound in routine monitoring of RA.<sup>(a)</sup> This has made it difficult for clinicians to justify its use in the management and monitoring of disease activity, even when they see clinical value in doing so
- Typically three months or more pass between a person first experiencing symptoms and obtaining a correct diagnosis of RA<sup>1(b)</sup>
- An audit conducted by the British Society of Rheumatology (BSR), published in 2016 showed that 45% of patients had severe disease at presentation<sup>2</sup>, reflecting late detection of RA<sup>(c)</sup>

## UK healthcare system overview:



### Publicly funded universal healthcare:

- The National Health Service (NHS), operates under the principles of universality, free at the point of delivery, equity, and paid for by central funding from taxpayers
- Healthcare and health policy for England is the responsibility of the central government, whereas in Scotland, Wales and Northern Ireland it is the responsibility of the respective devolved governments
- In each of the UK's devolved countries, the NHS has its own distinct structure and organisation. However, overall it comprises of two broad sections;
  1. one dealing with strategy, policy and management
  2. the other dealing with medical/clinical care which is in turn divided into:
    - Primary care (community care, GPs, dentists, pharmacists etc.),
    - Secondary care (hospital-based care accessed through GP referral) and;
    - Tertiary care (regional specialist hospitals)
- The Health and Social Care Act (2012) came into effect in April 2013, giving GP-led clinical commissioning groups (formerly Primary Care Trusts (PCTs)) responsibility for commissioning most local non-GP NHS services<sup>(e)</sup>
- In England, NHS England commissions GP services for the country - this split in funding between NHS England and CCGs can act as a barrier to more integrated local working

## Rheumatoid Arthritis in the UK:



### Patients:

- Prevalence: 0.83% <sup>(f)</sup>
- The overall occurrence of RA is two to four times greater in women than in men <sup>(g)</sup>

### Physicians:

- 572 rheumatologists (consultants) & 277 training rheumatologists (registrars) in the UK <sup>(h)</sup>

### Guidelines:

- RA: Rheumatoid arthritis in adults: management. NICE guideline [NG100] & EULAR recommendations on the management of RA
- Comorbidities: National Rheumatoid Arthritis Society Osteoporosis Quality Standard [QS149] & EULAR recommendations for cardiovascular disease risk management in patients with rheumatoid arthritis and other forms of inflammatory joint disorders: 2015/2016 update

### PAGs / Medical societies

- British Society for Rheumatology (BSR)
- National Rheumatoid Arthritis Society (NRAS)
- Versus Arthritis (formerly Arthritis Research UK merged with Arthritis Care Research)

**Notes:** 1. Patients perceive the main bottlenecks to be: the GP; waiting times to see a rheumatologist; complexities associated with RA and its diagnosis; difficulties accessing diagnostic tests; and inadequate referral criteria for GPs from primary to secondary care. 2. For those with available data  
**Sources:** (a) Rheumatoid arthritis in adults: management. NICE guideline [NG100] Published date: July 2018 (b) Patient View (2009. Patient Groups on Rheumatoid Arthritis and the NHS. A national survey of patient organisations and other health campaigners. (c) British Society for Rheumatology. National Clinical Audit for Rheumatoid and Early Inflammatory Arthritis 2nd Annual Report 2016 (d) Grosios K, Gahan PB, Burbidge J. Overview of healthcare in the UK. The EPMA Journal. 2010;1(4):529-534 (e) <https://www.bbc.com/news/health-19674838> (f) <https://www.arthritisresearchuk.org/arthritis-information/data-and-statistics/musculoskeletal-calculator.aspx> (g) <https://patient.info/doctor/rheumatoid-arthritis-pro> (h) <https://www.healthcareers.nhs.uk/explore-roles/doctors/roles-doctors/medicine/rheumatology>

# The Rheumatology unit



The rheumatology unit is based at Chapel Allerton Hospital, part of Leeds Teaching Hospitals NHS Trust. The hospital hosts several departments, that have a worldwide reputation for being leaders in their fields for specialist patient care and cutting-edge research. It serves as an elective centre for patients from Leeds and the wider Yorkshire region



Chapel Allerton Hospital			
<b>Type</b>	— Elective specialist centre (as part of a multi-site tertiary centre)	<b>Locations</b>	— Services based at Chapel Allerton Hospital are also offered across two other acute sites: Leeds General Infirmary and St James's Hospital, and an additional modest elective site, Wharfedale Hospital
<b>Core services</b>	— Clinical genetics, dermatology, Leeds musculoskeletal centre (plastic and reconstructive surgery, trauma and orthopaedics and rheumatology), outpatients, pathology, pharmacy services, — Physiotherapy, ultrasound, x-ray, Leeds biomedical research centre, neuro-rehabilitation	<b>Population served</b>	— Serves a population of 5.4m people and treat 1.5m patients annually — Last year the centre provided care for over 20,000 inpatients and over 111,000 outpatients
<b>Size</b>	— 132 inpatient beds	<b>Demographics</b>	— Wide age range, socio-economic; predominant caucasian



The Rheumatology unit			
<b>Services</b>	— Inpatient service, outpatient service, ambulatory / day case service, associated specialist physiotherapy and occupational therapy services — The unit has been EULAR centre of excellence in Rheumatology since 2005 — The service is centrally based at Chapel Allerton Hospital but provides care across the Trust and includes some inpatient facilities at St James's University Hospital <sup>1</sup>	<b>Collaborations</b>	— Strong collaborative links between the Leeds Teaching Hospitals NHS Trust (LTHT) and University of Leeds — The centre hosts infrastructure for the National Institute for Health Research (NIHR) with a particular focus on industrial partnerships. Partners include large Pharma, small-medium enterprises (SMEs) and contract research organisations (CROs)
<b>Funding and Resources</b>	— Leeds Teaching Hospitals NHS Trust — Research grants and associated clinical research activity	<b>Teaching/ research scope</b>	— Leeds Institute of Rheumatic & Musculoskeletal Medicine (LIRMM), University of Leeds, and the NIHR Leeds Biomedical Research Centre, Leeds Teaching Hospitals NHS Trust deliver world class research — In 2017/2018, the centre was the second highest recruiting NHS Trust in the UK for clinical research

**Notes:** 1. The majority of services are directly bookable via the Choose and Book system to ensure rapid access to care  
**Sources:** (a) <http://www.leedsth.nhs.uk/patients-visitors/our-hospitals/chapel-allerton-hospital/> (b) <http://www.leedsth.nhs.uk/research/>



