KPMG

Improvement in the management of Psoriatic Arthritis

Summer 2016

GBL/HUD/0616/0720

This study was commissioned and solely funded by AbbVie

AbbVie had no role in the conduct of the study, collection, management, analysis and interpretation of data, or preparation of this report

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Executive summary

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Executive summary (1/7)

Executive summary

Context

Psoriatic Arthritis (PsA) is a form of chronic inflammatory arthritis associated with psoriasis, a skin condition characterised by red, flaky patches on the skin. **PsA occurs in approximately 30% of patients with psoriasis** and develops on average 10 years after the onset of psoriasis [1]

PsA is characterised by a varied clinical course but can lead to **progressive joint destruction**, **disability** and **impaired quality of life**. In addition, patients with PsA are at an increased risk of a number of **comorbidities**, including diabetes, metabolic syndrome, depression and cardiovascular diseases [2]

Over the last decade, the management of PsA has been improved by the introduction of new treatment options. However, a number of **unmet needs in PsA care** remain, which place a significant **clinical, social and economic burden** on patients, their families and society

Goals

AbbVie sponsored **KPMG** to produce an **independent report** on PsA care in collaboration with the Group for Research and Assessment of Psoriasis and Psoriatic Arthritis (**GRAPPA**) with the aim of **improving the quality and efficiency of care** for PsA patients globally

The goal of this project was **to collate information and views on key initiatives to improve care** from clinicians and patients in multiple worldwide centres

By doing so, we aimed to **identify, document and share practices** to help increase the awareness of PsA, promote timely and accurate diagnosis, increase the consistency of care and, ultimately, improve outcomes for patients with PsA

Sources: 1: Gladman, D.D. et al (2005) Psoriatic arthritis: epidemiology, clinical features, course, and outcome. Ann Rheum Dis. 64:ii14–ii17; 2: Ogdie, A., et al (2015) Recognizing and managing comorbidities in psoriatic arthritis. Curr Opin Rheumatol. 27(2):118-26

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Executive summary (2/7)

Approach

GRAPPA selected **7 centres around the world** to participate in this project. They were picked to represent a **variety of geographies, healthcare systems, care settings** and **different access to specialties**

Whenever possible, nearby **community centres** were included to understand the challenges in PsA care within this particular ecosystem

A group of **ex–scientists and ex–clinicians from KPMG** visited these centres and engaged with a **range of stakeholders** including rheumatologists, dermatologists, nurses, patients and patient organisations

KPMG gathered **stakeholders' views on five key areas**: challenges in PsA care, interventions likely to address them, networks, patient–centricity and benefit creation

Findings were collated into the following report which was then **reviewed by the participating centres** as well as members of **GRAPPA** to ensure the **validity of the findings presented**

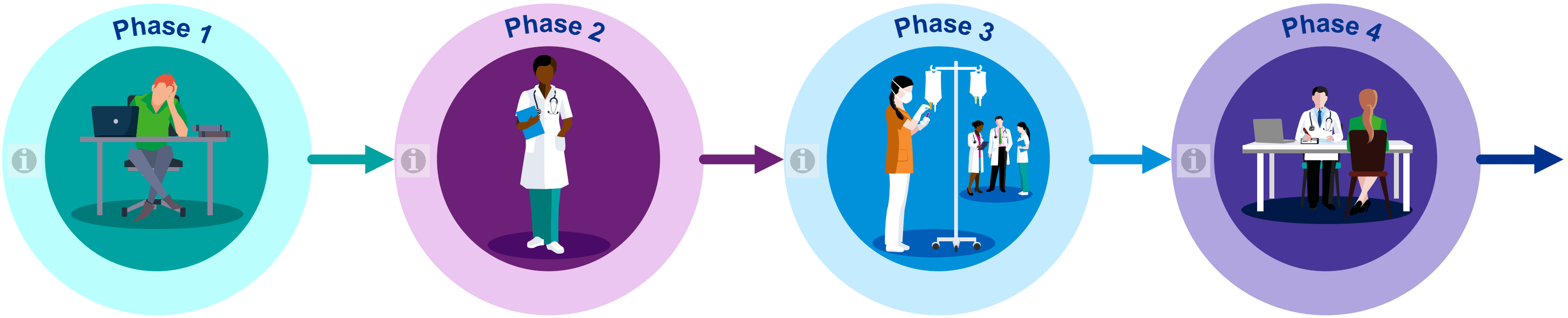
Click on each row of the table below to go to the relevant site specific section

Centre	**Location**
BRIGHAM AND WOMEN'S HOSPITAL	Boston, US
Note: We also interviewed a dermatologist-rheumatologist from the Tufts Medical Center in Boston	
Toronto Western Hospital	Toronto, Canada
Note: We also interviewed a rheumatologist from the Women's College Hospital in Canada	
University of Lübeck UKSH UNIVERSITÄTSKLINIKUM Schleswig-Holstein	Lübeck, Germany
HOSPITAL ITALIANO de Buenos Aires	Buenos Aires, Argentina
Guy's and St Thomas' NHS Foundation Trust NHS	London, UK
Groote Schuur Hospital Cape Town	Cape Town, South Africa
The Prince of Wales Hospital, Hong Kong	Hong Kong, China

Executive summary (3/7)

Key findings (1/5):

- Following the discussions with specialists and patients, the patient pathway in PsA was divided into four phases: **1. Pre–diagnosis, 2. Referral and diagnosis, 3. Treatment initiation and management and 4. Follow–up**
- **Challenges:** The stakeholders identified a number of challenges that persist along the patient pathway. **Limited awareness of PsA** among non–rheumatologists was recognised as a challenge by all the visited centres (100%) followed by a **siloed approach to care** (86%), **late referral and diagnosis** (71%) and an **inadequate management of comorbidities** (57%)



Pre–diagnosis
- Limited of awareness of PsA among HCPs and patients

Referral and diagnosis
- Lack of screening
- Delayed referrals
- Challenges with differential diagnosis

Treatment initiation and management
- Siloed approach to care in secondary, tertiary and community centres
- Gaps in clinical management
- Challenges associated with the use of biologics
- Lack of patient centricity

Follow–up
- Inadequate management of comorbidities
- Lack of regular follow–up

Click on each small circle to go to the relevant 'challenge'

Source: KPMG interviews

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Executive summary (4/7)

Click on each small circle to go to the relevant 'challenge'

Click on flag row to go to the relevant case study

Key findings (2/5):

— **Interventions:** During the centre visits we identified 24 solutions to improve care across the different phases of the patient pathway. These are further supported by 29 detailed case studies which provide detailed descriptions of how the visited centres have implemented them

Pre–diagnosis

Limited awareness of PsA among HCPs and patients

Many clinicians are not aware of the risk of musculoskeletal disease in patients with psoriasis

- **Education of GPs and dermatologists**
  1. As easy as 'PSA' 🇺🇸
  2. Peer education 🇦🇷
- **Education of patients with psoriasis**
  3. Patient and peer education 🇭🇰

Referral and diagnosis

Lack of screening

There is a lack of regular screening among patients with psoriasis

- **Regular screening**
- **Refinement and/or development of new screening tools**
  4. PASE 🇺🇸
  5. ToPAS 🇨🇦
  6. PEST

Delayed referral to a rheumatologist

Patients are often referred to a rheumatologists several years after symptom onset

- **Early referral**
  7. Referral forms for GPs 🇨🇦
  8. Self-referral scheme 🇨🇦
  9. Outreach activities 🇿🇦
- **Networks and referral pathways**
  10. Hospital network 🇦🇷

Challenges with differential diagnosis

Following a referral, diagnosis of PsA can remain challenging even to experienced rheumatologists

- **Consistent assessment criteria**
- **Interdisciplinary approach**
- **Use of diagnostic equipment**
  11. Radiologists–ultrasonographers 🇦🇷

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Note: The flags represent the country of the centre in which the intervention was observed
Source: KPMG interviews

Executive summary (5/7)

Click on each small circle to go to the relevant 'challenge'

Click on flag to go to the relevant case study

Key findings (3/5):

— **Interventions:** During the centre visits we identified 24 solutions to improve care across the different phases of the patient pathway. These are further supported by 29 detailed case studies which provide detailed descriptions of how the visited centres have implemented them

Treatment initiation and management

Siloed approach to care in secondary, tertiary and community centres

Although PsA affects both joints and skin, there is often little coordination of care between different specialties, especially in community–based clinics

- **Improved coordination of dermatology and rheumatology services**
  - 12. – 16. Combined clinics 🇺🇸 🇨🇦 🇩🇪 🇦🇷 🇬🇧
  - 17. Multidisciplinary care 🇭🇰
- **Development of networks and relationship between community–based centres**
  - 18. The Arthritis Programme 🇨🇦
  - 19. Developing relationships between HCPs 🇨🇦

Gaps in clinical management

Although many effective PsA therapies have been introduced over the last decade, many patients do not respond to their treatment or may lose the initial response over time

- **Use of protocols and treatment algorithms**
- **Development and validation of new outcome measures in PsA**

Challenges associated with the use of biologics

Many effective treatment options are available for PsA; however, access to these therapies can be reduced or delayed for some patients, especially in lower–income areas

- **Enrolment of patients into clinical trials**
  - 20. PsA research clinic 🇭🇰
- **Development of relationships with commissioners**

Lack of patient centricity

As patients become more engaged in healthcare, they want to be empowered to manage their own health. However, many centres could do more to be truly patient–centric

- **Improved communication between HCPs and patients and engagement of patients in their care**
  - 21. Pregnancy clinics 🇬🇧
- **Development of educational programmes for patients**
  - 22. Patient centricity 🇨🇦
- **Patient education by the medical office staff**
- **Collaboration with patient associations**

Note: The flags represent the country of the centre in which the intervention was observed
Source: KPMG interviews

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Executive summary (6/7)

Click on each small circle to go to the relevant 'challenge'

Click on flag to go to the relevant case study

Key findings (4/5):

— **Interventions:** During the centre visits we identified 24 solutions to improve care across the different phases of the patient pathway. These are further supported by 29 detailed case studies which provide detailed descriptions of how the visited centres have implemented them

Follow–up

Inadequate management of comorbidities

There is a lack of regular screening for PsA among patients with psoriasis

— **Peer and patient education**

— **Nurse–led clinics**

23. Nurse–led clinics for newly diagnosed patients 🇺🇸
24. Nurse–led clinics 🇭🇰

Lack of regular follow–up

In current practice some patients may not be followed–up and their disease not monitored after their initial consultation

— **Regular monitoring**

— **Use of databases and Electronic medical records**

25. Cohort for psoriasis and PsA 🇺🇸
26. PsA and psoriasis database 🇨🇦
27. National registry for psoriasis and PsA 🇩🇪
28. Electronic Medical Record System 🇦🇷
29. Inflammatory Disease database 🇬🇧

— **Patient education**

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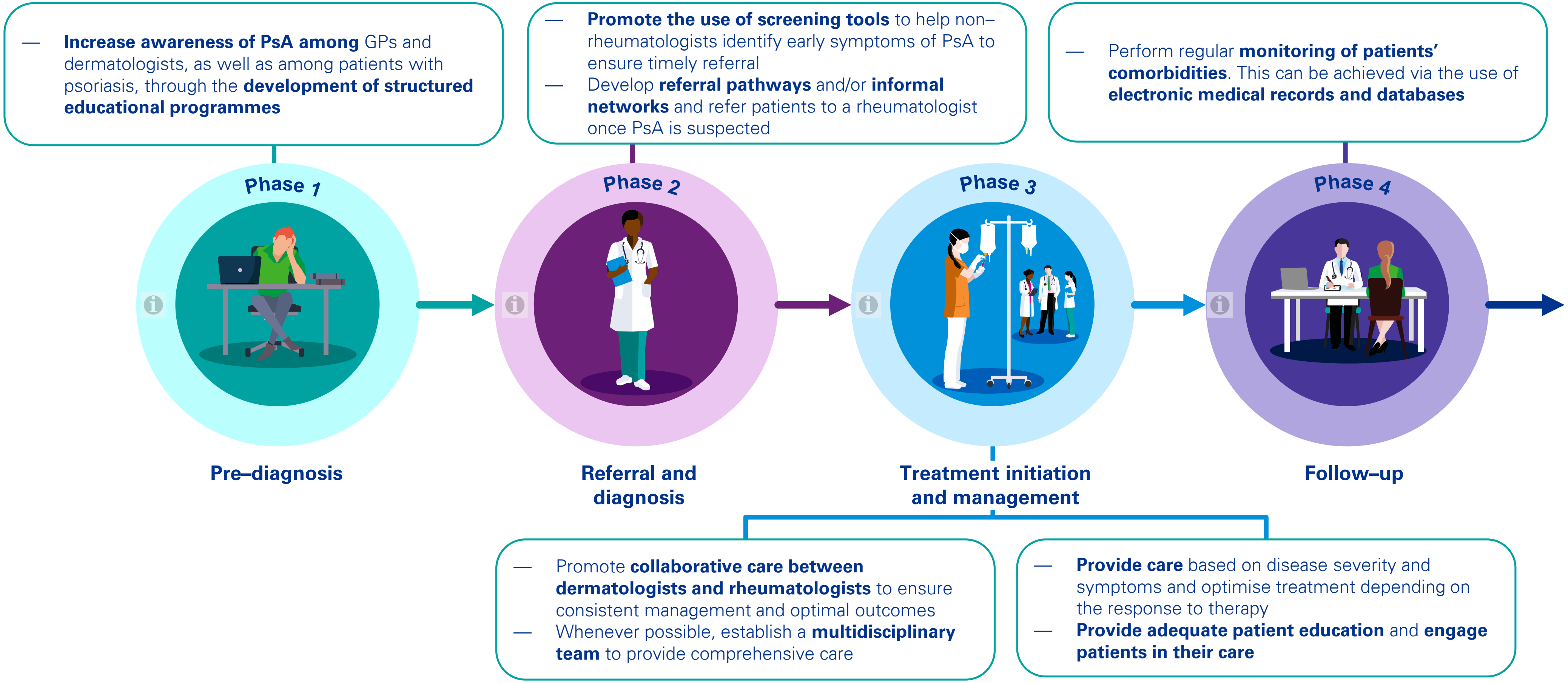
Key findings

Note: The flags represent the country of the centre in which the intervention was observed
Source: KPMG interviews

Executive summary (7/7)

Key findings (5/5):

- **The priority actions** identified by stakeholders include **increasing awareness of PsA**, **driving collaboration between dermatologists and rheumatologists** and **setting up databases to monitor PsA patients**. Stakeholders also agreed on the value of **establishing specialist PsA clinics** which allow clinicians to focus on the various domains of PsA, so that a protocol–driven, treat–to–target approach would be feasible



Pre–diagnosis

- **Increase awareness of PsA among** GPs and dermatologists, as well as among patients with psoriasis, through the **development of structured educational programmes**

Referral and diagnosis

- **Promote the use of screening tools** to help non–rheumatologists identify early symptoms of PsA to ensure timely referral
- Develop **referral pathways** and/or **informal networks** and refer patients to a rheumatologist once PsA is suspected

Treatment initiation and management

- Promote **collaborative care between dermatologists and rheumatologists** to ensure consistent management and optimal outcomes
- Whenever possible, establish a **multidisciplinary team** to provide comprehensive care

- **Provide care** based on disease severity and symptoms and optimise treatment depending on the response to therapy
- **Provide adequate patient education** and **engage patients in their care**

Follow–up

- Perform regular **monitoring of patients' comorbidities**. This can be achieved via the use of **electronic medical records and databases**

Source: KPMG interviews

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PsA is a form of chronic inflammatory arthritis associated with psoriasis

What is Psoriatic Arthritis?

Psoriatic Arthritis (PsA) is a form of chronic inflammatory arthritis associated with psoriasis, a skin condition characterised by red, flaky patches on the skin

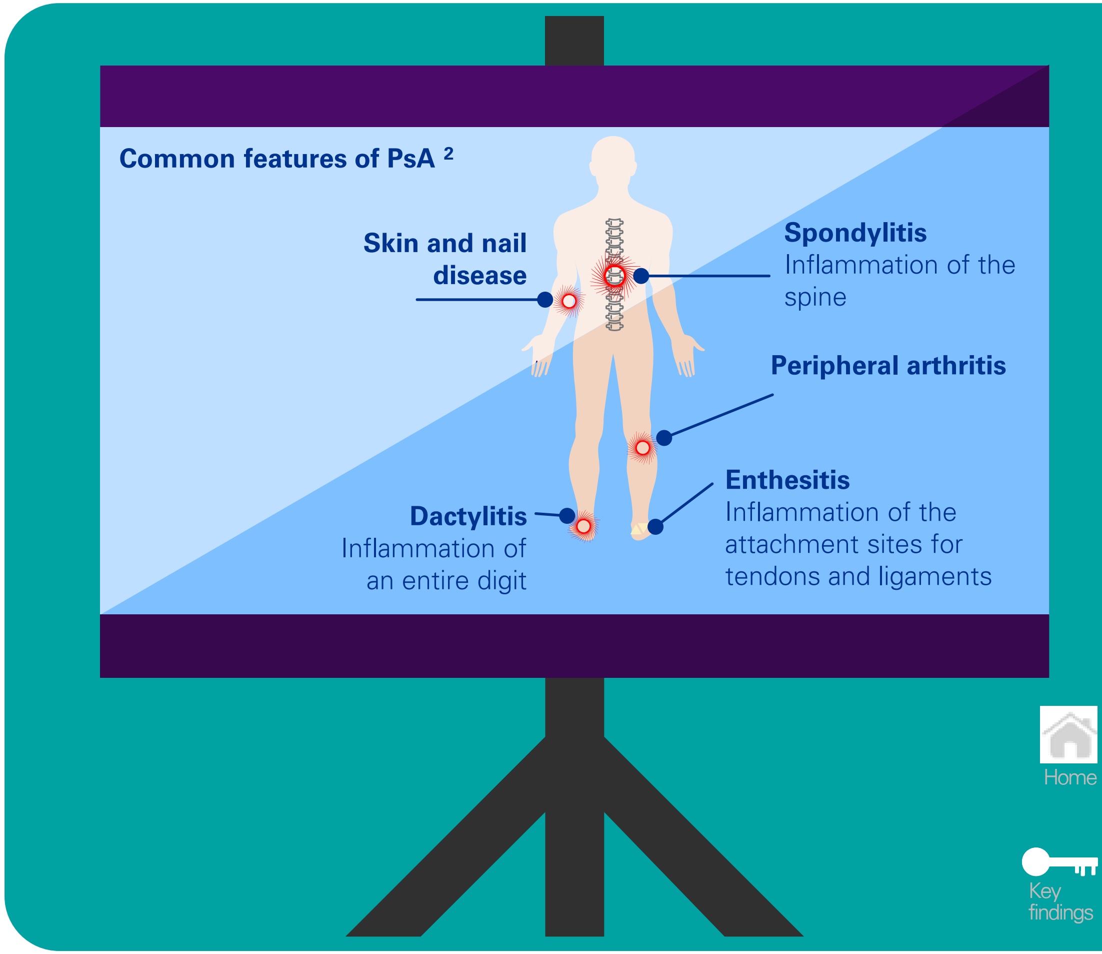
PsA occurs in approximately 30% of patients with psoriasis and develops on average 10 years after the onset of skin symptoms [1]

What are the symptoms?