# The Rheumatology unit (cont.)



## Overview of Services

Service Division	Outpatient service	Ambulatory care service	Inpatient service
<b>Duration of stay</b>	20-minute appointments with rheumatologist 30-minute appointments with CNS	Dependent on therapy being given	Variable
<b>Hours of availability</b>	09:00 – 17:00	09:00 – 17:00	24/7
<b>Capacity (no. of beds/rooms)</b>	Located across 3 sites: Chapel Allerton Hospital, Leeds General Infirmary, St. James' Hospital and Wharfedale Hospital	12	12
<b>No. of patients seen</b>	Centre caters to ~30,000 Rheumatology patients	2,000-3,000 patients receive biologic therapy	~ 3-4 patients/week under rheumatology care; additional consults provided
<b>Patient type catered to</b>	All RA patients	Patients with moderate-severe RA	Patients with RA flares requiring urgent investigation and hospitalisation
<b>Services offered</b>	<ul style="list-style-type: none"> <li>— Blood tests (on-site wet labs for investigation analysis)</li> <li>— Dedicated diagnostic suite including MRI and ultrasound</li> <li>— Outpatient rheumatologist / CNS review</li> <li>— Outpatient therapies services</li> </ul>	<ul style="list-style-type: none"> <li>— Biologics administration</li> <li>— Blood tests (on-site wet labs for investigation analysis)</li> </ul>	<ul style="list-style-type: none"> <li>— Blood tests (on-site wet labs for investigation analysis)</li> <li>— Daily inpatient rheumatology review</li> <li>— Rapid neurology or dermatology comorbidity review (usually within 24 hours)</li> <li>— Inpatient therapies services</li> </ul>

Sources: (a) KPMG interviews with HCPs treating RA and associated comorbidities

# The team

## Core team profiles

- 20 rheumatologists
- 10.5 clinical nurse specialists
- 8 - 9 research nurses
- > 80 rheumatology researchers/academics
- 5 pharmacists
- 1 service coordinator
- physiotherapists
- occupational therapists
- 22 orthopedic surgeons
- 6 podiatrists
- dieticians

## Affiliate team profiles

- cardiologist
- endocrinologist / diabetologist
- ophthalmology
- psychologist
- pulmonologist
- renal



## Key features of the care delivery team

### Specialist care

- As the only Rheumatology centre for a population of 5.4 million people, the centre has evolved to cater to multiple rheumatological subspecialties

### Integrated multidisciplinary working

- There is a strong multidisciplinary presence within the team with a strong spread of physicians, CNSs, pharmacists, physical and occupational therapists as well as close links with comorbidity specialists

### Standardisation of care

- Patient volumes mean that patients will have touchpoints with multiple members of staff at different times when in contact with the centre. To ensure that care is delivered at a high level and with consistency, the team proactively coordinates services through team meetings and education sessions

## Governance and processes

### Team meetings:

- 4-6 weekly working group meetings for operational management issues
- Monthly biologics MDT

### Protocols:

- Follow NICE guidance for RA management

### Patient records:

- Trust-wide patient pathway manager (PPM) system
- Electronic prescribing system

### Pharmacy:

- Provide protocol for any investigational or non-investigational medicinal products, as well as the funding strategy and exit strategy for medication use in research programmes
- Electronic prescribing system

Sources: (a) KPMG interviews with HCPs treating RA and associated comorbidities

# Overview of interventions in place for RA

## Awareness & Prevention

Symptom identification



## Referral, Diagnosis & Treatment initiation

In secondary care



## Treatment and Management

Medical management



### 'Pre-RA' research clinic

- Caters to patients who have clinically suspicious RA<sup>1</sup> but do not fulfil RA diagnosis criteria
- Patients are closely monitored for signs of disease manifestation as well as some participating in interventional treatment studies

### Communications with primary care physicians

- Referral criteria and informal education communications are sent to GPs when new services are set up to provide understanding of how services will operate. These may also be supplemented by periodic refresher notices

### Region-wide training and education

- Weekly region-wide education meetings are held at the centre for training rheumatologists; open to all MDT members
- Education is provided to patients and rheumatology nurses, co-ordinated by the lead educational nurse

### Patient and Public Involvement (PPI) group

- Working group consisting of patients and lead HCPs with the aim of co-ordinating patient-HCP communication media (e.g. telephone, email and social media) and actioning feedback points

### Early arthritis clinic

- Caters to patients <12 months from first symptom recognition. Data from the clinic feeds into research
- Patients are followed up for approximately 18 months after which their care can be transferred to the general rheumatology clinic or targeted therapy clinic

### Integrated use of ultrasound

- Ultrasound is used regularly in clinic for diagnosis and the monitoring of disease progression
- This is a useful tool to confirm RA and/or rule out borderline cases
- Ultrasound is made available in most clinics, with 4/15 rheumatologists trained to perform scans

### Expanded role of the Clinical Nurse Specialist (CNS)

- CNSs see patients following diagnosis, deliver outpatient review clinics and nurse-led day care services, co-ordinate the management of community medication prescriptions and support research studies

### On-site wet labs

- On-site laboratories for analysis of biochemical and immunological investigations to aid rapid RA diagnosis

### Targeted therapy clinic

- Patients receiving biologic therapy are reviewed in six-monthly clinics which alternate between CNS review and rheumatologist review

### Weekly radiology meetings

- Rheumatologists meet with a radiologist once a week to discuss imaging from interesting or complex cases

### Weekly informal biologics meeting

- Informal weekly lunchtime meetings to identify cases for discussion

### Monthly Biologics MDT meeting

- Monthly 'targeted therapeutics-RA' meetings; attended by CNSs, clinical and research nurses, pharmacists, lead clinicians and rheumatologists
- Topics discussed include challenging biologic patient cases, requests for funding and updates on policies and protocols

### Integrated with research by dedicated research team

- Research studies provide a significant part of medical treatment alongside standard of care
- There is a dedicated team of nurses who manage and coordinate research studies, and take ownership of care delivery to patients in interventional studies. They are the main point of contact for research patients, providing a 'bespoke service'

# Overview of interventions in place for RA

## Treatment and Management

Non-medical  
management



## Medical care & Follow-up

Monitoring of chronic disease /  
flare up



### Physiotherapy services

- Inpatient and outpatient physiotherapy (PT) services are provided to RA patients referred from rheumatologists and CNSs
- Patients are seen for RA-specific mobility issues as well as non-RA 'mechanical flares' i.e. when something other than their RA is impacting mobility or their physical ability to cope with the disease

### Occupational therapy services

- Inpatient and outpatient occupational therapy (OT) services are provided to all patients who are identified as requiring support
- Appointments last 1 hour and often emotional support is provided in addition to traditional OT services

### Podiatry service

- A podiatry team within the unit provides clinical care to patients with foot manifestations of RA
- Three of the team are qualified in independent prescribing
- Also involved in research with several clinical academic fellows

### Nurse-led patient education

- Education is provided to patients by the CNS following diagnosis
- Biologics CNSs provide patient education on the risks and benefits of biologic therapy
- Research nurses and general RA CNSs also provide education to patient focus groups once monthly (successfully piloted recently)

### Heavy emphasis on patient self-management

- CNS and other therapy services work with patients, advocating and encouraging patient self-management

### Remission clinic

- A clinic started through research to monitor patients in remission receiving dose tapering according to guidelines developed at the centre
- This has now been transferred into clinical practice as a pilot study and is offered as part of the NHS service at the centre
- Patients are followed-up every three months

### Protected emergency slots in general RA clinic

- Up to six slots are protected in each of the rheumatologist-supervised / nurse-led clinics for last-minute appointments for non-research patients

### Tailored patient review appointments

- General RA patients with stable disease are given a 'waiting list' review appointment, whereby they can schedule one follow-up appointment within a time frame of 18 months in order to suit their disease progression and management needs, rather than within a pre-prescribed timeframe

### Multi-site outpatient services

- Outpatient services are provided across three sites in the region to widen accessibility to different patient geographies and mobility needs

### Integrated electronic record keeping systems

- The department uses the Trust-wide patient pathway manager (PPM) system
- In addition, an electronic prescribing system with integrated scheduling and patient records has recently been integrated to co-ordinate the use of biologics

### Patient advice line

- Patients are able to call an advice line messaging service for non-urgent advice (e.g. regarding flares, emergent symptoms or non-life threatening treatment side effects)
- Details are entered into a database and patients will receive a response within approximately 48 hours

### Electronic patient feedback

- In addition to the 'Friends and Family Test', (which asks patients about the good and bad aspects of their care and whether they would recommend the service) patients are able to provide feedback on their care via email and text message

### Research studies

- Observational and interventional research studies are coordinated so that research patients are monitored closely with more HCP touchpoints than NHS patients
- They are given care by both clinical and research practitioners

### Research cohort 'Flare Care' line

- Patients participating in the remission and dose-tapering study are able to call a dedicated line, manned by the trials assistant, in the event of a flare
- Arrangements can be made for flare patients to be seen in one of the protected 'flare slot' appointments in the remission clinic

### Podiatry hotline

- Telephone service for general RA patients to access if they have foot health concerns

# Overview of interventions in place for RA comorbidities

## Awareness & Prevention

Symptom identification



## Referral, Diagnosis & Treatment initiation

In secondary care



## Treatment and Management

Medical management



### Comorbidity screening at annual review clinic

- Risk factors for comorbidities including CVD and osteoporosis (BMD measurements, FRAX-2 score) are routinely screened for at the annual review for patients with RA. Blood glucose monitoring may be done in patients with pre-existing diabetes
- Patients with a 5-year cardiovascular risk of >10% are referred back to their GP
- Patients with dental signs or symptoms will be referred for a dental check

### Rapid access to inpatient comorbidity review

- The inpatient rheumatology service shares a ward with both inpatient neurology and dermatology services. This allows for rapid referral and inpatient review (often the next day) if required

### Research links with dentists

- The centre has research links with a dental unit who perform gum checks on at-risk patients due to gum disease being an early indicator of RA

### Joint rheumatology-dermatology clinic

- This clinic occurs two to three times a week, catering to RA patients with dermatological comorbidities (e.g. Raynaud phenomenon, rheumatoid nodules, callouses and leg ulcers)

### Joint clinic with obstetric specialists

- There is a once-monthly regional rheumatology and obstetrics clinic which is hosted by a rheumatologist and an obstetrician for patients with RA who are pregnant

### Joint rheumatology-respiratory clinic

- There is a once-monthly clinic in which patients with RA and respiratory comorbidities e.g. interstitial lung disease (ILD) are seen

### Joint rheumatology-podiatry-diabetes clinic

- This clinic service has been provided since 2007 to address the need for podiatry care in patients with comorbid RA and diabetes

# Overview of interventions in place for RA comorbidities

## Treatment and Management

Non-medical management



## Medical care & Follow-up

Monitoring of chronic disease / flare up



### Nurse-led education

- Education is provided to patients and rheumatology nurses on lifestyle factors relating to CVD and diabetes, available emotional support and means of improving quality of life
- This service is co-ordinated by the lead educational nurse

### Annual review clinic

- Comorbidity risk factors are screened for and monitored annually. If continued comorbidity care is required, referrals are made to the GP or relevant comorbidity specialist

# These interventions have improved outcomes



How do you quantify the benefits in RA?

**Objective measures (KPIs):**

- DAS-28/components, CRP, ESR, remission rates

**PROs:**

- HAQ-DI, Pain-VAS

**Centre routinely measures comorbidity outcomes by:**

- Objective measures:
  - 5-year cardiovascular risk, FRAX-2 fragility score, BMD, PHQ-9

**Research PROs**

- RAQoL, HAD, RAND-36 QoL survey, pain, mood



How have these interventions improved patient outcomes?