Clinically, PsA is characterised by peripheral or axial joint inflammation which is associated with varying degrees of pain, swelling and stiffness in some or several joints in the hands, feet, knees, neck, spine and elbows

Common features include dactylitis (inflammation of an entire digit), enthesitis (inflammation of the attachment sites for tendons and ligaments) and spondylitis (inflammation of the spine) [2]

PsA is highly heterogeneous in terms of the skin and joint involvement – patients may experience mild skin and severe joint symptoms, mild joint and severe skin symptoms, or severe joint and skin symptoms. Whereas some PsA patients may have a mild, non–destructive clinical presentation, others may rapidly develop a progressive condition that can lead to joint destruction, disability, impaired quality of life and even increased mortality [3]



Common features of PsA [2]

Skin and nail disease

Spondylitis
Inflammation of the spine

Peripheral arthritis

Dactylitis
Inflammation of an entire digit

Enthesitis
Inflammation of the attachment sites for tendons and ligaments

> **Approximately 30% of psoriasis patients develop PsA but only half of them are aware of the risk of the disease**
>
> Rheumatologist, University Hospital Schleswig–Holstein, Lübeck

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Key findings

Sources: 1: Gladman, D.D. et al (2005) Psoriatic arthritis: epidemiology, clinical features, course, and outcome. Ann Rheum Dis. 64:ii14–ii17; 2: Olivieri, I., et al (2014) Advances in the management of psoriatic arthritis. Nat Rev Rheum. 10:531–542; 3: Sritheran, D., Leung, Y. (2015) Making the next steps in psoriatic arthritis management: current status and future directions. Ther Adv Musculoskelet Dis. 7(5): 173–186

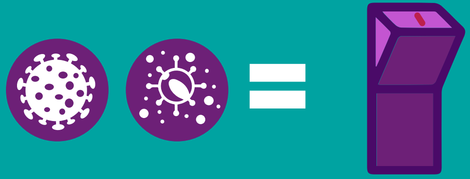
PsA is caused by an interplay of immune, genetic and environmental factors

What causes PsA?

The exact causes of PsA are unclear; however, it is likely to be caused by a combination of genetic and environmental factors

Genetics
PsA has a strong heritable component. The risk of developing PsA among first-degree relatives of PsA patients is approximately 30 times higher than in the general population [1]

Environment
There is some evidence that prior infections and physical trauma can trigger PsA in people with a genetic predisposition [2]



What are the risk factors for PsA?

Patients with greater psoriatic skin involvement are at an increased risk of developing PsA in their lifetime [2]. Other features which are independently associated with PsA risk include nail dystrophy, scalp lesions, and intergluteal/perianal lesions [3]

How is it diagnosed?

There is currently no definitive diagnostic test for PsA and diagnosis remains challenging due to the heterogeneous nature of the disease [2]

The CASPAR classification criteria are often used in clinical practice to distinguish patients with PsA from those with other inflammatory diseases. CASPAR bases diagnosis on clinical symptoms and history, as well as radiographic and laboratory evidence [4]

Classification Criteria for PsA (CASPAR) [4]

	Description	Points
Clinical	Current psoriasis **or** Personal history or family history of psoriasis	**2 or** **1**
	Dactylitis (current or history) recorded by a rheumatologist	**1**
	Psoriatic nail dystrophy observed on current physical examination	**1**
Radiology	Juxtaarticular new bone formation appearing as ill–defined ossification near joint margins (but excluding osteophyte formation)	**1**
Serology	Rheumatoid factor negative	**1**

Note: To meet the CASPAR criteria for PsA, a patient must have a musculoskeletal disease (either arthritis, spondylitis or enthesitis) and at least three points from the five categories above

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Sources: 1: Chandran, V., et al (2009) Familial aggregation of psoriatic arthritis. Ann Rheum Dis. 68:664-667; 2: Vlam, K., et al (2014) Current concepts in psoriatic arthritis: pathogenesis and management. Acta Derm Venereol.; 94(6):627–34; 3: Wilson, F.C., et al (2009) Incidence and clinical predictors of psoriatic arthritis in patients with psoriasis: a population-based study. Arthritis Rheum. 61(2):233-9; 4: Taylor W,, et al. (2006) Classification criteria for psoriatic arthritis: development of new criteria from a large international study. Arthritis Rheum. 54(8):2665–73

PsA is an underdiagnosed condition with varied prevalence and incidence rates

Context

3 Epidemiology

Global prevalence and incidence of PsA [1-3]

Key

● Prevalence ≤ 0.05%:

● Prevalence > 0.05%;

○ # Incidence rate expressed per 100,000 population

Note: There epidemiological data on PsA remains limited

PsA is most prevalent in Western Europe and Northern America

PsA has an estimated prevalence of 0.3–1% in the general population and is distributed equally across men and women [4]

There is substantial variation in the epidemiology of PsA globally, with both prevalence and incidence rates higher in Europe and Northern America than in Asia:

- The incidence rates of PsA vary from 0.1 per 100,000 in Japan to 23.1 per 100,000 in Finland [1]
- The estimated prevalence of PsA is between 0.001% in Japan and 0.42% in Italy [1]

Underdiagnosis of PsA in psoriasis population

The exact prevalence of PsA is unknown and its estimation has been difficult, partly due to the lack of widely accepted diagnostic criteria as well as the under–recognition of PsA symptoms [4]

> **Patients with PsA tend to be underdiagnosed. This is both in the dermatology clinic and in primary care where patients might not even be diagnosed with psoriasis**
>
> Dermatologist, Brigham and Women's Hospital, Boston

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Sources: 1: Liu, J.T., et al (2014) Psoriatic arthritis: Epidemiology, diagnosis, and treatment. World J Orthop. 5(4): 537–543; 2: Ogdie, A., et al (2013) Prevalence and treatment patterns of psoriatic arthritis in the UK; Rheumatology (Oxford). 52(3):568–75; 3: Usenbo, A., et al (2015) Prevalence of Arthritis in Africa: A Systematic Review and Meta–Analysis. PLoS One. 10(8): 1–19; 4: Gladman, D.D. et al (2005) Psoriatic arthritis: epidemiology, clinical features, course, and outcome. Ann Rheum Dis. 64:ii14–ii17

PsA places a significant clinical and economic burden on affected patients and society

Patient's and clinical burden

- PsA places a substantial burden on patients, diminishing their capacity to carry out daily activities and reducing their quality of life [1]
- Patients with PsA have an increased risk of comorbidities [1,2], including:

Cardiovascular diseases

Uveitis

Gastrointestinal conditions

Depression and anxiety

Diabetes

> Joint pain can get really bad but it is the psoriasis that has been the biggest challenge. It is so embarrassing and stigmatising, it makes you feel so excluded. And it is difficult to talk about it even to my husband
>
> **PsA patient, Guy's and St Thomas' NHS Foundation Trust, London**

Economic burden

- PsA is associated with increased healthcare costs and loss of productivity, especially in patients with more severe forms of the disease (due to their disability) and those in whom standard therapies have failed
- In the US alone, the annual healthcare cost of PsA has been estimated to be as high as $1.9 billion [2]

Both direct costs (in–patient, out–patient, and pharmaceutical services) and indirect costs (loss of productivity) increase with worsening physical function and disease activity [2]

Loss of productivity is the highest single driver of costs associated with PsA and accounts for 52–72% of all total costs of PsA [2]

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Sources: 1: Ogdie, A., et al (2015) Recognizing and managing comorbidities in psoriatic arthritis. Curr Opin Rheumatol. 27(2):118-26; 2: Lee, S., et al. (2010) The burden of psoriatic arthritis: a literature review from a global health systems perspective. P.T.; 35(12): 680–689

Several PsA therapies have been introduced to control symptoms and slow disease progression

How can PsA be treated?
There is currently no cure for PsA. The main goals of treatment are to prevent disease progression, relieve symptoms, improve the quality of life and restore functional ability. There are a number of options available for patients and the treatment is largely determined by the severity of the disease and response to prior therapy used

Self–care
The patient should [1]:

…stop smoking

…monitor their diet

…lose weight in case of obesity

…moderate their alcohol intake

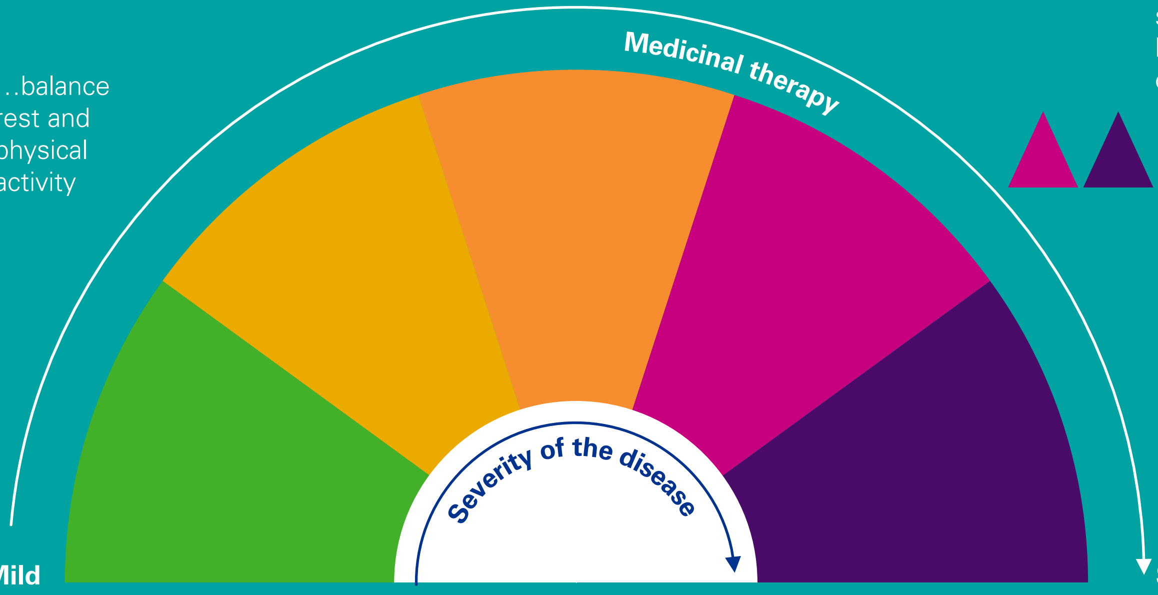
…balance rest and physical activity

NSAIDS (non–steroidal anti–inflammatory drugs) are prescribed to relieve pain and reduce inflammation but they are not effective in treating skin lesions [1]

Steroids can be administered locally to relieve pain and swelling although there are limited data confirming their utility in PsA [1]

Synthetic DMARDs (disease–modifying antirheumatic drugs) are used widely as a first–line systemic therapy for PsA; however, clinical evidence of their efficacy is scant [1]

In moderate to severe PsA, **biologics** are administered to slow joint damage and the progression of PsA. Some new biologics are currently being tested as potential treatments for PsA [1]



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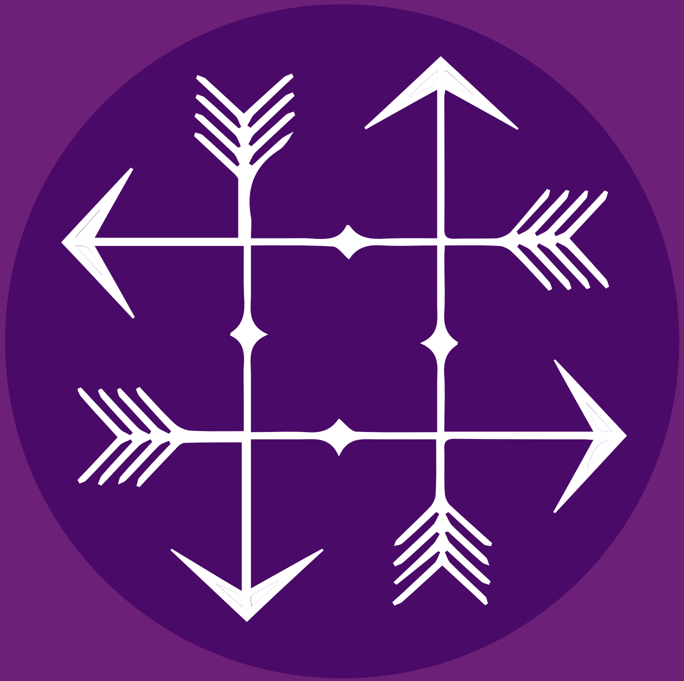
Note: Synthetic DMARDs refer to the conventional systemic drugs such as methotrexate and sulfasalazine, as this is commonly used nomenclature; biologics refer to the group of biological therapies targeting TNF, IL12/23, IL17 and others. Sources: KPMG interviews; secondary research: 1: The Arthritis Foundation (2016) http://www.arthritis.org/about-arthritis/types/psoriatic-arthritis/self-care.php; accessed: 6th April 2016; 2: Huynh, D. Kavanaugh, A. (2015) Psoriatic arthritis: current therapy and future approaches. Rheumatology. 54:20-28

Goals



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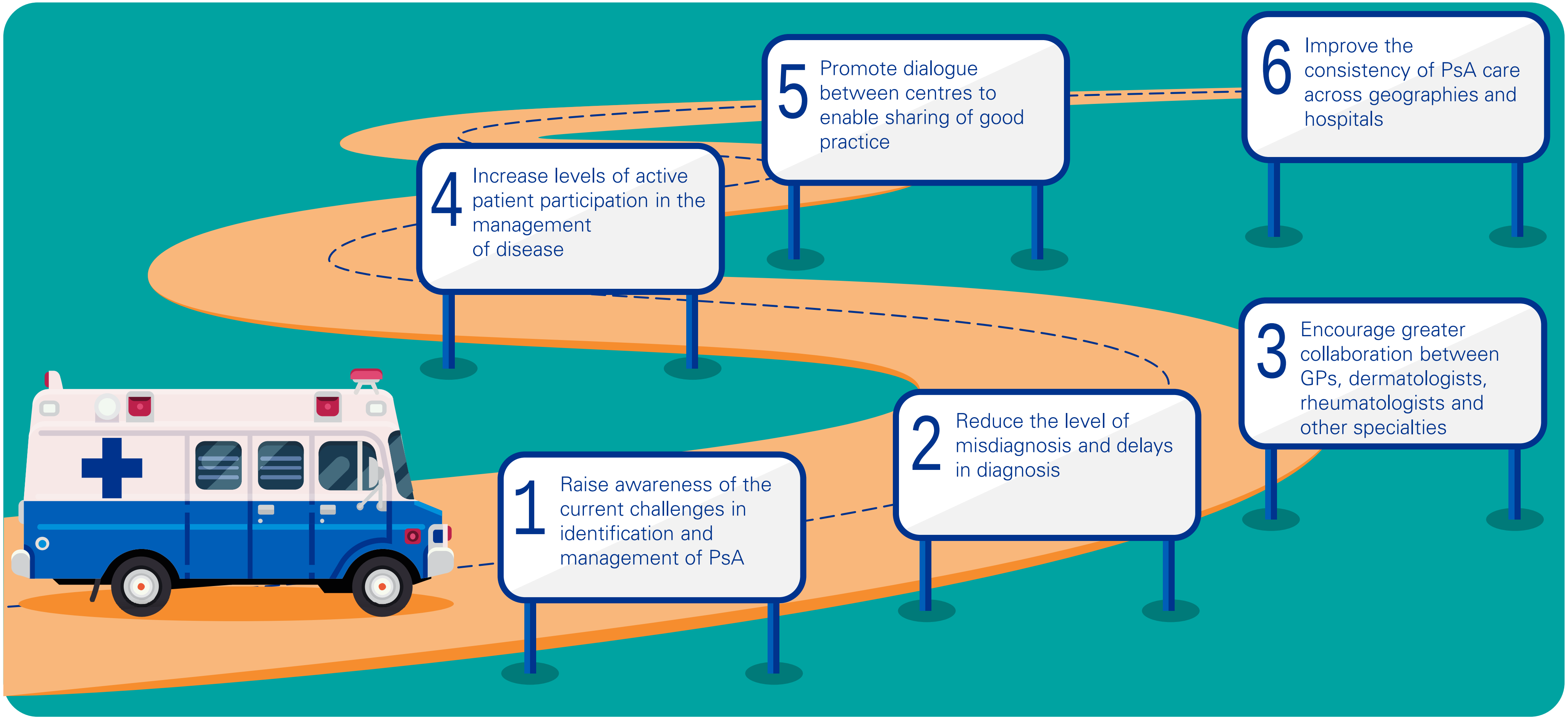
The goal of our initiative is to help improve the quality and efficiency of PsA care globally

What is the goal of this report?