**RA**

- Benefit: Patients are on optimal systemic therapy due to the clinical and research interventions in place
- Quantitative output: Improved DAS-28 scores for remission cohort patients

**Comorbidities**

- Close monitoring and comprehensive management of comorbidities through joint clinics

**“We stay ahead of the curve by starting research initiatives first”**  
- Rheumatologist

# How can care be improved?



## What is next for the centre?

### Overview: Annual review

#### — Why?

- The centre is in the process of developing an annual review process for all RA patients. Annual consultation will assess disease activity and medication as well as screen for commonly associated comorbidities such as osteoporosis and cardiovascular disease by assessing bone health and cardiovascular risk factors respectively

#### — How?

- This process is being overseen by the lead clinician and lead CNS to ensure coordination and provision of a comprehensive annual review
- With regards to interim management, consideration is being given to whether certain aspects of care could be managed in a primary care setting or virtually by the unit. The team are aware that there is still value in a rheumatological clinical examination and work to the overall aim of improving access to HCPs

### Overview: E-proforma

#### — Why?

- Due to large numbers of patients and service performance outcomes requirements from healthcare payers, the centre has to be able to demonstrate measurable improvements. They do this through the use of a paper-based biologics initiation form. This is a clinical document which captures prescribing and performance related data. Due to the volume of data collected and to improve efficiency and integration, this system is now being made electronic

#### — How?

- The Rheumatology department is working with their IT department to create an electronic input system, 'E-proforma' on their current trust-wide electronic patient record system, PPM. This system hosts the entire patient record including clinical correspondence, blood test and radiological investigation results. The aim is to add the capability of recording biologics data, disease activity (DAS-28) and comorbidity data, with graphical representation of reports and trends
- An electronic prescribing system with integrated scheduling and patient records has recently been integrated to co-ordinate the use of biologics. It is currently in use for biologic administration and links in with treatment dates and blood test results

### Overview: Greater budgetary control

#### — Why?

- Only 40% of patients achieve the T2T six-month remission target. NICE guidance advises that treatment can only be escalated to biologics in severe disease (DAS-28 > 5.1). In the past, based on this, CCGs required centres to adhere very strictly to this guidance with regards to provision of medications
- As a result, many patients with low but particularly moderate disease activity would not be eligible for biologic therapy and therefore may not achieve remission

#### — How?

- The budget for medications has previously been managed by the CCG, however in April 2018 this responsibility was given to the local CSU as a pilot
- This will allow the department to negotiate budgets and allowances with healthcare payers and could help the them to combat the problem of low remission rates

Sources: (a) KPMG interviews with HCPs treating RA and associated comorbidities

# How can care be improved?



## What is next for the centre? (cont.)

### Overview: Regional rheumatology network

#### — Why?

- The centre is creating a professional and clinical rheumatology network inclusive of district general hospitals (DGHs) and regional hospitals. This will allow sharing and standardisation of practices and thus minimisation of variations in care

#### — How?

- The Trust has now allocated dedicated funding to this network rather than it relying on funding from ongoing research as done previously



## What advice would you give less specialised centres?

### Overview of advice: Have scope for urgent appointments

#### — Why?

- To ensure that patients experiencing flares or other urgent disease complications are able to access appropriate care in a timely manner to prevent worsening outcomes

#### — How?

- This can be achieved by:
  1. Enforcing protected clinic appointment slots
  2. Having a dedicated hotline for patients to receive urgent advice or request an urgent appointment
  3. Employing a waiting list initiative, i.e. providing extra capacity for non-urgent appointments to reduce waiting lists

### Overview of advice: Have a liaison role in place between primary care and secondary care

#### — Why?

- To aid the standardisation of care delivery across care settings and ensure visibility of respective roles and responsibilities with regards to RA management. This limits the duplication or omission of services, ensuring efficient and effective provision of care

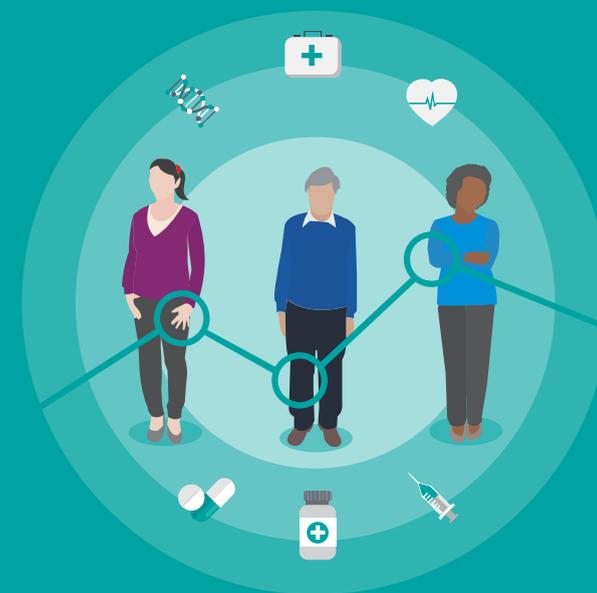
#### — How?

- In the UK, this could be a clinical nurse specialist 'bridge' between the two healthcare settings

Sources: (a) KPMG interviews with HCPs treating RA and associated comorbidities

# Case studies

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# Case study 1

## Early arthritis (EA) clinic

### Overview

Leeds pioneered the concept of management of early arthritis in the 1980s

The clinic accepts patients <12 months from first symptom recognition and rapidly places them on a Treat to Target protocol

Patients are followed up for approximately 18 months after which their care can be transferred to the general Rheumatology clinic

The clinic forms the basis for a highly dynamic research portfolio, with several active research fellows

Sources: (a) KPMG interviews with HCPs treating RA and associated comorbidities

### What is the rationale?



- Leeds pioneered the concept of management of early arthritis in the 1980s
- Clinical evidence shows early appropriate treatment is important because:
  - Current treatments are more effective in reducing inflammation early in the disease process
  - It delays progression of the disease and therefore prevents the cumulative damage that causes joint deformation

### What are the key features of the intervention?



- Accepts patients with suspected inflammatory arthritis coming through the suspected arthritis clinic or referred by other rheumatologists
- Includes patients detected late - but still < 12 months from first symptom onset
- Patients referred to EA clinic are seen within one week of referral
- The clinic has rapid access to diagnostics including bloods, imaging
- Ultrasound of the joint(s) is performed by a specialist in the clinic - where indicated
- Once diagnosed, the patient is treated on the same day
- 4-week review for all newly diagnosed patients (via telephone for those on biologics)

### What are the key features of the intervention? (cont.)



- Currently investigating biomarkers in EA patients that can predict course of disease progression
- A clinical nurse specialist with a specialist interest in early arthritis leads the reviews according to the T2T protocol, and provides a greater emphasis on patient education

<b>Frequency</b>	Weekly
<b>Timings</b>	Patients remain under EA for 1- 2-years before transfer to general clinic
<b>Referral routes</b>	Suspected arthritis clinic; General Rheumatology clinics; Other Rheumatology
<b>Staff members involved</b>	
<b>Members of the core team</b>	Rheumatologists; US specialist; Clinical Nurse Specialist

### What are the outcomes so far?



- Approximately 40% of patients achieve remission
- >75% of patients are put on a T2T treatment within 6 weeks of referral

## Early arthritis (EA) clinic (cont.)

### Benefits



Patients are rapidly put onto Treat-to-Target (T2T) pathway – target of 6 weeks from community to treatment

Early diagnosis and treatment is the key factor for delaying disease progression and maintaining QoL / independence

Streamlined patient journey, contributing to improved patient experience

Early access to holistic treatment including strong emphasis on patient education

### Tips to replicate this intervention



'Ring-fence' slots in the Rheumatology general clinic for early arthritis / suspected inflammatory arthritis patients to maintain availability

Availability of ultrasound in the clinic (by a trained specialist) may assist in some borderline cases, improving diagnosis rates and preventing unnecessary further appointments

Trainee rheumatologists may be able to take on greater workload of seeing patients – under the supervision of an experienced specialist



Early diagnosis is woven into our DNA as a centre. It is part of our raison d'être.

– Rheumatologist



### Challenges



- Balancing the trade-off between sensitivity and specificity in detecting rheumatoid arthritis
  - Lowering the threshold or acceptance into the clinic improves detection rates but can create unmanageable demand with higher numbers of non-inflammatory cases
- Maintaining the availability of clinic slots required to diagnose and treat RA in a timely way
- Requires having a strong presence in the mind of GPs. The caveat is that this can raise referral rates and overload the service

### What else could be done?



- Refine the criteria to improve the quality of GP referrals and raise detection rates
- Raise awareness amongst GPs around when to suspect inflammatory arthritis and when to refer
- Train more rheumatologists in the use of ultrasound
- Leeds is comprehensively investigating the assessment of 'pre-RA' – with the aim to find opportunities for treatment even earlier in the disease course

Sources: (a) KPMG interviews with HCPs treating RA and associated comorbidities

# Case study 2

## Routine use of ultrasound

### Overview

- Ultrasound is used routinely in consultations to aid diagnosis, monitoring and treatment decisions (i.e. whether to taper / increase dosage; or switch therapies)

**Notes:** 1. As an example, ~6/15 patients on the initial triage list for the Monday early arthritis clinic may receive ultrasound scans. 2. The centre are aiming for all trainee rheumatology doctors to have 'entry level' practical ultrasound skills (not necessarily required to reach the level required for use as a diagnostic aid)

**Sources:** (a) KPMG interviews with HCPs treating RA and associated comorbidities (b) Möller I, Janta I, Backhaus M, et al. The 2017 EULAR standardised procedures for ultrasound imaging in rheumatology. *Annals of the Rheumatic Diseases* 2017;76:1974-1979 (c) <https://omeract.org/>



### What is the rationale?



- Radiological imaging of joints using ultrasound is seen as an additional element of clinical examination of patients with RA
- It serves to enable the monitoring of disease activity, rule out alternative pathologies and assist with treatment decisions
- EULAR guidelines support the use of ultrasound to supplement clinical assessment of joints which are not found to be swollen on physical examination<sup>(b)</sup>

### What are the key features of the intervention?



<b>Uses</b>	— Acts as a decision aid and tool which can be used to answer a clinical question e.g. "Is this patient in remission?"
<b>Frequency</b>	Ultrasound is used in the following instances: <ul style="list-style-type: none"> <li>— At the general ultrasound clinics (4 per week)</li> <li>— Monday early arthritis clinic<sup>1</sup></li> <li>— Wednesday early arthritis clinic (half of the clinic slot is reserved for ultrasound scanning)</li> </ul>
<b>Patient type catered to</b>	<ul style="list-style-type: none"> <li>— All Rheumatology referrals</li> <li>— Patients with equivocal signs of inflammation</li> </ul>
<b>Guidelines used</b>	<ul style="list-style-type: none"> <li>— As per EULAR and ACR recommendation</li> <li>— Use is employed largely according to clinical judgement – where there is an element of doubt remaining after the use of clinical examination alone</li> </ul>
<b>Staff members involved</b>	<ul style="list-style-type: none"> <li>— <i>Rheumatologists (fully trained)</i> 4 out of the 15 rheumatologists in the department are trained to perform ultrasound</li> <li>— <i>Rheumatology trainees (in training)</i> Rheumatology trainees are currently required to have working knowledge of radiological imaging. Practical application is not a requirement<sup>2</sup></li> </ul>

### What are the outcomes so far?



#### Research

- The use of ultrasound feeds into ongoing research looking at discrepancies between DAS28 scores and clinical signs

#### Medical Education

- The department has helped to launch an undergraduate ultrasound course for Leeds Medical School – the first of its kind in the UK

#### Standardisation of practices

- The rheumatologists' work in ultrasound at the centre has informed the outputs of an OMERACT (Outcome Measures in Rheumatology) working group setting standard methods of acquiring and reading images and defining radiological outcome measures<sup>(c)</sup>

#### Guideline formation

- The leading ultrasound rheumatologist at the centre has assisted in the development of preliminary guidelines for use of ultrasound in RA in Scotland

#### Adoption of ultrasound practices

- When the centre first started using ultrasound [~20 years ago], there were no other rheumatology units at the time offering the service. Now, all major teaching hospitals have access to an ultrasound service for use in the rheumatology care setting

## Routine use of ultrasound (cont.)

### Benefits



#### Managing patient expectations

Use of ultrasound can help to meet and manage patients' expectations of disease outcomes by providing a more accurate clinical evaluation

#### Reassurance

Scanning reassures those patients who are anti-CCP-antibody positive but have a normal scan that they are confirmed as pre-RA

#### Clinical guidance

Ultrasound use allows physicians to identify when it is clinically appropriate to start DMARD therapy

#### Patient education

Ultrasound is useful as an educational tool for patients as well as rheumatologists and the wider team. During consultations, rheumatologists can visually demonstrate the pathology to the patient and explain what it means for them

#### Improved doctor-patient relationship

Performing an ultrasound scan gives the physician additional time to take a more thorough history and to demonstrate the technique to patients

### Benefits (cont.)



#### Upskilling

Incorporation of ultrasound into clinical practice improves clinical acumen as it provides validation to the practitioner of their clinical examination findings