The goal was to collate information and views on key initiatives to improve care from clinicians and patients in multiple worldwide centres. By doing so, we aimed to identify, document and share practices to help increase the awareness of PsA, promote timely and accurate diagnosis, increase the consistency of care and, ultimately, to improve outcomes of patients with PsA



1 Raise awareness of the current challenges in identification and management of PsA

2 Reduce the level of misdiagnosis and delays in diagnosis

3 Encourage greater collaboration between GPs, dermatologists, rheumatologists and other specialties

4 Increase levels of active patient participation in the management of disease

5 Promote dialogue between centres to enable sharing of good practice

6 Improve the consistency of PsA care across geographies and hospitals

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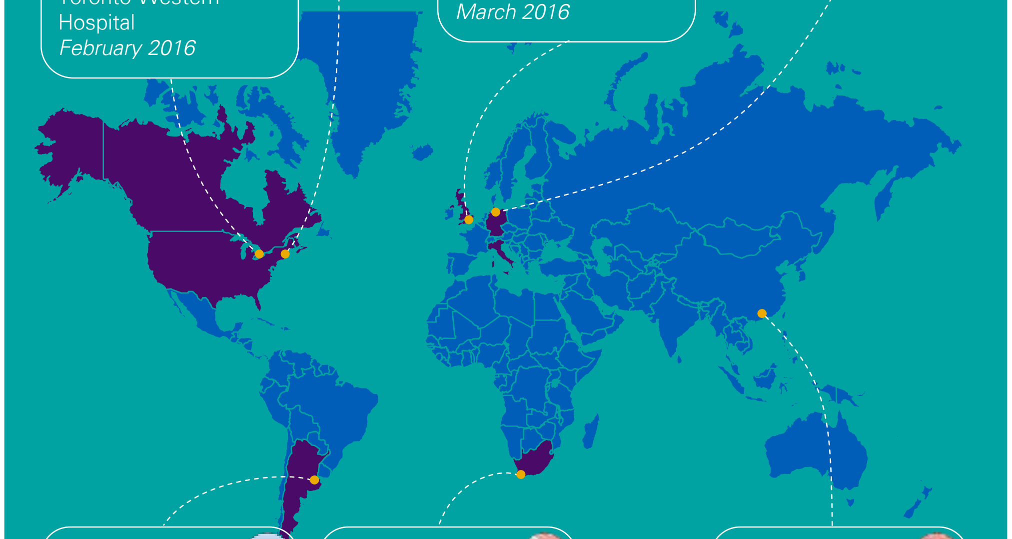
To understand what PsA care looks like, we visited seven centres across the world

Which centres did we visit?



US
BOSTON
Brigham and Women's Hospital
January 2016

Canada
TORONTO
Toronto Western Hospital
February 2016

UK
LONDON
Guy's and St Thomas' NHS Foundation Trust
March 2016

Germany
LÜBECK
University Hospital Schleswig–Holstein
February 2016

Argentina
BUENOS AIRES
Hospital Italiano de Buenos Aires
February 2016

South Africa
CAPE TOWN
Groote Schuur Hospital
March 2016

Hong Kong
HONG KONG
Prince of Wales Hospital
March 2016

Note: We also interviewed a dermatologist-rheumatologist from the Tufts Medical Center in Boston and a rheumatologist at Women's College Hospital in Toronto

— Members of the **Group for Research and Assessment of Psoriasis and Psoriatic Arthritis** (**GRAPPA**) chose seven centres across the world to participate in the project

— The centres were selected to represent a **variety of geographies**, **healthcare systems**, **care settings**

(i.e. academic versus non–academic centres)

and **different access to specialties** (i.e. dermatology versus rheumatology)

We also looked for **novel models of care** and **referral pathways**

— Whenever possible, we visited nearby community centres to understand the challenges in PsA care within this particular setting

Click on flag in the map to go to the relevant site specific section

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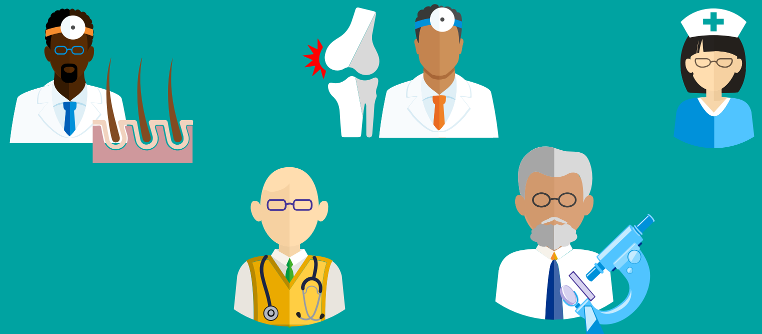
Within these designated centres, we talked to a number of stakeholders to understand how care is delivered in different settings

Who did we engage with?

We talked to a range of stakeholders, including:

○ **Dermatologists** ○ **Rheumatologists** ○ **Nurses**



○ **GPs** ○ **Researchers…**

… to understand how care is delivered

We also engaged with:

○ **Patients**

○ **Patient associations**

…to understand the personal impact of the disease and the way the standards of care influenced their experience

What did we observe?

During the visits we observed:

Premises

We observed practices across a typical patient journey

Processes

We observed the holistic management of skin and joint issues in the dermatology and rheumatology teams we visited

Team interaction

To assess the level of interaction between rheumatologists and dermatologists, we attended group meetings in which patient cases and team issues were discussed. To ensure patient confidentiality, no patient– identifiable data was shared during those meetings

Educational materials

To understand the patient experience, we asked centres to share any educational material and information support provided to the patients

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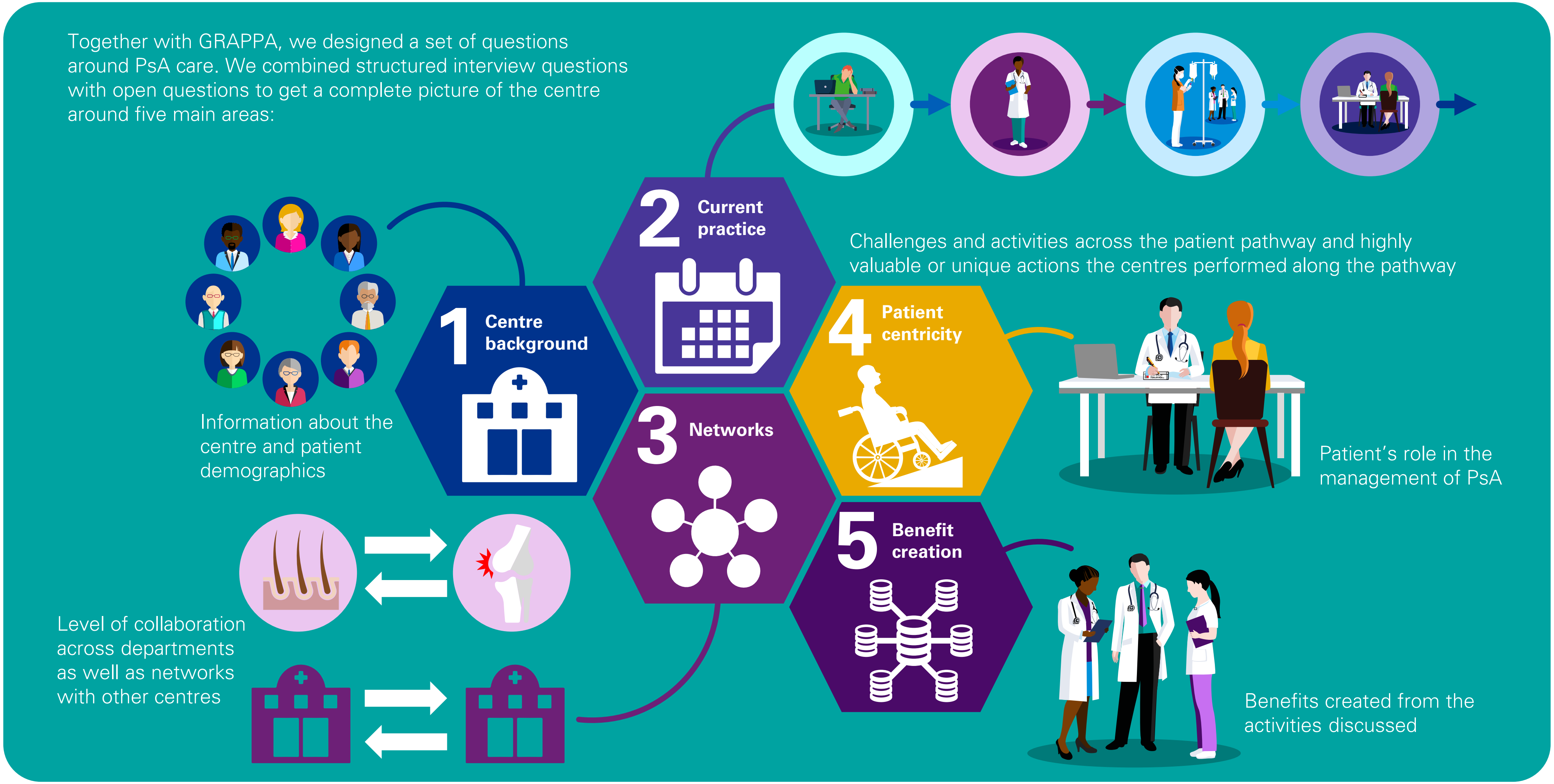
We engaged with stakeholders in five key areas to get a holistic view of PsA care at their centre

Approach

What did we ask about?



Together with GRAPPA, we designed a set of questions around PsA care. We combined structured interview questions with open questions to get a complete picture of the centre around five main areas:

1 Centre background

Information about the centre and patient demographics

2 Current practice

Challenges and activities across the patient pathway and highly valuable or unique actions the centres performed along the pathway

3 Networks

Level of collaboration across departments as well as networks with other centres

4 Patient centricity

Patient's role in the management of PsA

5 Benefit creation

Benefits created from the activities discussed

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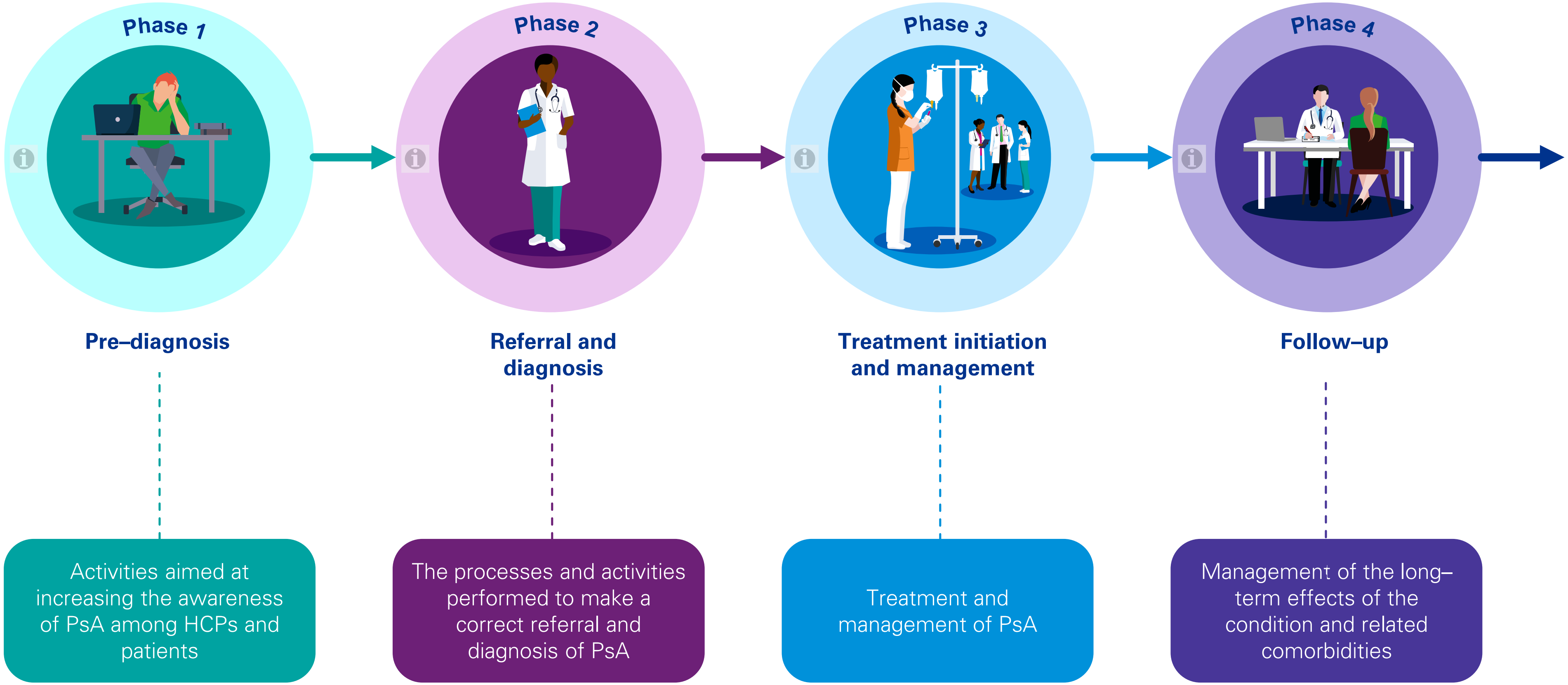
The PsA patient pathway may be separated into four distinct stages

Following our discussions with Healthcare Professionals (HCPs) and patients, we divided the patient journey into four phases: 1. Pre–diagnosis, 2. Referral and diagnosis, 3. Treatment initiation and management and 4. Follow–up. The clinicians we interviewed universally agreed that this was a fair reflection of the patient pathway for PsA



Pre–diagnosis

Activities aimed at increasing the awareness of PsA among HCPs and patients

Referral and diagnosis

The processes and activities performed to make a correct referral and diagnosis of PsA

Treatment initiation and management

Treatment and management of PsA

Follow–up

Management of the long–term effects of the condition and related comorbidities

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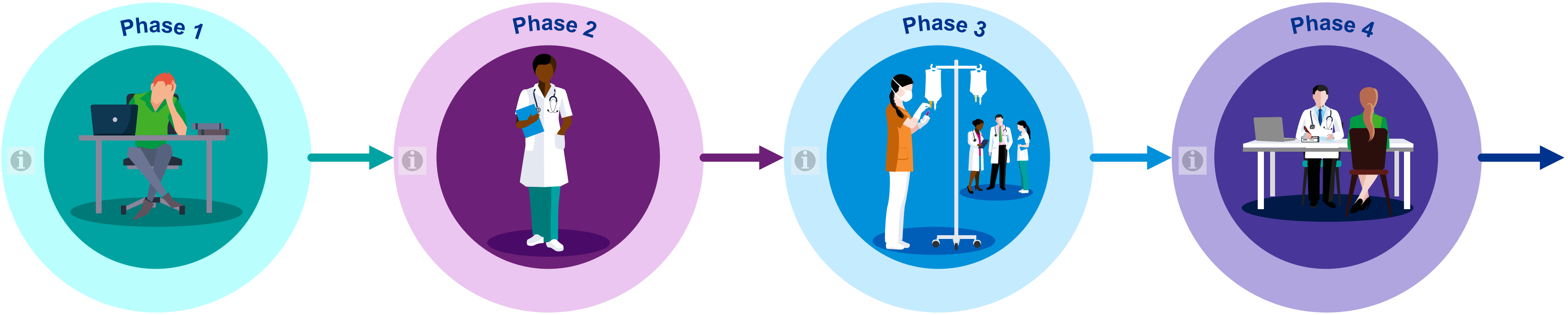
Source: KPMG interviews

We have identified a range of challenges that persist along the PsA pathway

Click on each small circle to go to the relevant 'challenge'

We engaged with HCPs and patients across the world to understand the challenges faced along the patient pathway



Pre–diagnosis

- **Limited awareness of PsA among HCPs and patients**

Referral and diagnosis

- **Lack of screening**
- **Delayed referrals**
- **Challenges with differential diagnosis**

Treatment initiation and management

- **Siloed approach to care in secondary, tertiary and community centres**
- **Gaps in clinical management**
- **Challenges associated with the use of biologics**
- **Lack of patient centricity**

Follow–up

- **Inadequate management of comorbidities**
- **Lack of regular follow–up**

Source: KPMG interviews

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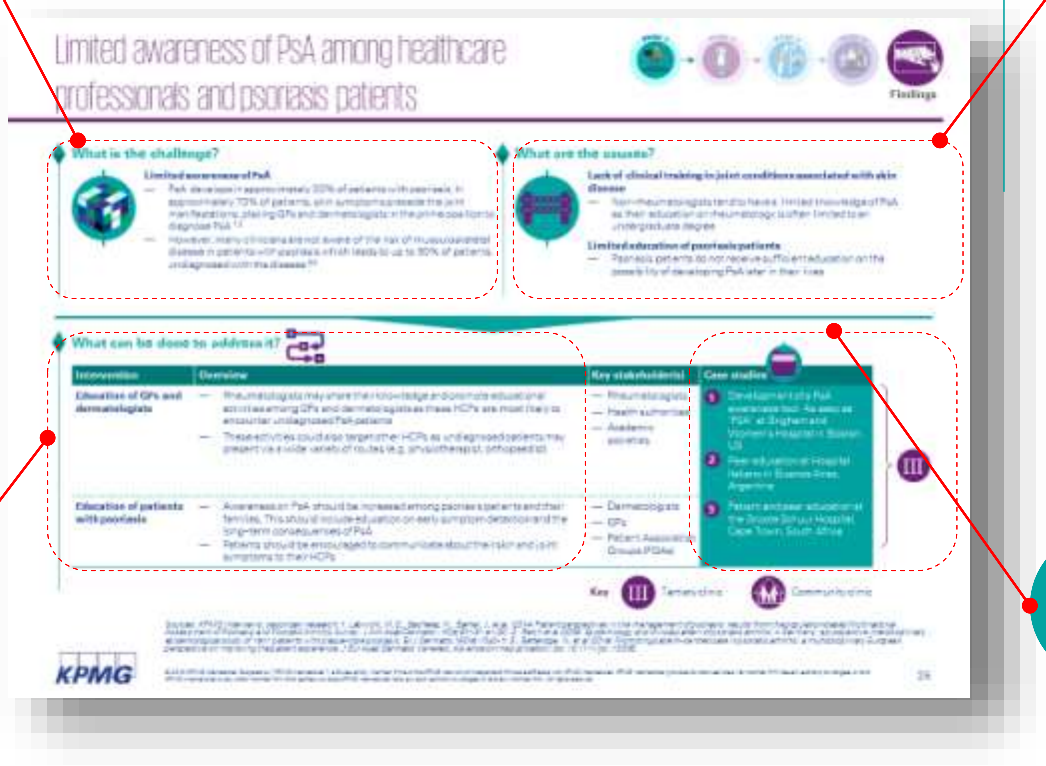
We have then captured the interventions that address these challenges, as well as their benefits and how to implement them

What is the challenge?