#### Adherence

One study showed that ultrasound can help improve patient adherence to treatment<sup>(b)</sup>

### Challenges



#### Differential / overlapping diagnoses

It has recently been discovered that osteoarthritis can occasionally cause joint inflammation<sup>(c)</sup>  
This raises a new difficulty in accounting for background osteoarthritis inflammation when monitoring RA

#### Lack of support from national guidelines

The most recent NICE guidelines for the management of RA in adults (2018)<sup>(d)</sup> do not advocate the use of ultrasound in the diagnosis and monitoring of RA even when other findings are equivocal  
This poses a barrier to the spread and adoption of ultrasound practices outside of the centre in the wider RA community



Ultrasound creates a bond between physicians and patients because it gives us time to show and explain to the patient their pathology

– Rheumatologist



**Sources:** (a) KPMG interviews with HCPs treating RA and associated comorbidities (b) de Wit, M.P.T., Koelwijn-van Loon, M.S., Collins, S. et al. Patient (2013) 6: 179. <https://doi.org/10.1007/s40271-013-0017-0> (c) X. Wang, D.J. Hunter, X. Jin, C. Ding, The importance of synovial inflammation in osteoarthritis: current evidence from imaging assessments and clinical trials, Osteoarthritis and Cartilage, Volume 26, Issue 2, 2018, 165-174 (d) <https://www.nice.org.uk/guidance/ng100>. Recommendation 1.9.5.

# Case study 3

## Expanded role of the Clinical Nurse Specialist (CNS)

### Overview

- Clinical Nurse Specialists (CNSs) are experts in evidence-based nursing practice within a specialty area, treating and managing the health concerns of patients and populations
- Nurse-led services at the centre include outpatient clinics and a day case unit where CNSs oversee the delivery of biologics to patients
- “Rheumatology nurse specialists are the cornerstone of the multidisciplinary team. One of the vital roles performed by a nurse specialist is being able to talk through all the emotional issues and fears a patient may have following diagnosis.”  
*National Rheumatoid Arthritis Society* <sup>(c)</sup>

**Note:** 1. The key features of the CNS role in the centre are outlined on the next page

**Sources:** (a) KPMG interviews with HCPs treating RA and associated comorbidities (b) RCN Policy Unit (2009), *Specialist Nurses Make a Difference* (c) National Rheumatoid Arthritis Society (2007). Results of the NRAS survey on the role of the rheumatology nurse specialist

### What is the rationale?



- The aim of expanding the nurse role is to enhance the quality of care delivered, as well as to distribute the workload and remove bottlenecks encountered by medical colleagues
- Specialist nurses provide leadership and have a positive impact on the training and education of other staff <sup>(b)</sup>

### What are the key features of the intervention?



In total, there are 10.5 CNSs in the department across two teams:

- General rheumatology (pre-biologic) CNS team; Involved in the care of patients not receiving biologic treatment
- Biologics CNS team; Involved in the care of patients receiving biologic treatment

In addition to the touchpoints outlined along the patient pathway,<sup>1</sup> the role of the CNS includes:

#### Prescribing

- CNSs play a significant role in drug counselling to aid concordance
- There are 5 trained nurse prescribers in the team who are able to provide drug counselling and repeat treatment prescriptions (i.e. once initially prescribed by a rheumatologist in secondary care)

### What are the key features of the intervention? (cont.)



#### Prescribing (cont.)

- CNSs also manage and renew community-based prescriptions for the ongoing use of DMARDs or biologics in the community

#### Making referrals

- CNSs make comorbidity and affiliate specialty referrals (i.e. to physiotherapy, occupational therapy and podiatry)

#### Having an integral MDT presence

- Biologics CNSs attend and partake in a monthly departmental meeting for difficult cases with biologics patients

#### Providing patient support

- CNSs are on hand to answer patient queries received on the patient advice line. Patients are able to call and leave a message which will be addressed by a CNS
- They frequently signpost patients to PAGs (particularly NRAS and AR UK)

#### Coordinating Education

- The lead CNS coordinates patient and nurse education within the department
- One of the main goals of nurse education is to train nurses to the level that is required for their individual consultations

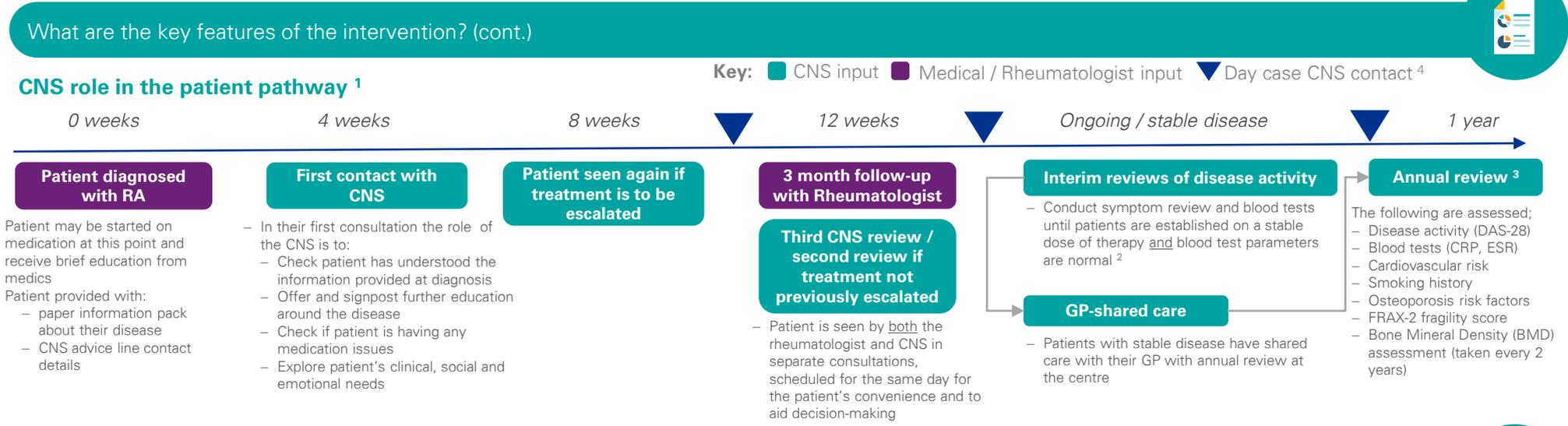


CONTENTS



APPENDIX  
CENTRE REPORTS

# Expanded role of the Clinical Nurse Specialist (cont.)



## What are the outcomes so far?

- The role of the CNS has enabled nurse-delivered annual review clinics to be re-established for the monitoring of stable RA patients not on biologics. This allows for structured annual review as these patients were previously seen in general RA management clinics at varying time intervals
- The department is currently formulating a transition pathway from paediatric to adult rheumatology care. CNSs attend the transition clinic once every three months with adult-care rheumatologists in order to meet patients who will be transferring to adult services
- The CNS team have conducted an audit on the post-diagnosis information pack provided to patients to see if it is sufficient for patient needs and whether anything else can be provided. Outcomes of this audit showed that patients would like web / IT support for education purposes. This is now in the process of being developed, having looked closely at a model operated at another Trust
- For the future, the CNS team are aiming to set biannual "meet the team" group sessions for patients to be able to attend

**Notes:** 1. The above pathway is not an exhaustive view of the entire patient pathway at the centre. For the purposes of this case study, it reflects the events surrounding CNS input i.e. medical input is not limited to the above visualisation. 2. This is part of Leeds shared care guidelines for DMARDs. 3. This is timed 6 months after the annual medical review so that patients are seen bi-annually. 4. Timelines are estimated and shown for illustrative purposes.

**Sources:** (a) KPMG interviews with HCPs treating RA and associated comorbidities

# Expanded role of the Clinical Nurse Specialist (cont.)

## Benefits

### Benefits to patients

#### Standardisation of care

The sharing of patients among the CNS team encourages the team to standardise care delivery practices in order to minimise variations

#### Support provided to Patient and Public Involvement (PPI) Group

CNSs help to coordinate patient involvement group meetings which take place once a month at the centre, with interim communication coordinated via social media groups

#### Improved patient outcomes

The CNS role has proven to have positive impacts on patient outcomes and on the systems and processes of care delivery

### Benefits to the rheumatology team

#### Streamlined decision making and autonomy

The ability to exercise clinical judgement can avoid bottlenecks of having to wait for medical input from the rheumatologist

CNSs have more autonomy within their role, and are able to make clinical management decisions and in some cases, prescribe treatments and advise treatment changes

## Benefits (cont.)

### Shared expertise

CNSs in the department are encouraged to have a specialist rheumatological disease area / area of special interest. The combined expertise of the CNSs is a useful resource for both the department and patients

## Challenges

### Continuity of care

Patients are unable to have a named nurse specialist as the team is small in relation to the large patient pool, meaning they are likely to see a different CNS for each visit

### Ensuring an even spread of expertise

The team have to be mindful of not becoming dependent on individual CNSs for expertise in certain disease areas as a knowledge gap can arise if someone leaves the department

### Psychological support

The team have very limited access to psychological support for patients. The current referral process involves a written referral to a clinical psychologist who provides reviews based on their limited availability. This can cause delays in care. In cases where the CNS sees that a patient is evidently depressed, they are referred back to their GP, as this is quicker, however patients still experience lengthy waiting times for assessment and treatment

**Notes:** 1. Except in the T2T (treat-to-target) clinic where patients see the same two nurses consistently  
**Sources:** (a) KPMG interviews with HCPs treating RA and associated comorbidities

“ CNS bring consultation skills and this is the most important thing

– Clinical Nurse Specialist ”

“ A big part of the CNS role is making sure patients are happy with their treatment

– Clinical Nurse Specialist ”



# Case study 4

## Joint comorbidity services

### Overview

The centre operates a number of joint comorbidity clinics in collaboration with comorbidity specialists, catered to RA patients

There are joint clinics operational in all of the following specialty areas: <sup>1</sup>

- Dermatology
- Diabetes
- Immunology
- Neurology
- Obstetrics
- Orthopaedics
- Renal
- Respiratory
- Transition from paediatric to adult rheumatology care

However, given the wealth of services covered, this case study will be focused primarily on respiratory, which illustrates effective cross-site and cross-disciplinary workings

**Notes:** 1. Please see page 21 for an overview of the joint specialty services at the centre

**Sources:** (a) KPMG interviews with HCPs treating RA and associated comorbidities

### What is the rationale?



#### Dermatology:

- Dermatological input caters to the cutaneous (skin) features of RA as well as skin sensitivity secondary to treatment

#### Diabetes:

- Joint decision-making between rheumatologist and diabetic specialist can benefit RA patients with diabetes who can have complex issues e.g. those patients: who find it difficult to manage their blood sugars; with cardiovascular disease, who have foot problems

#### Immunology:

- With the immunological basis of inflammatory and autoimmune diseases, we enjoy close and integrated working with our clinical immunology colleagues; also informing new concepts and research initiatives

#### Neurology:

- The department have close inpatient links with the neurology team as well as hosting joint outpatient clinics – to address the nerve damage that can sometimes occur in RA secondary to the inflammation process

#### Obstetrics:

- Given that RA is more prevalent among women, the team aim to provide support, advice and encouragement to those who are planning to have children, or are pregnant, ensuring there is good communication between the patient and the rheumatology and obstetrics teams

#### Orthopaedics:

- The two specialties work closely together within the musculoskeletal centre as RA and orthopaedic problems such as advanced osteoarthritis can commonly coexist

#### Respiratory:

- Joint decision-making with the respiratory team can be beneficial e.g. where there are competing priorities in treatment such as negative impact on the control of ILD with some RA drug treatments

### What are the activities undertaken?



#### Respiratory:

- There is a **dedicated, monthly combined clinic between rheumatologists and respiratory at CAH**. Patients with RA and CTD with respiratory involvement benefit from this integrated clinical assessment towards efficient diagnosis and treatment, and management.
- In addition, a dedicated team of rheumatologists meet with respiratory every month at the St.James' University Hospital site for a multi-disciplinary meeting. Here, new patients in need of review by either specialty are discussed for referral to the combined clinic. Patients already known to the team but in need of closer monitoring are also discussed at this meeting.
- The collaboration also ensures our rheumatology patients get **access to wider respiratory education and rehabilitation services**.
- **The combined service enables cross-disciplinary education of the respective specialties to clinicians at all levels**
- The **rheumatology-respiratory team is increasingly involved in collaborative research**, including intervention studies of B-cell depletion and anti-fibrotics in RA and CTDs; as well as novel imaging studies to identify biomarkers to aid early diagnosis