This paragraph provides details of the challenge associated with PsA care

What can be done to address it?

This paragraph explains the interventions that can be introduced to address the challenge



Limited awareness of PsA among healthcare professionals and psoriasis patients

What is the challenge?

Limited awareness of PsA

What are the causes?

Lack of clinical training in joint conditions associated with skin disease

Limited education of psoriasis patients

What can be done to address it?

Intervention	Overview	Key stakeholder(s)	Case studies
Education of GPs and dermatologists			
Education of patients with psoriasis			

What are the causes?

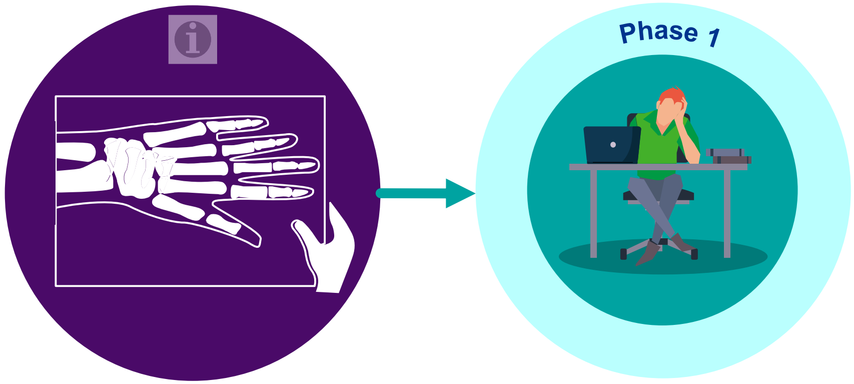
This paragraph explains what causes this issue

Case studies

This is a list of the case studies which are detailed on the following pages, presenting the overview, key features, benefits, challenges and next steps

Home

Key findings



Findings

Pre–diagnosis

— **Limited awareness of PsA among HCPs and patients**

> **My knowledge of PsA is based on the undergraduate training in rheumatology and I have not had any formal training since. I am never able to tell whether a patient's pain is related to PsA or not**
>
> Dermatologist, Prince of Wales Hospital, Hong Kong

Home

Key findings

Limited awareness of PsA among healthcare professionals and psoriasis patients

What is the challenge?

Limited awareness of PsA

- PsA develops in approximately 30% of patients with psoriasis [1]. In about 70% of patients, skin symptoms precede the joint manifestations, placing GPs and dermatologists in prime position to diagnose PsA [1,2]
- However, many clinicians are not aware of the risk of musculoskeletal disease in patients with psoriasis which leads to many patients undiagnosed with the disease [2]

What are the causes?

Lack of clinical training in joint conditions associated with skin disease

- Non–rheumatologists tend to have limited knowledge of PsA as their education on rheumatology is often limited to their undergraduate degree

Limited education of psoriasis patients

- Psoriasis patients do not receive sufficient education about the possibility of developing PsA later in their lives

What can be done to address it?

Click on each number below to go to the relevant case study

Intervention	Overview	Key stakeholder(s)	Case studies
Education of GPs and dermatologists	— Rheumatologists may share their knowledge and promote educational activities among GPs and dermatologists as these HCPs are most likely to encounter undiagnosed PsA patients — These activities could also target other HCPs as undiagnosed patients may present via a wide variety of routes (e.g. physiotherapist, orthopaedist)	— Rheumatologists — Health authorities — Academic societies	① PsA awareness tool: As easy as 'PSA', Brigham and Women's Hospital in Boston, US ② Peer education at Hospital Italiano in Buenos Aires, Argentina
Education of patients with psoriasis	— Awareness about PsA should be increased among psoriasis patients and their families. This should include education about early symptom detection and the long–term consequences of PsA — Patients with psoriasis should be encouraged to educate themselves on PsA through educational materials provided at their doctor's office and with help from Patient Association Groups (PAGs) — Patients should also be encouraged to communicate about their skin and joint symptoms to their HCPs	— Dermatologists — GPs — Patient Association Groups — Patients	③ Patient and peer education at the Groote Schuur Hospital, Cape Town, South Africa

III

Key III Tertiary clinic Community clinic

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Sources: KPMG interviews; secondary research: 1: Reich et al (2009) Epidemiology and clinical pattern of psoriatic arthritis in Germany: a prospective interdisciplinary epidemiological study of 1511 patients with plaque–type psoriasis. Br J Dermatol.160(5):1040–7; 2: Lebwohl, M.G., et al. (2014) Patient perspectives in the management of psoriasis: results from the population-based Multinational Assessment of Psoriasis and Psoriatic Arthritis Survey. J Am Acad Dermatol. 70(5):871-81.e1-30

KPMG

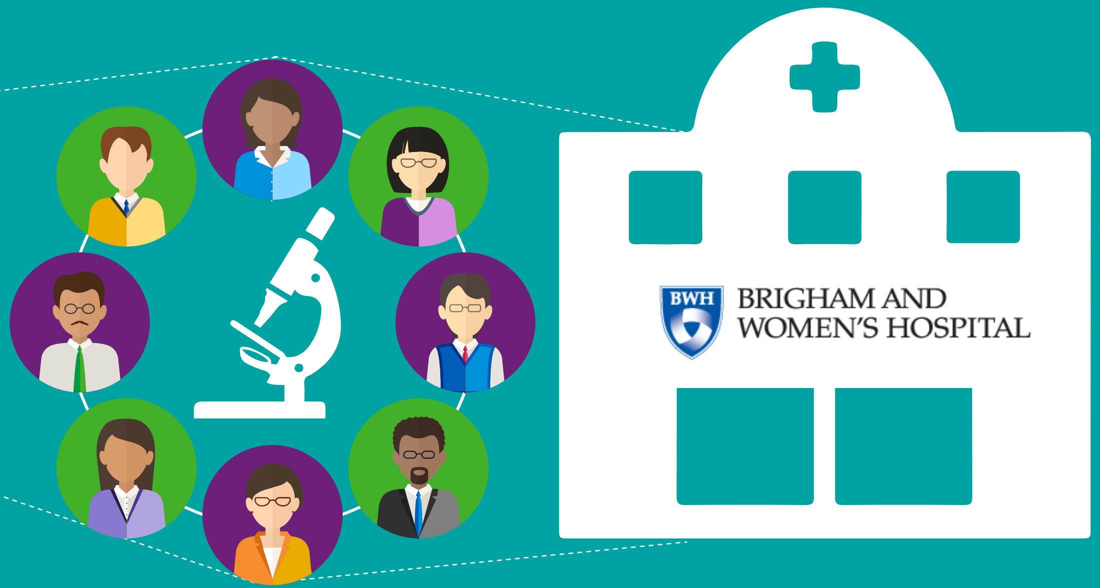
As 'easy as PSA' awareness tool (1/2)

BRIGHAM AND WOMEN'S HOSPITAL

Case study 1

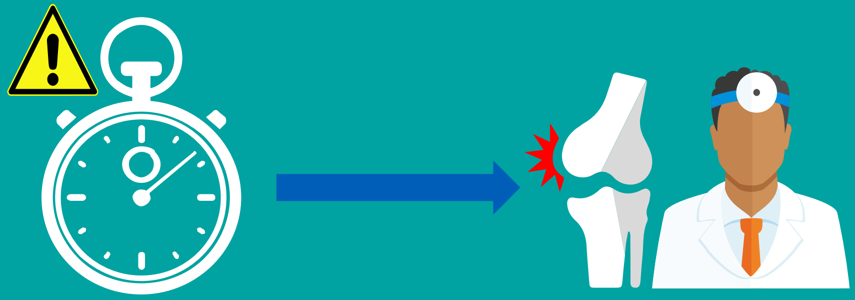
What is 'as easy as PSA'?

Researchers at Brigham and Women's Hospital developed a simple teaching tool to promote awareness of PsA [1]. They proposed the acronym 'PSA' to serve as a mnemonic to help non–rheumatologists remember the main hallmarks of PsA (Pain, Swelling or Stiffness, Axial disease)



This tool helps with early recognition of PsA symptoms and can be followed by a validated screening test and referral to a rheumatologist

This awareness tool is being validated as a simple screening tool for PsA



Challenge
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Sources: KPMG interviews; secondary research: 1: Cohen, J.M et al (2014) Psoriatis arthritis: It's as easy as 'PSA'. J Am Acad Dermatol. 72: 905-906

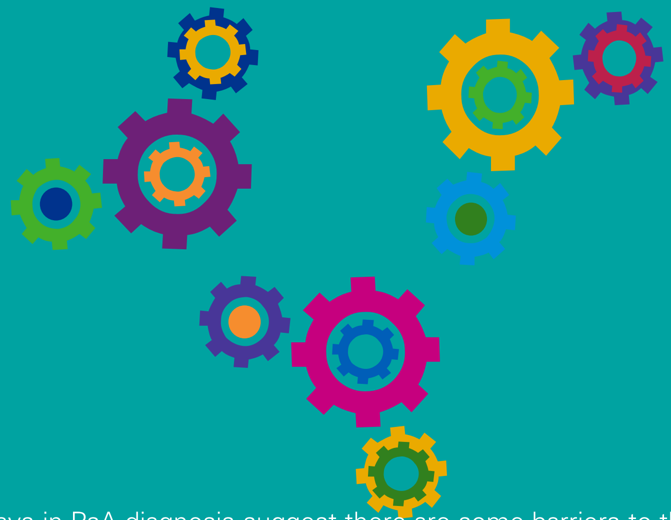
As 'easy as PSA' awareness tool (2/2)

BRIGHAM AND WOMEN'S HOSPITAL

Case study 1

What was the rationale for developing the tool?

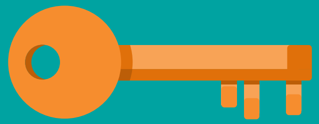
Although a number of PsA screening tools exist…



…delays in PsA diagnosis suggest there are some barriers to their use in the primary and dermatology care setting

This simple tool was developed to increase PsA awareness among medical students, residents and all HCPs to improve screening and contribute to more rapid diagnosis

What are the key features of 'as easy as PsA'?



The mnemonic follows the PsA acronym and is composed of three key themes that a non–rheumatologist should look out for in patients [1], namely:

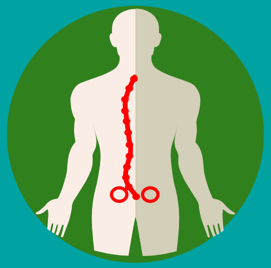
1. Pain

Joint pain is a key feature of PsA

2. Swelling/stiffness

Involved joints often become swollen due to inflammatory effusions

'Sausage digit' is the classic description of dactylitis. Joint stiffness after >30 minutes of inactivity or upon waking in the morning is a classic feature of PsA



3. Axial disease

PsA may clinically develop as a spondyloarthritis with involvement of the axial spine and sacroiliac joints

Sources: KPMG interviews; secondary research: 1: Cohen, J.M et al (2014) Psoriatis arthritis: It's as easy as 'PSA'. J Am Acad Dermatol. 72: 905-906

Peer education

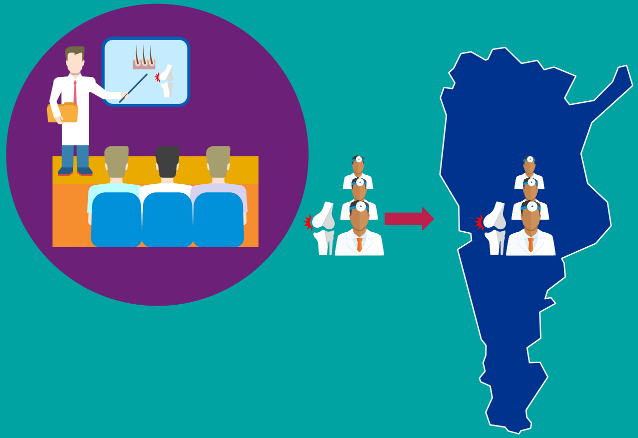
HOSPITAL ITALIANO
de Buenos Aires

Case study 2

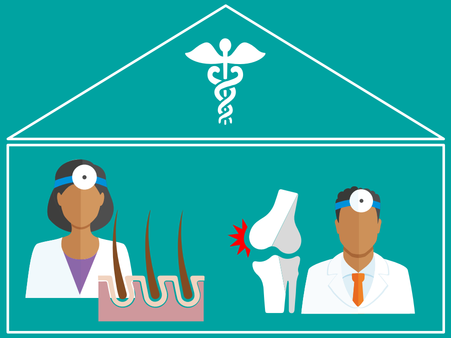
Overview:
The level of awareness of PsA can be relatively low among GPs as well as specialists (rheumatologists and dermatologists). This can lead to a delay in diagnosis or even misdiagnosis. Patients from Hospital Italiano attested to delays in diagnosis of a few years. Earlier diagnosis enables patients to be treated before PsA becomes more advanced and more severe

What are the key features of peer education?

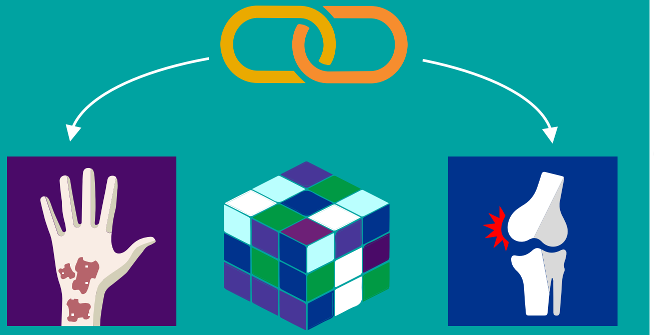
Rheumatologists: The hospital organises annual preceptorships that run over two–and–a–half days and are attended by rheumatologists from both within Argentina and outside the country. Dr Soriano and his team have built the courses themselves. In the past few years preceptorships have covered topics such as new therapies in psoriasis, diagnosis of early–stage arthritis and how to evaluate a patient's joints



Dermatologists: The crucial component of the team's peer education as they may not always relate musculoskeletal symptoms to skin conditions. Having a combined clinic is one way of ensuring a close relationship between the rheumatology and dermatology teams, and the yearly preceptorships include both rheumatologists and dermatologists



GPs: Rheumatologists also work with GPs within the network to raise their awareness about PsA, train on how to identify symptoms of the disease and educate them about comorbidities associated with PsA. The training is provided via grand rounds with rheumatologists, journal clubs and seminars



Challenge
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Key findings

Source: KPMG interviews

Patient, peer and student education

Groote Schuur Hospital
Cape Town

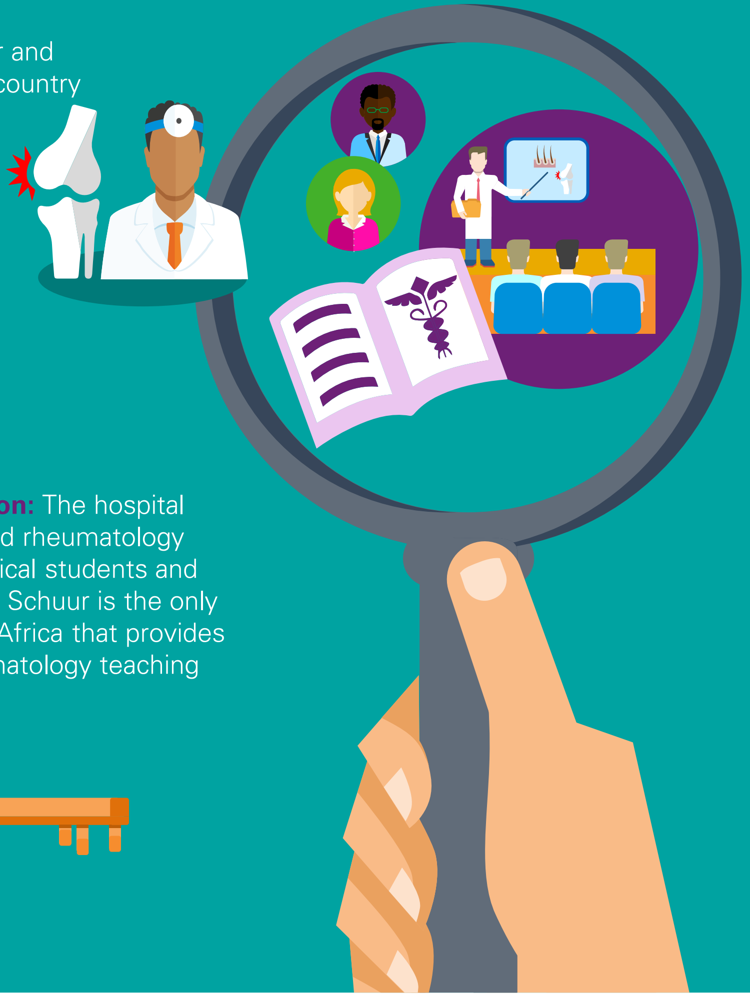
Overview

Rheumatologists from the Groote Schuur Hospital in Cape Town place a strong focus on patient, peer and student education. This is especially important because of the low number of rheumatologists in the country and the limited knowledge of rheumatology among other clinicians

What is the rationale?

Training programmes and education of HCPs and patients:

- Enable doctors to recognise symptoms of PsA and to relate musculoskeletal symptoms to skin problems
- Improve awareness of a disease that is highly undiagnosed
- Improve referrals to rheumatologists who can initiate the correct treatment
- Help patients understand the disease and be more familiar with the treatment



What are the key features of patient and peer education?

Patient education: Rheumatologists from the Groote Schuur Hospital run sessions for patients during which they try to increase their understanding of the disease and help them cope with any challenges they may encounter. These sessions are organised every couple of months and the meetings are broadcast at community health centres to ensure that patients who are unable to reach the hospital can benefit from them as well

Peer education: The team organises educational sessions for primary care which focus on signs of arthritis and help doctors identify which patients to refer to the rheumatologist. They also give lectures to the entire department of medicine to up–skill the team in rheumatology. These sessions are considered useful by both experienced and junior doctors. Within the hospital they also have trainees from other African countries to improve knowledge transfer and share learnings

Student education: The hospital provides dedicated rheumatology education to medical students and registrars. Groote Schuur is the only hospital in South Africa that provides specialised rheumatology teaching courses

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Source: KPMG interviews

These interventions can lead to a number of potential benefits

During our site visits, we asked the stakeholders to highlight the potential benefits that may be achieved through the implementation of discussed interventions. Although the centres we visited do not have formal systems in place that allow the impact to be measured, most of them agreed on the benefits that can be achieved

Intervention	Clinical benefits					Economic benefits		Patient experience	
	Improved time to referral/ diagnosis	Improved disease control	Improved adherence	Adequate control of comorbidities	Improved QoL	Fewer hospital admissions	Reduced productivity loses	Improved empowerment	Increased convenience
Challenge: Limited awareness of PsA among HCPs and psoriasis patients									
Education of GPs and dermatologists	✓	✓		✓	✓	✓	✓		
Education of patients with psoriasis	✓	✓	✓	✓	✓	✓	✓	✓	

Challenge
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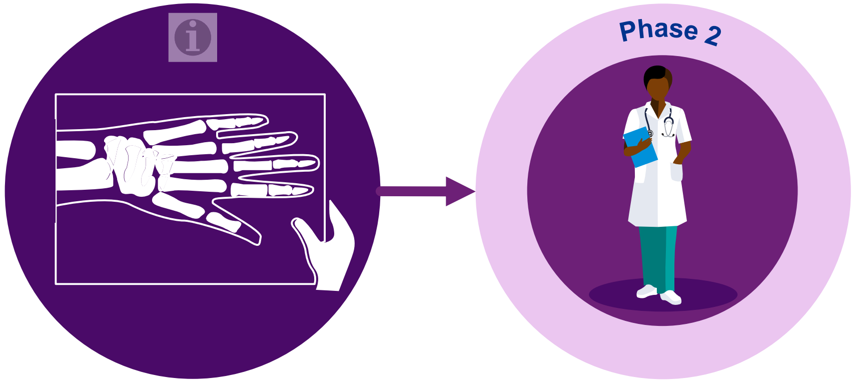
Key findings

Source: KPMG interviews



Findings

Referral and diagnosis

- **Lack of screening**
- Delayed referrals
- Challenges with differential diagnosis

> **Recently published guidelines recommend that dermatologists screen their psoriasis patients for PsA. However, it is still not standard practice and dermatologists tend not to do it**
>
> Rheumatologist–dermatologist, Tufts Medical Center, Boston

Home

Key findings

Lack of screening for PsA

What is the challenge?

Lack of screening

- Multiple screening tools have been developed to help non–rheumatologists identify patients who would benefit from a referral to a rheumatologist; however, these tools are not regularly used by dermatologists and GPs

What are the causes?

Limited awareness and short appointment times

- Lack of adequate training about the clinical symptoms of PsA among non–rheumatologists, combined with short consultation appointments, prevent a thorough clinical examination [1]

Limited specificity and/or sensitivity

- Although a number of screening tools exist, their limited sensitivity and specificity may hinder accurate identification of PsA patients, both in the general population and among psoriasis patients [2]
- There is also no consensus about which screening tools should be used in dermatology and GP clinics

What can be done to address it?

Click on each number below to go to the relevant case study

Intervention	Overview	Key stakeholder(s)	Case studies
Regular screening	— GPs and dermatologists should regularly screen their PsA patients for signs or symptoms of PsA which can be done through the use of screening tools	— GPs — Dermatologists	List of existing screening tools for PsA
Refinement and/or development of new screening tools	— Rheumatologists should implement studies aimed at the refinement and/or development of new screening tools that are more specific and sensitive but, at the same time, place minimal administrative burden on HCPs	— Rheumatologists — Dermatologists — Patients	1 Development of a screening tool at Brigham and Women's Hospital, Boston, US (Psoriatic Arthritis Screening Evaluation, PASE) 2 Development and refinement of screening tools at the Toronto Western Hospital in Canada (Toronto Psoriatic Arthritis Screening, ToPAS/ToPAS 2) 3 Use of the Psoriasis Epidemiology Screening Tool (PEST) III

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Key findings

Key III Tertiary clinic Community clinic

Sources: KPMG interviews; secondary research: 1: Betteridge, N. et al (2015) Promoting patient–centred care in psoriatic arthritis: a multidisciplinary European perspective on improving the patient experience. J Eur Acad Dermatol Venereol. Advance online publication; doi: 10.1111/jdv.13306; 2: Helliwell, P., et al. (2014) Qualifying Unmet Needs and Improving Standards of Care in Psoriatic Arthritis. Arthritis Care Res (Hoboken). 2014 Dec; 66(12): 1759–1766

There are several validated screening tools for PsA which demonstrate comparable sensitivity and specificity

Various screening tools, including self–administered questionnaires, have been developed with the aim of helping dermatologists and GPs identify patients who might suffer from PsA. During our centre visits we spoke to specialists involved in the development of two of such tools, PASE and ToPAS 2, which are presented in more detail on the following pages. In addition, PEST is also described in more detail as some of the clinicians indicated that this questionnaire is used frequently in the clinical practice

Tool	Setting in which the tool was developed/validated			Number of items	Visual cues	Cut–off score	Sensitivity (%)	Specificity (%)	Axial involvement	Nail or skin involvement
	Dermatology clinic	Rheumatology clinic	Other							
PASE	✓	✓		15	No	47 44	82 76	73 76	Yes	No
ToPAS/ ToPAS 2	✓	✓	Phototherapy centres, family medicine clinics	12 12	ToPAS/ToPaS 2: Pictures of skin and nail lesions ToPAS 2: Inflamed joints and dactylitis	8 8	87 96	93 99	Yes Yes	Yes Yes
PEST	✓		Primary–care–based population with psoriasis	5	A manikin (to specify areas of tenderness)	3	92	78	Yes	Yes
PASQ	✓	✓		10	A manikin (for joint areas involved)	7	93 98	75 75	Yes	Yes
EARP	✓			10	No	3	85	92	Yes	No

Challenge
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Abbreviations: EARP: Early Arthritis for Psoriatic patients; PASE: Psoriatic Arthritis Screening Evaluation; ToPAS: Toronto Psoriatic Arthritis Screen; PEST: Psoriatic Epidemiology Screening Tool; PASQ: Psoriatic Arthritis Screening Questionnaire

Sources: KPMG interviews; secondary research: Table adapted from: Olivieri, I. et al (2014) Advances in the management of psoriatic arthritis. Nat Rev Rheum. 10:531–542

Psoriatic Arthritis Screening Evaluation (PASE) (1/2)

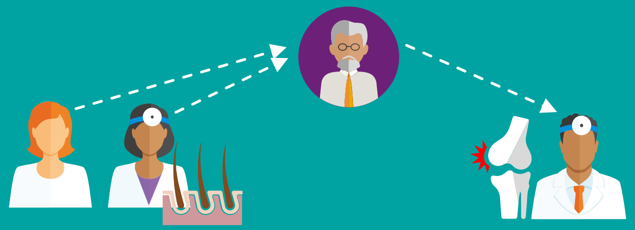
BRIGHAM AND WOMEN'S HOSPITAL

Case study 1

What is the PASE questionnaire?

The Psoriatic Arthritis Screening and Evaluation (PASE) questionnaire is a tool developed by a multidisciplinary team of dermatologists, rheumatologists and patient focus groups at the Brigham and Women's Hospital to assist dermatologists and GPs screening patients with psoriasis for evidence of PsA [1]

The tool is intended to help GPs and dermatologists identify patients who are likely to suffer from PsA and should be further evaluated by a rheumatologist

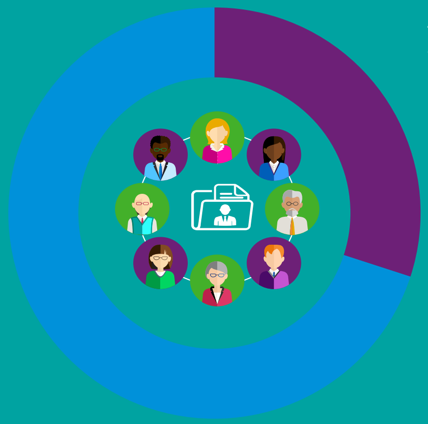


Since its development in 2004, the PASE questionnaire has been translated into more than 30 languages

What was the rationale for developing the tool?

Although approximately **30% of psoriasis patients develop PsA,** the condition is often unrecognised in dermatology and primary care settings. Early diagnosis of symptoms are important since delaying treatment may lead to **irreversible joint damage** [1]

The questionnaire was developed to provide a **quick** and **easy** tool to identify patients who might suffer from PsA



Challenge
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Key findings

Sources: KPMG interviews; secondary research: 1: Husni, M.E., et al (2007) The PASE questionnaire: pilot-testing a psoriatic arthritis screening and evaluation tool. J Am Acad Dermatol. 57(4):581-7

Psoriatic Arthritis Screening Evaluation (PASE) (2/2)

BRIGHAM AND WOMEN'S HOSPITAL

Case study 1

What are the key features of the tool?

i PASE is **self–administered** and takes a **few minutes to complete**

ii PASE consists of a 15–item scoring system grouped into two sections:

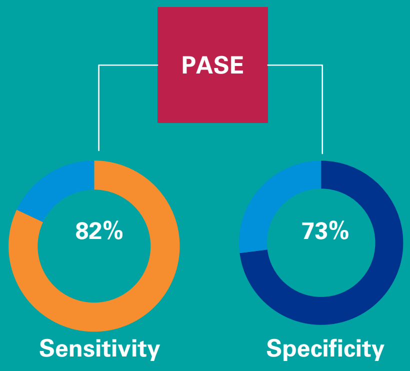
1. **Symptoms** (e.g. 'I feel tired most of the day')
2. **Function** (e.g. 'I have had trouble getting out of a car')

iii The questionnaire includes a five–point response scale (1: strongly disagree to 5: strongly agree)

1 2 3 4 5

What are the benefits of using this tool?

PASE is an effective tool for identifying early symptoms of PsA among psoriasis patients. PASE total score of 47 is able to distinguish PsA from non–PsA patients with 82% sensitivity and 73% specificity



What are the challenges faced by PASE?

Similarly to the other tools described, PASE is a screening tool for PsA and does not replace a comprehensive musculoskeletal evaluation by a rheumatologist

In addition, its performance needs to be validated in a real–world setting

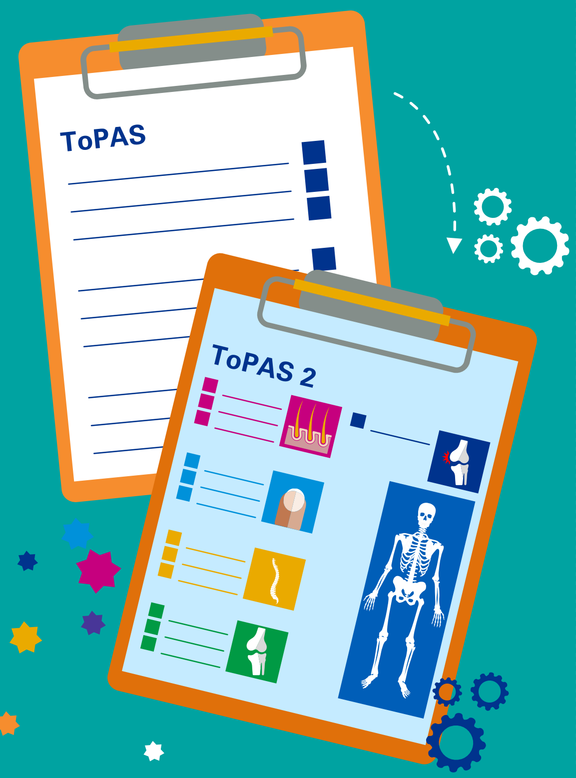
Challenge
Home
Key findings

Sources: KPMG interviews; secondary research: 1: Husni, M.E., et al (2007) The PASE questionnaire: pilot-testing a psoriatic arthritis screening and evaluation tool. J Am Acad Dermatol. 57(4):581-7

The Toronto Psoriatic Arthritis Screen 2 (ToPAS 2) (1/2)

What is ToPAS 2?

ToPAS 2 is the successor to ToPAS, the Toronto Psoriatic Arthritis Screen, a diagnostic screening tool developed at Toronto Western Hospital [1]



What was the rationale behind the creation of ToPAS2?

ToPAS 2 was developed as a screening tool for dermatologists and GPs to increase the referral rates of patients who present with PsA symptoms and for epidemiological studies

This early referral is key to avoid the accumulation of irreversible joint damage. Studies have shown that patients who are reviewed by rheumatologists earlier in the course of their disease have better radiographic and functional outcomes [2]

Challenge
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Key findings

Sources: KPMG interviews; secondary research: 1: Tom, B.D, et al (2015) Validation of the Toronto Psoriatic Arthritis Screen Version 2 (ToPAS 2). J Rheumatol. 42(5):841-6; 2: Haroon, M., et al (2015) Diagnostic delay of more than 6 months contributes to poor radiographic and functional outcome in psoriatic arthritis. Ann Rheum Dis;74:1045-1050

The Toronto Psoriatic Arthritis Screen 2 (ToPAS 2) (2/2)

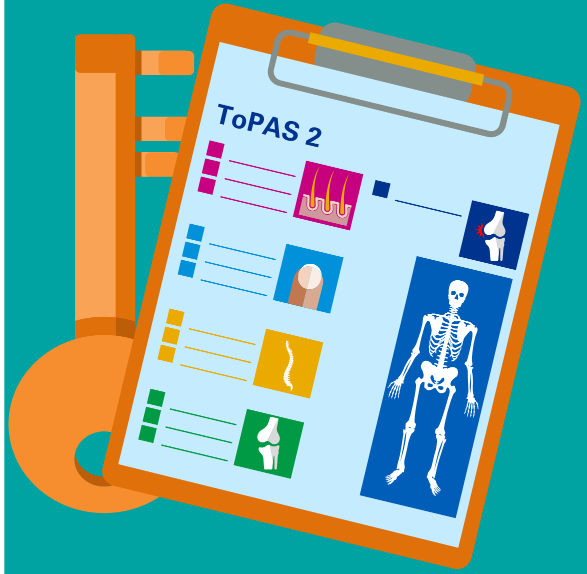
Toronto Western Hospital

Case study 2

What are the key features of ToPAS 2?

The questionnaire was developed with **input from both patients and physicians**

It includes 13 questions about psoriasis, nail lesions, joint pain and swelling, back pain and stiffness, and dactylitis. The questionnaire also contains images representing skin and nail lesions, joint disease and dactylitis to help physicians recognise the symptoms [1]

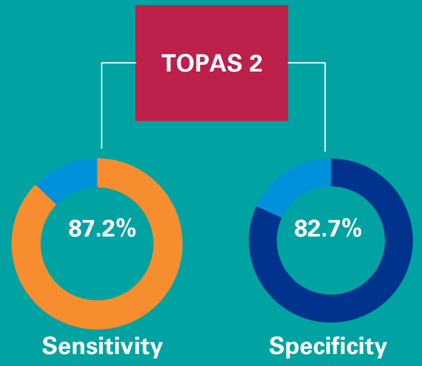


Example question:

(9) Have you **ever** had low back pain **and** stiffness lasting at least three months that was not the result of injury? If yes,
(a) Have you ever seen a doctor about this?
(b) What was the diagnosis?

What have been the benefits of using ToPAS 2?

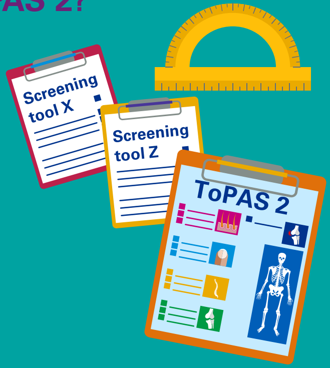
ToPAS 2 proved to be highly sensitive (87.2%) and specific (82.7%) in recognising patients with PsA [1]



What are the challenges for using ToPAS 2?

The tool has proved to be highly specific and sensitive in identifying patients with PsA, which was further validated in the Turkish population [2]

However, there is limited evidence on its usefulness in a real–world setting and its performance against other screening tools



Sources: KPMG interviews; secondary research: 1: Tom, B.D, et al (2015) Validation of the Toronto Psoriatic Arthritis Screen Version 2 (ToPAS 2). J Rheumatol. 42(5):841-6

Psoriasis Epidemiology Screening Tool (PEST) (1/2)

Overview

PEST is a simple screening tool designed to identify cases of PsA in a population of patients with known psoriasis. The tool was developed on the basis of the Swedish modification of the Psoriasis Assessment Questionnaire (PAQ) [1]

Although none of the centres we visited was directly involved in its development, clinicians indicated that PEST is frequently used by non–rheumatologists to screen psoriasis patients for signs of PsA

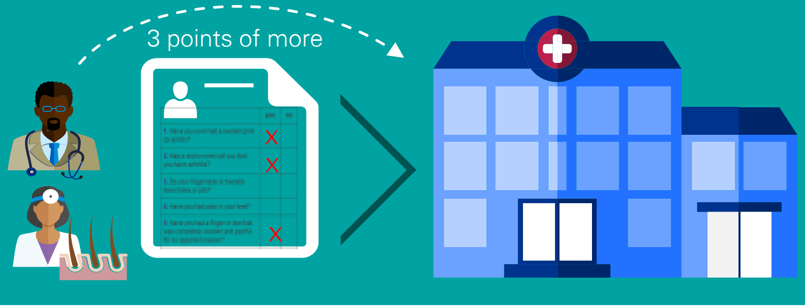
What was the rationale for developing the tool?