# Case study 5

## Therapies services

### Overview

Therapies services such as podiatry, physiotherapy, occupational therapy provide complementary services to ongoing medical care

The emphasis is on maintaining independence and autonomy through placing the onus on the patient to self-manage their RA

Provision of these services gives the opportunity of developing more holistic approaches to RA care, so cross-disciplinary team members are working with the patient to achieve his / her goals from treatment

This case study will particularly focus on podiatry, given it is the area most integrated within the Rheumatology department. The inpatient podiatry team has been operational since 2000, and was originally specialty agnostic prior to getting involved with rheumatology research

### What is the rationale?

- Patient outcomes in RA are improved with the involvement of non-medical specialists in the wider care team
- There are opportunities for both directly addressing the pathology, and in enabling functional improvements in RA patients

### What are the key features?

- A variety of therapy disciplines are represented in the Rheumatology team including:
    - **Podiatry**
    - **Physiotherapy**
    - **Occupational therapy**
    - Dietetics
    - Psychology
- Physiotherapy and occupational therapy have a particular focus on RA:
- Physiotherapy:
    - Inpatient and outpatient physiotherapy (PT) services are provided to RA patients referred from rheumatologists and CNSs
  - Occupational therapy
    - Inpatient and outpatient occupational therapy (OT) services are provided to all patients who are identified as requiring support

### What are the activities undertaken?

#### Podiatry:

- There is a **specific pathway for RA patients with an identified foot problem**; including radiological imaging, clinical review, and potentially a change of medication
- The podiatry team provide an **annual foot health appointment** for RA patients
- The team offer **structural MSK support** through offloading treatments e.g. insoles to accommodate deformity, redistribute pressure and provide cushioning. They have made a shift away from orthopaedic footwear to cheaper, more 'off-the-shelf' modular footwear
- There is a **podiatry hotline** for general RA patients to have their foot health queries addressed if not already in contact with a podiatrist
- The podiatry team at the centre **send out communications to community practitioners and GPs** to raise awareness and improve symptom identification of the 'three Ss'; symmetry, stiffness and swelling in the foot
- **Outpatient clinics** (please see next page)
- Three podiatrists at the centre have completed **independent prescribing** courses
- The **podiatry team is heavily involved in research**, with a strong academic presence on the team. There are five clinical academic pathways on their own National Institute for Health Research (NIHR) fellowship with PhD or post-doctorate positions; one in scleroderma, one in connective tissue diseases (CTD), and one in RA



CONTENTS



APPENDIX  
CENTRE REPORTS



Foot care is important as once you've dampened down inflammation the other things become the bottlenecks

- Podiatrist



Occupational therapy has a lot to offer women who are pregnant

- Rheumatologist



## What are the activities undertaken?



### Physiotherapy

- Physiotherapy aims to provide a 'safety net' for patients who are struggling to manage physical impact of their RA
- Patients are seen for RA-specific mobility issues and well as non-RA 'mechanical flares' i.e. when something other than their RA is impacting mobility or coping with the disease
- Has a strong emphasis on self-management i.e. training patients to understand their condition and perform useful exercises
- Covers a variety of treatments requiring specialist equipment or skills e.g. wax therapy, hydrotherapy, acupuncture

### Occupational therapy

- Aims to improve ability to carry out day-to-day activities both in and out of the home including a specific focus on RA patients struggling with their hands
- Provide 'reablement services' e.g. training the patient to self-manage or provision of aids
- Appointments last 1 hour and often emotional support is provided in addition to traditional OT services

## What's next?



- The podiatry team are researching the mechanical changes that occur in the feet of RA patients (through quantifying pressures). Using these observations, they will assess how these can be alleviated with sole supports
- This is underway as a response to the outcomes of a study which showed that the common practice of callous removal has no significant improvement on localized pressure or gait function for RA patients and that external supports should be provided<sup>(b)</sup>



**Sources:** (a) KPMG interviews with HCPs treating RA and associated comorbidities (b) H. J. Davys, D. E. Turner, P. S. Helliwell, P. G. Conaghan, P. Emery, J. Woodburn; Debridement of plantar callosities in rheumatoid arthritis: a randomized controlled trial, *Rheumatology*, Volume 44, Issue 2, 1 February 2005, Pages 207–210. <https://doi.org/10.1093/rheumatology/keh435>

## Therapies services (cont.)

### What are the outcomes so far?



Improved patient-reported outcomes e.g. [QoL, pain, ability to activities of daily living]

### Benefits



#### Benefits to patients

- Greater focus on the wider impact of RA on quality of life, and specifically on the patient's ability to function from day to day
- Practical improvements and tips for dealing with RA that promote self-management and greater autonomy

#### Benefits to the Rheumatology team

- There is specialist resource to support with issues around the more practical issues for patients
- There are greater possibilities overall to detect significant issues and flare-ups early, through communication and cross-referral between the medical and therapies teams

### Challenges



Waiting times for physiotherapy can be long due to imbalance in capacity versus demand

Introducing a newly diagnosed patient to the various disciplines early on can be overwhelming for the patient

As Leeds is a tertiary centre, a significant proportion of patients have to travel long distances to access therapy services

### Tips to replicate this intervention

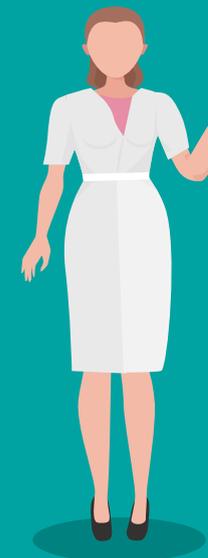


- To make the most of the variety of disciplines providing care, a forum for communication e.g. regular meetings with rheumatologists, can help - by making 'joined-up' decisions that take into account the patient's overall goals from treatment e.g. to stay at work, or maintain a hobby
- Training for each discipline on the role of their colleagues will be helpful in embedding cross-disciplinary team-working
- Require patients to 'opt in' for therapy services, placing onus on patient to take control of the management of their RA
- Where patients need to see specialists from multiple disciplines, schedule appointments on the same day with time slots close together for their convenience



I love working here. We provide a really well-rounded service to RA patients and rheumatology patients in general.

- Physiotherapist



[kpmg.com/uk](https://kpmg.com/uk)



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