Several screening tools have been developed to date but their uptake in dermatology and GP clinics has been rather poor. PEST was developed in order to provide non–rheumatologists with a simple but powerful tool to identify patients with psoriasis who might also suffer from PsA

What are the key features of the PEST tool?

The tool consists of five simple questions (right) which ask about patient's history of swollen joints, nail psoriasis, heel pain, dactylitis and previous diagnosis of arthritis [1]. Score of 1 is given for each affirmative answer; a total score of 3 or more is indicative of PsA and it is recommended that patients are referred to a rheumatologists for further assessment and advice [1]

The questionnaire is supported by a manikin (next page) which enables physicians and patients to identify problematic joints, thus facilitating the referral process [1]



Psoriasis Epidemiology Screening Tool (PEST) Questionnaire [1]

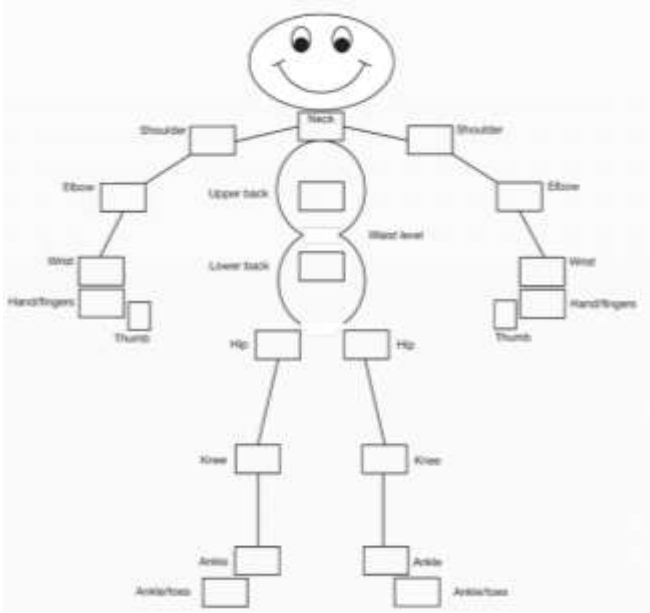
	yes	no
1. Have you ever had a swollen joint (or joints)?		
2. Has a doctor ever told you that you have arthritis?		
3. Do your fingernails or toenails have holes or pits?		
4. Have you had pain in your heel?		
5. Have you had a finger or toe that was completely swollen and painful for no apparent reason?		

Score 1 point for each question answered in the affirmative. A total score of 3 or more is indicative of PsA

Sources: KPMG interviews; secondary interviews: 1: Ibrahim, G.H. (2009) Evaluation of an existing screening tool for psoriatic arthritis in people with psoriasis and the development of a new instrument: the Psoriasis Epidemiology Screening Tool (PEST) questionnaire. Clin Exp Rheumatol. 27(3):469-74

Psoriasis Epidemiology Screening Tool (PEST) (2/2)

Manikin to identify stiff, swollen or painful joints [1]



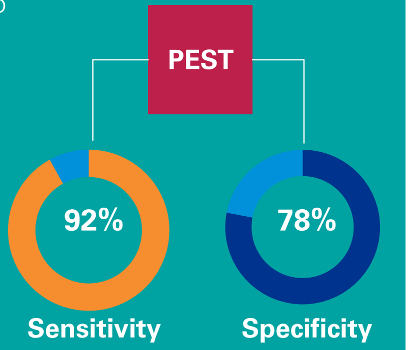
What are the benefits of using such a tool?

During its development, PASE demonstrated 92% sensitivity and 78% specificity, suggesting that its performance is comparable to that of the more complex tools (i.e. PASE and ToPAS) [1]

In a recent head–to–head study (CONTEST) conducted in secondary care dermatology clinics comparing three screening questionnaires, PEST had similar sensitivity to ToPAS and PEST (76.6%, 74.5% and 76.6%, respectively) [2]

In contrast to other tools, PEST has the advantage of simplicity and ease of use as it consists of only five simple questions. The questionnaire is also supported by a manikin to help physicians and patients identify stiff, swollen or painful joints

The tool does not require a licencing agreement which means that it is easily accessible for clinicians



What are the challenges associated with the tool?

Although PEST is a validated screening tool, it does not have specific questions to detect axial disease which can be associated with PsA [3]

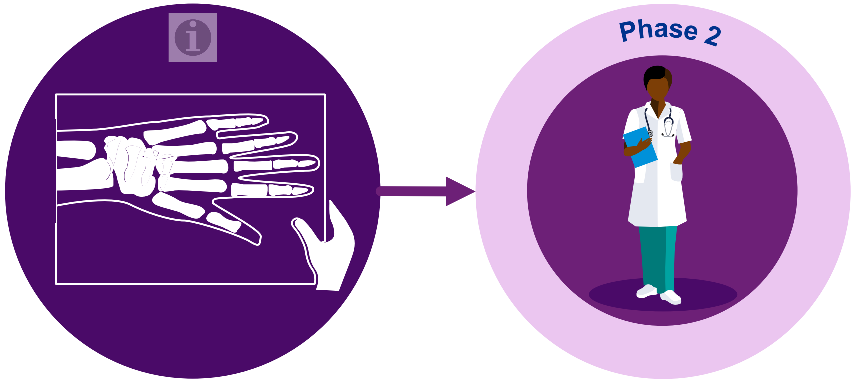
The CONTEST study demonstrated that, similarly to PASE and ToPAS, PEST can identify cases of musculoskeletal disease other than PsA, putting additional burden on rheumatologists [2]

What are the next steps for PEST?

Similarly, as for PASE and ToPAS tools, PEST requires further evaluation and comparison of its performance with other instruments in a real–world setting [2]

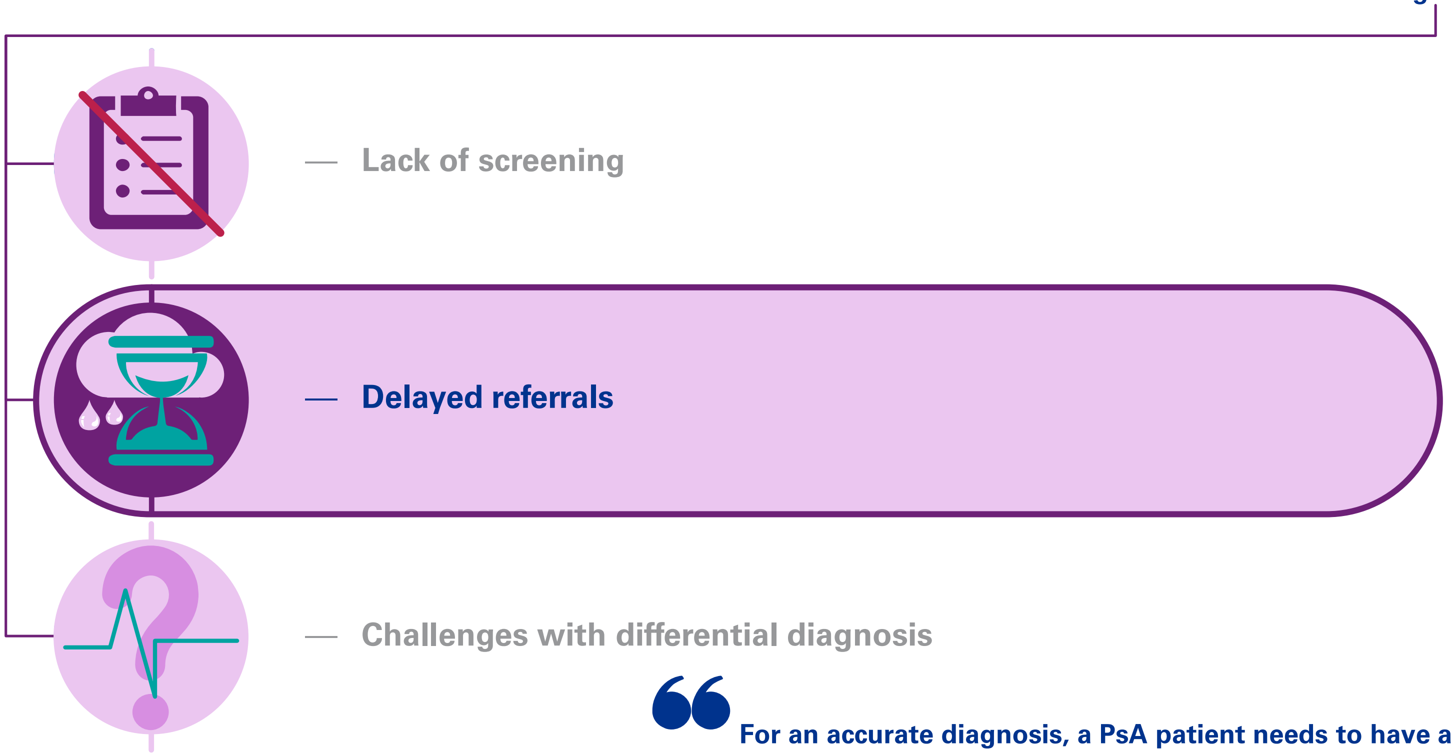
Challenge
Home
Key findings

Source: KPMG interviews; secondary interviews: 1: Ibrahim, G.H. (2009) Evaluation of an existing screening tool for psoriatic arthritis in people with psoriasis and the development of a new instrument: the Psoriasis Epidemiology Screening Tool (PEST) questionnaire. Clin Exp Rheumatol. 27(3):469-74; 2: Coates, L.C. et al, (2013) Comparison of three screening tools to detect psoriatic arthritis in patients with psoriasis (CONTEST study). Br J Dermatol. 168(4):802-7; 3: Ganatra, B. et al (2015) Use of a validated screening tool for psoriatic arthritis in dermatology clinics. BMJ Qual Improv Rep. 4(1): u203335.w2644;



Findings

Referral and diagnosis



— Lack of screening

— **Delayed referrals**

— Challenges with differential diagnosis

> **For an accurate diagnosis, a PsA patient needs to have access to a rheumatologist. But you cannot diagnose the patient in a timely manner if they need to wait 6 months to see the specialist**
>
> Rheumatologist, Hospital Italiano de Buenos Aires, Buenos Aires

Home

Key findings

Delayed referral to a rheumatologist

What is the challenge?

Delayed referral to a rheumatologist

- Patients with PsA tend to remain undiagnosed until seen by a rheumatologist. The correct diagnosis is made approximately five years after the onset of symptoms [1]
- This delay in diagnosis and, hence, in treatment initiation, can result in an increased rate of progression of irreversible joint damage [2]

What are the causes?

Lack of awareness and incentives

- Some dermatologists may be unaware of PsA, have no interest in the disease or lack the incentives to refer their patients

Lack of established referral pathways

- Many community–based dermatologists and GPs do not have established links with rheumatology clinics which can lead to low referral rates

Shortage of rheumatologists

- In some areas there might also be a shortage of rheumatologists leading to long waiting times for an appointment

Wrong referrals

- Some patients might be initially referred to a wrong specialists (e.g. an orthopaedist or a physiotherapist)

What can be done to address it?

Click on each number below to go to the relevant case study

Intervention	Overview	Key stakeholder(s)	Case studies
Early referral	— Patients should be referred to a rheumatologists as soon as PsA is suspected to ensure an accurate diagnosis and initiation of the adequate treatment — Patients should seek medical advice if they believe they have symptoms which indicate PsA	— GPs — Dermatologists — Patients	1 Referral forms for GPs which improve the quality and speed of referrals community clinics in Ontario, Canada
Networks and referral pathways	— **Informal networks:** Close collaboration between GPs/dermatologists and rheumatologists can ensure prompt and accurate referrals — **Formal networks:** Development of novel referral pathways to improve efficiency of referrals from GPs and dermatologists	— Rheumatologists — GPs — Dermatologists	2 Development of a self–referral scheme at Women's College Hospital in Toronto, Canada 3 Outreach activities at the Groote Schuur Hospital in Cape Town, South Africa 4 Network of hospitals in Buenos Aires, Argentina III

> **It can take up to seven years before the patient is referred to us. It is often surprising that they do not have the PsA diagnosis made before. Their symptoms are simply overlooked**
>
> Rheumatologist, University Hospital Schleswig–Holstein, Lübeck

Key III Tertiary clinic 🏠 Community clinic

Sources: KPMG interviews; secondary research: 1: Lebwohl, M.G., Bachelez, H., Barker, J. et al (2014) Patient perspectives in the management of psoriasis: results from the population-based Multinational Assessment of Psoriasis and Psoriatic Arthritis Survey. J Am Acad Dermatol.; 70:871–881.e30; 2: Gladman et al (2011) Do patients with psoriatic arthritis who present early fare better than those presenting later in the disease? Ann Rheum Dis. 2011 Dec;70(12):2152–4

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Key findings

Referral forms for GPs

Community clinics

Case study 1

Overview

Rheumatologists at one of the community–based clinics in Toronto developed a referral form for GPs and dermatologists to ensure that patients are referred in a timely manner with all required tests completed before the visit

What was the rationale behind developing the referral form?

When physicians refer their patients to rheumatologists, they tend not to include all the relevant patient information. However, for specialists to make the correct diagnosis and initiate timely treatment, they need to have access to up–to–date data on their patient's medical history and test results. The referral form was developed to ensure that referring doctors include all the required details in the referral

What are the key features of the referral form?

The referral form contains information on:

- **Patient medical history:** vaccinations, allergies, other chronic disorders, use of certain medicines (e.g. warfarin)
- **Clinical history/specific clinical questions**: the rationale behind the referral
- **Previous test/scan results:** ESR (erythrocyte sedimentation rate test to detect inflammation), hepatitis screening, CRP (C–reactive protein) test, spine x–ray, SI (sacroiliac) joint x–ray

What are the benefits of the referral form?

Providing all relevant clinical history with a specific question to be answered can facilitate the community clinic to:

- Provide timely and accurate diagnosis, and initiate relevant treatment
- Assess the priority of requests relative to others
- Apply the appropriate protocol to maximise the quality and utility of examination

Challenge
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Key findings

Source: KPMG interviews

Self-referral scheme (1/2)

Women's College Hospital, Toronto

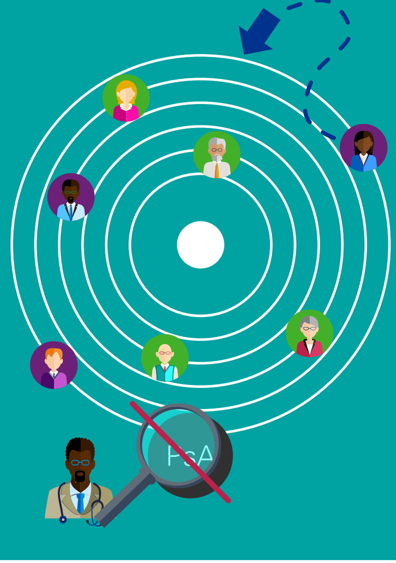
Case study 2

What is the self–referral scheme?

At Women's College Hospital, Dr Eder, a rheumatologist who is also a researcher at Toronto Western Hospital, is developing a model of self–referral where psoriasis patients with musculoskeletal issues would be able to bypass a GP referral which is usually required to see a rheumatologist

What was the rationale behind it?

The primary objective of the self–referral scheme is to identify patients who either do not realise they have PsA, or who are not properly diagnosed by their GPs



What are the key features of the self–referral scheme?

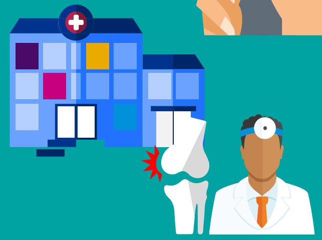
Identification of patients: The plan is to identify psoriasis patients from the psoriasis databases using their diagnostic code, send them PsA information and invite them to take part in the self–referral scheme

This will be supported by distributing flyers and posters in dermatology clinics as well as using online advertisements

Psoriasis patients identified in the dermatology clinic would still be able to self–refer by filling–in electronic forms

Triage clinic: Due to limited resources, not all potential PsA patients will be assessed by a rheumatologist. The triage clinic will form a necessary component of this model

Patients will first be prioritised based on the likelihood of having PsA. The clinic will involve an assessment by an advanced practice physiotherapist who has experience of distinguishing inflammatory and non–inflammatory symptoms. The clinical assessment will be supported by a targeted ultrasound exam and compared to screening questionnaires (e.g. ToPAS 2)



Appointment with a rheumatologist: Patients with suspected PsA will then be assessed by a rheumatologist to confirm the diagnosis and initiate the correct treatment

Source: KPMG interviews

Self-referral scheme (2/2)

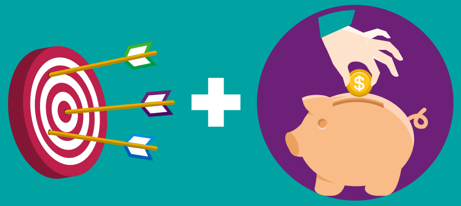
Women's College Hospital, Toronto

Case study 2

What would be the benefits of the self–referral scheme?

It will lead to earlier diagnosis of psoriasis patients with PsA which is likely to contribute to better clinical results

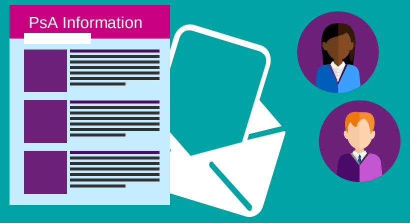
As patients are self–referring it will free up primary care capacity, whilst also making the referral process more efficient and cost effective



What are the challenges facing the self–referral scheme?

The self–referral scheme could lead to an increased workload for rheumatologists as previously undiagnosed patients will need to be assessed and treated

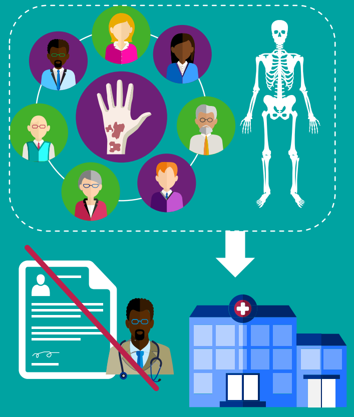
Bespoke PsA information may have to be designed to send to psoriasis patients



Nurses would need spare capacity to identify psoriasis patients and send them the PsA information and self–referral questionnaire

What are the next steps for the self–referral scheme?

Assess the efficiency, feasibility and cost of this model compared with standard practice in Canada



Challenge
Home
Key findings

Source: KPMG interviews

Outreach activities (1/2)

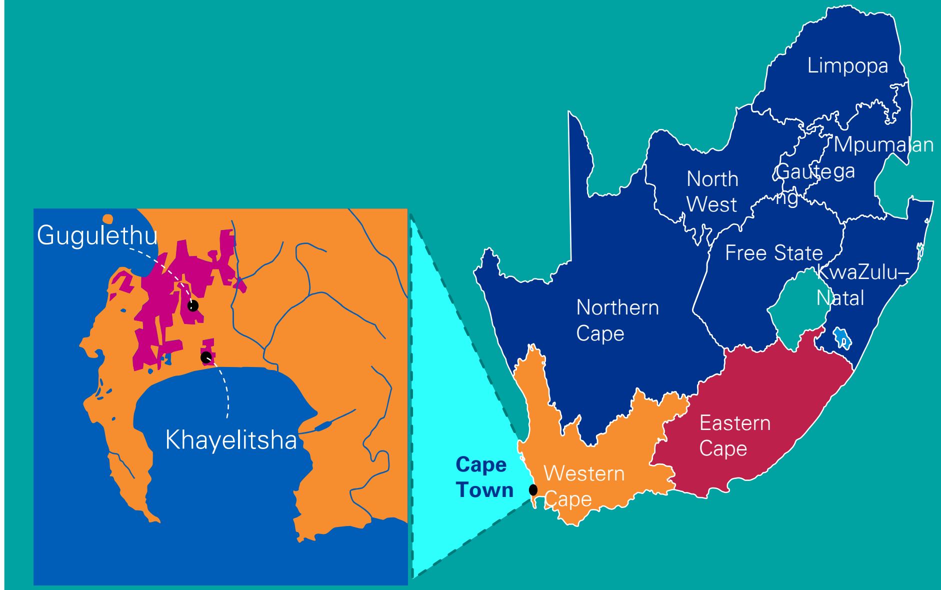
Groote Schuur Hospital
Cape Town

Case study 3

Overview

Professor Kalla, a rheumatologist from the Groote Schuur Hospital, offers consultations for patients located in lower income areas of Cape Town, including Khayelitsha, Gugulethu and Eastern Cape

These activities provide access to specialist services which would otherwise not be available to some patients. They are possible here as the Groote Schuur Hospital allows to set up the outreach clinics under the hospital coverage



What is the rationale for the outreach activities?

Currently there are only 64 registered rheumatologists in South Africa, giving an estimated ratio of one rheumatologist for every 820,000 inhabitants [1]. Other physicians are often not trained in rheumatic diseases, leading to a very low rate of diagnosis and treatment of PsA

In addition, some of the population across the area are socio–economically disadvantaged with many being unemployed and unable to reach the centre and obtain appropriate care

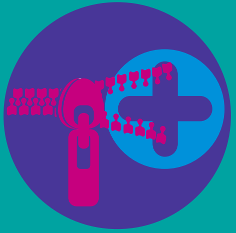
Although the Groote Schuur Hospital is understaffed and is facing challenges relating to limited funding and high prevalence of TB, professor Kalla decided to set up the outreach activities to provide care to patients who would otherwise be unable to reach it

Sources: KPMG interviews; secondary research: Bester, F. et al (2016) The specialist physician's approach to rheumatoid arthritis in South Africa. Korean J Intern Med: 31(2): 219–236

Outreach activities (2/2)

What are the benefits of these outreach clinics?

Improved diagnosis of PsA: The diagnosis rates of PsA in South Africa are very low due to the limited number of rheumatologists and the lack of awareness among general practitioners who are not trained to recognise symptoms of PsA. Therefore, outreach clinics can provide specialist advice to patients who would otherwise remain undiagnosed



Better access to care: Improved diagnosis rates can increase the number of patients who obtain appropriate treatment for their condition which can slow further progression of the disease and improve their quality of life

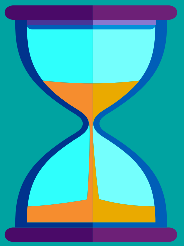
Better monitoring of patients: PsA patients require regular monitoring to assess disease progression and early detection of drug–related side effects

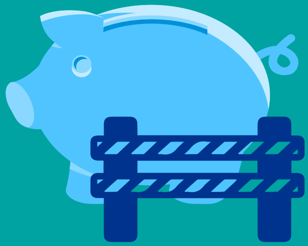
Improved patient experience: Outreach clinics are valued by patients as they reduce the inconvenience of having to travel to distant centres

What are the challenges associated with the outreach clinics?

Involvement in outreach activities can be time consuming and place a significant burden on rheumatologists

It may also be challenging to secure funds for outreach programmes





Challenge
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Key findings

Source: KPMG interviews

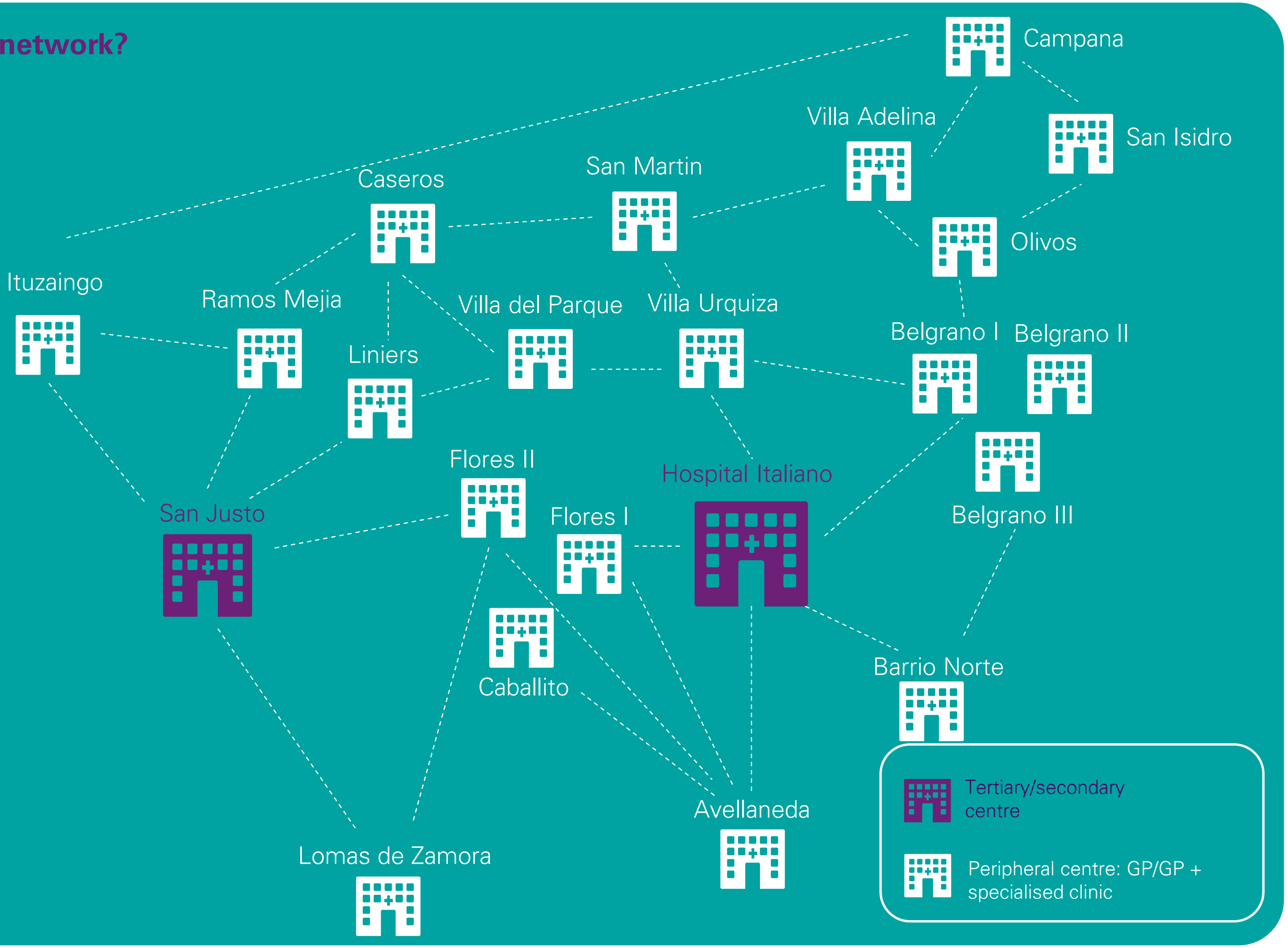
Healthcare network (1/2)

HOSPITAL ITALIANO
de Buenos Aires

Case study 4

What is the Hospital Italiano healthcare network?

The network is over 150 years old and includes **Hospital Italiano** (tertiary hospital), **San Justo** (secondary hospital) and 20 peripheral community healthcare centres. These peripheral centres include both GPs and specialists. The peripheral centres refer PsA patients to Hospital Italiano. All the centres belong to the same Health Maintenance Organisation (HMO)[1]



Challenge
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Key findings

Sources: KPMG interviews; secondary research: 1:Hospital Italiano de Buenos Aires website: https://www.hospitalitaliano.org.ar/centros/index.php?contenido=mapa.php; accessed: 5th Apr 2016

Healthcare network (2/2)

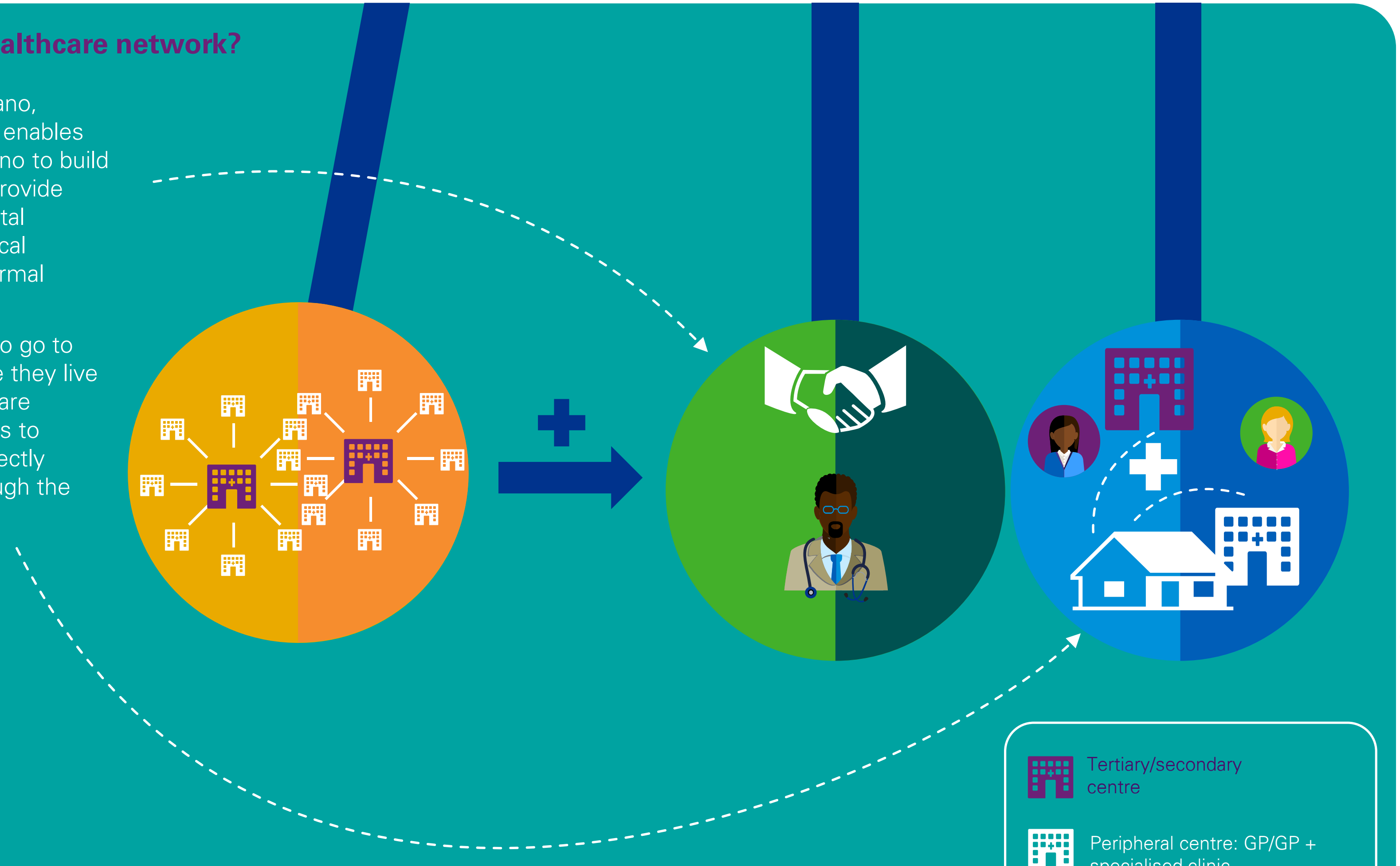
HOSPITAL ITALIANO
de Buenos Aires

Case study 4

What is the impact of this healthcare network?

The network between Hospital Italiano, San Justo and primary care centres enables rheumatologists from Hospital Italiano to build strong relationships with GPs and provide them with training on musculoskeletal complaints. This is done during clinical rounds, journal clubs as well as informal training which is provided to GPs

The network also enables patients to go to primary care centres close to where they live whilst getting access to specialist care through the specialist clinics. Access to specialist can be obtained either directly within the peripheral centre or through the links with other centres



Tertiary/secondary centre

Peripheral centre: GP/GP + specialised clinic

Challenge
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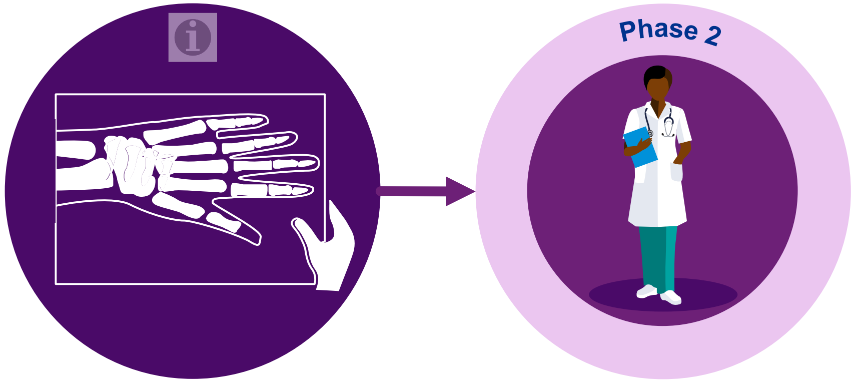
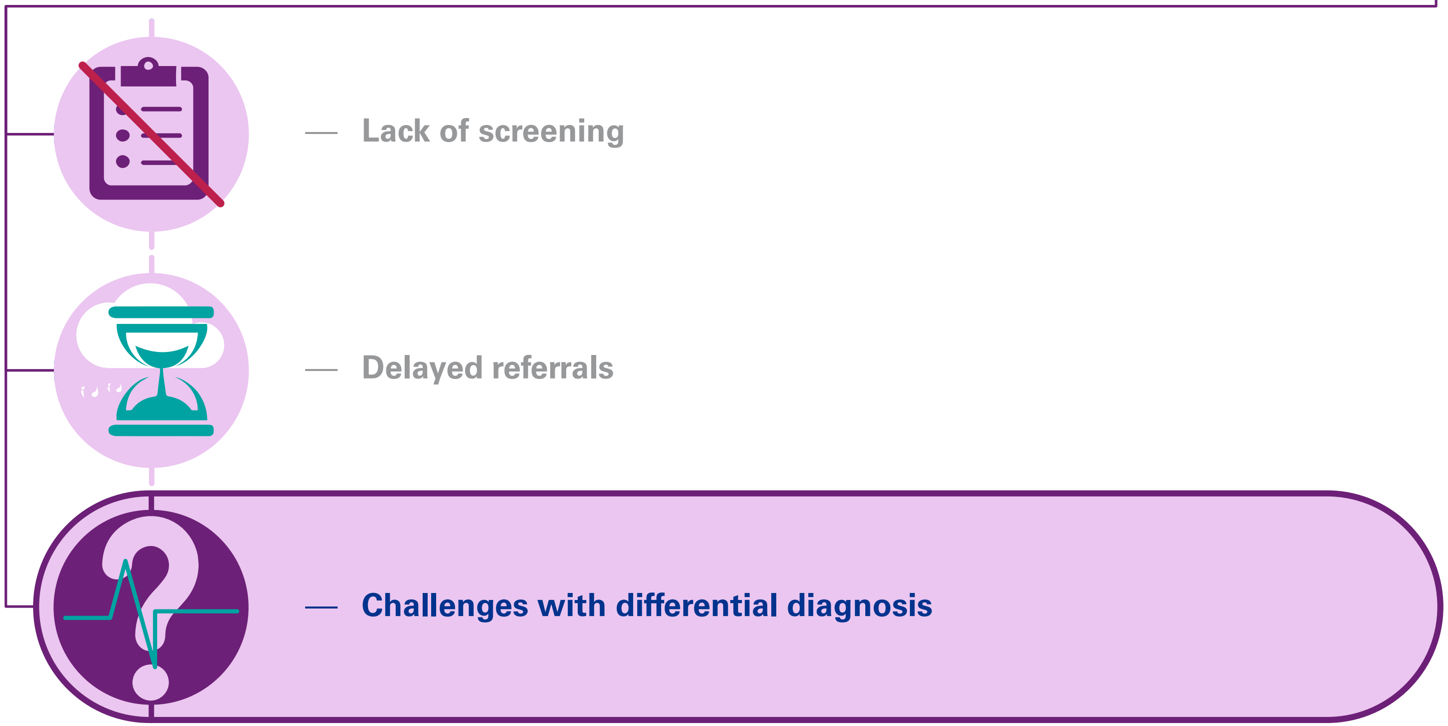
Key findings

Source: KPMG interviews



Findings

Referral and diagnosis



— Lack of screening

— Delayed referrals

— **Challenges with differential diagnosis**

> **The majority of patients who come to us do not have the correct diagnosis. PsA is overlooked and not classified – we have had patients with bone erosion easily visible on X–rays and doctors were still unable to make the correct diagnosis**
>
> Rheumatologist, University Hospital Schleswig–Holstein, Lübeck

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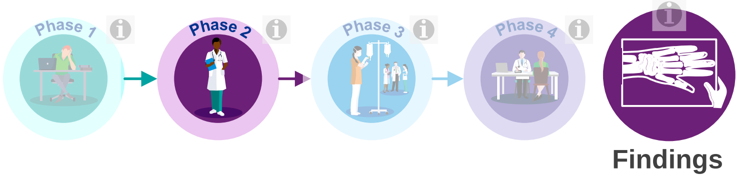
Key findings

Challenges with differential diagnosis



What is the challenge?

Challenges with PsA diagnosis

- Following a referral, diagnosis of PsA remains challenging even to experienced rheumatologists
- Lack of correct diagnosis and misdiagnosis of PsA patients further delays access to accurate treatment

What are the causes?

Overlap of symptoms

- PsA remains difficult to diagnose as symptoms of PsA may overlap with those of other inflammatory disorders, including rheumatoid arthritis. In addition, it can be difficult to differentiate between inflammatory pain associated with arthritis and non–inflammatory pain due to degenerative or mechanical causes

Lack of biomarkers

- There are no biomarkers that allow the identification of PsA patients

Lack of consensus on assessment criteria

- There is currently no consensus about best practice for assessing PsA

What can be done to address it?

Click on each number below to go to the relevant case study

Intervention	Overview	Key stakeholder(s)	Case studies
Consistent assessment criteria	— Rheumatologists should use a consistent approach to PsA diagnosis	— Rheumatologists — Dermatologists	Example of assessment criteria used at the centres visited
Interdisciplinary approach	— When diagnosis is not straightforward, support should be obtained from other services (e.g. dermatology, orthopaedics) to complete the assessment	— Rheumatologists — Dermatologists	Combined dermatology–rheumatology clinics that enable correct diagnosis at Brigham Women's Hospital in Boston, US, Toronto Western Hospital, Canada, Hospital Italiano in Buenos Aires, Argentina, and University Hospital Schleswig–Holstein, Lübeck, Germany *
Use of diagnostic equipment	— Access to diagnostic tools including X–ray scanners and ultrasounds can help identify PsA and improve diagnosis	— Rheumatologists	① Rheumatologists who are trained in performing ultrasonography at Hospital Italiano in Buenos Aires, Argentina

III

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Key findings

Source: KPMG interviews
* Note: Combined clinics are described in more detail on slides 64-77

Key III Tertiary clinic   Community clinic

The centres we visited follow the CASPAR criteria for diagnosing PsA patients

There is currently no definitive diagnostic test for PsA and its diagnosis remains challenging due to a heterogeneous nature of the disease[1]. In the centres we have visited, the CASPAR classification criteria are often used in clinical practice as they are effective in distinguishing patients with PsA from those with other inflammatory diseases. CASPAR bases diagnosis on clinical symptoms and history, as well as radiographic and laboratory evidence [2]

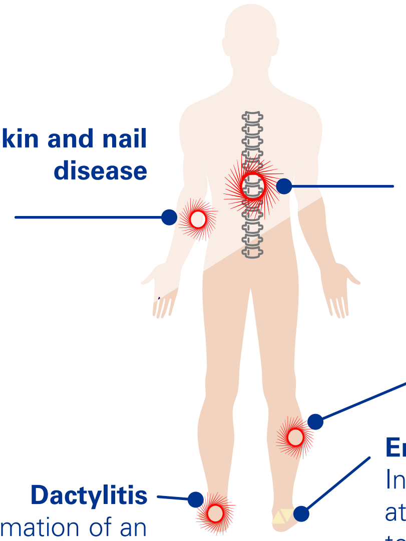
Classification Criteria for PsA (CASPAR) [2]

	Description	Points
Clinical	Current psoriasis **or**	**2 or**
	Personal history or family history of psoriasis	**1**
	Dactylitis (current or history) recorded by a rheumatologist	**1**
	Psoriatic nail dystrophy observed on current physical examination	**1**
Radiology	Juxtaarticular new bone formation appearing as ill–defined ossification near joint margins (but excluding osteophyte formation)	**1**
Serology	Rheumatoid factor negative	**1**

Note: To meet the CASPAR criteria for PsA, a patient must have a musculoskeletal disease (either arthritis, spondylitis or enthesitis) and at least three points from the five categories above

> Making the diagnosis early on is the hardest but also the most important step — you have to look for all the indicators holistically
>
> **Rheumatologist, Groote Schuur Hospital, Cape Town**

Common features of PsA [3]



Skin and nail disease

Spondylitis
Inflammation of the spine

Peripheral arthritis

Enthesitis
Inflammation of the attachment sites for tendons and ligaments

Dactylitis
inflammation of an entire digit

Challenge
Home
Key findings

Sources: KPMG interviews; secondary sources: 1: Vlam, K., et al (2014) Current concepts in psoriatic arthritis: pathogenesis and management. Acta Derm Venereol.; 94(6):627–34; 2: Taylor W, Gladman D, Helliwell P, et al. (2006) Classification criteria for psoriatic arthritis: development of new criteria from a large international study. Arthritis Rheum. 54(8):2665–73; 3: Olivieri, I., et al (2014) Advances in the management of psoriatic arthritis. Nat Rev Rheum. 10:531–542

Rheumatologists sonographers (1/3)

HOSPITAL ITALIANO
de Buenos Aires

Case study 1

What is a rheumatologist sonographer?

Rheumatologist sonographers are specifically trained in ultrasound, which helps in the clinical evaluation of PsA patients. The team includes four rheumatologist sonographers who hold on average six hours' worth of clinics each week. Each consultation is 15–20 minutes long so similar in length to the combined clinic

What is the rationale for having rheumatologists specialised in ultrasonography ?

Clinical assessment: Ultrasound imaging enables specialists to assess patients' skin, nails, joints, enthesis and joints for any abnormalities. If a rheumatologist has any doubts about a patient, they can be referred for an ultrasound to identify any specific inflammation, erosions, enthesophytes or the cause of tendon pain. Ultrasound is a particularly useful tool for the clinical evaluation of obese or overweight patients where it may be more difficult to assess joint involvement

Research: Having access to specialists who are specifically trained in both rheumatology and ultrasound techniques also strengthens the centre's research capacity. This is because with the EMR system, the centre is able to keep the ultrasound images on file and therefore have this information immediately available should it be needed to identify patients for a clinical trial

Quick access: Having ultrasound expertise within the team also enables the team to have quick and direct access to ultrasounds as and when needed rather than having to rely on a separate team of sonographers who may also have far less expertise in PsA

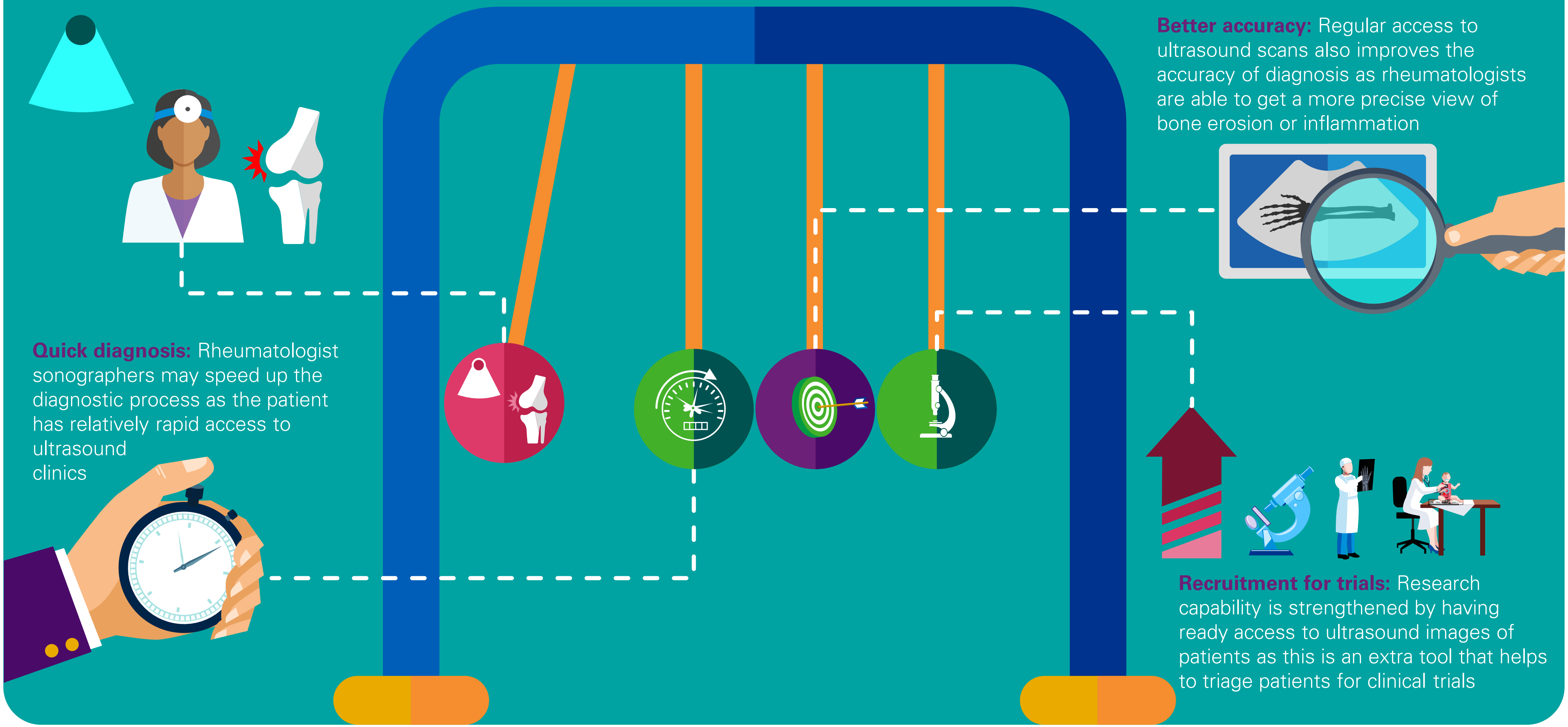
Source: KPMG interviews

Rheumatologists sonographers (2/3)

HOSPITAL ITALIANO
de Buenos Aires

Case study 1

What is the impact of having rheumatologist sonographers?



Quick diagnosis: Rheumatologist sonographers may speed up the diagnostic process as the patient has relatively rapid access to ultrasound clinics

Better accuracy: Regular access to ultrasound scans also improves the accuracy of diagnosis as rheumatologists are able to get a more precise view of bone erosion or inflammation

Recruitment for trials: Research capability is strengthened by having ready access to ultrasound images of patients as this is an extra tool that helps to triage patients for clinical trials

Challenge
Home
Key findings

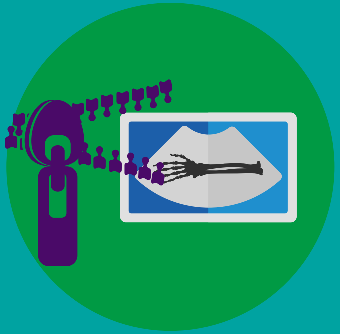
Source: KPMG interviews

Rheumatologists sonographers (3/3)

HOSPITAL ITALIANO
de Buenos Aires

Case study 1

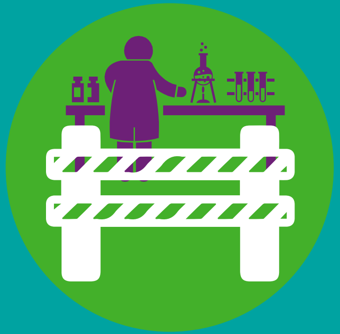
What are the challenges of replicating this model?



Access: Hospital Italiano has easy access to ultrasound technology which facilitates the specialist ultrasound clinics. The ultrasound technology is on site and the team does not have to fight or struggle for access

However, other centres may have difficulty accessing ultrasound machinery and therefore it may be difficult to train rheumatologist sonographers and set up special clinics for ultrasounds of PsA patients

Staffing: Having a team of rheumatologists trained in ultrasound means there is always someone to replace one of the rheumatologist sonographers should they be ill or on holiday. However, other centres may not have such depth in their team and may struggle when they are short–staffed to maintain the ultrasound clinics



Ultrasound and laboratory teams: The rheumatologist sonographers have good access to the laboratory team and so any additional test results they request are carried out immediately, with results received between two and three days. This enables the team to link its ultrasound capability seamlessly into the diagnostic process. Other centres may have more of a disconnect between the ultrasound team and the laboratory team which may make clinical evaluation and diagnosis a much slower process

Challenge
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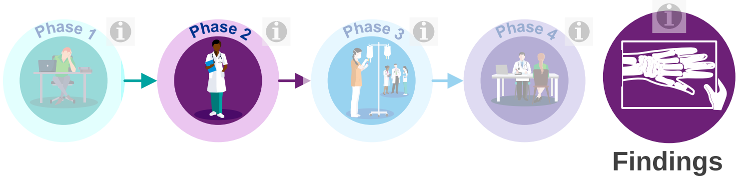
Key findings

Source: KPMG interviews

These interventions can lead to a number of potential benefits



During our site visits, we asked the interviewed clinicians to highlight the potential benefits that may be achieved through the implementation of interventions discussed. Although the centres we visited do not have formal systems in place that allow the impact to be measured, most of them agreed on the benefits that can be achieved

Intervention	Clinical benefits					Economic benefits		Patient experience	
	Improved time to referral/ diagnosis	Improved disease control	Improved adherence	Adequate control of comorbidities	Improved QoL	Fewer hospital admissions	Reduced productivity loses	Improved empowerment	Increased convenience
Challenge: Lack of screening									
Regular screening	✓	✓							
Refinement and/or development of new screening tools	✓	✓							
Challenge: Delayed referral to a rheumatologist									
Early referral	✓	✓		✓	✓	✓	✓	✓	✓
Networks and referral pathway	✓	✓				✓			✓
Challenge: Challenges with PsA diagnosis									
Consistent assessment criteria	✓	✓							✓
Integrated approach to diagnosis	✓	✓		✓	✓				✓
Use of diagnostic tools	✓	✓		✓					

Source: KPMG interviews

Challenge
Home
Key findings

> **In the past, my dermatologist used to treat my skin symptoms, completely ignoring my arthritis. Now I get to see both specialists at the same time and they decide on the best course of action together, while including me in that decision, too**
>
> PsA patient, Guy’s and St Thomas’ NHS Foundation Trust, London

Findings

Treatment initiation and management

— Siloed approach to care in secondary, tertiary and community centres (1/2)

— Gaps in clinical management

— Challenges associated with the use of biologics

— Lack of patient centricity

Home

Key findings

Siloed approach: tertiary and secondary centres

What is the challenge?

Lack of collaboration between dermatology and rheumatology departments

- Although PsA affects both joints and skin, there is often little coordination of care between rheumatology and dermatology teams
- Therefore, many PsA patients have limited access to the right specialists at the right time and the disease is not treated holistically

What are the causes?

Limited overlap between the specialties

- Even if located within the same hospital, dermatology and rheumatology teams often do not collaborate regularly as they typically deal with different patient groups

Cultural differences between dermatologists and rheumatologists

- Rheumatologists tend to make treatment decisions faster than dermatologists who often take a more slow–paced approach to treating skin disorders, since there is less of a time–limit on managing skin conditions

What can be done to address it?

Click on each number below to go to the relevant case study

Intervention	Overview	Key stakeholder(s)	Case studies
Improved coordination of dermatology and rheumatology services	— An integrated approach to PsA management can provide quality and tailored care and better prevention of disease progression — We observed a number of approaches that the centres have adopted to bring rheumatologist and dermatologists (as well as other specialties) together, including combined clinics, multidisciplinary team meetings and informal collaboration. These require different levels of resources and commitment from stakeholders and are discussed in more detail on the following pages	— Dermatologists — Rheumatologists — Other HCPs	① Combined clinic at Brigham Women's Hospital in Boston, US ② Combined clinic at Toronto Western Hospital, Canada ③ Combined clinic and MDT meetings at Hospital Schleswig–Holstein in Lübeck, Germany ④ Combined clinic at Hospital Italiano in Buenos Aires, Argentina ⑤ Combined clinic at Guy's and St Thomas' Hospital in London, UK ⑥ Multidisciplinary care at the Prince of Wales Hospital, Hong Kong

III

> **“Interdisciplinary care encourages effective biologics use. With the advent of biologics, which can address both rheumatological and dermatological symptoms, it made sense to work together, and to choose biologics that are suited to the full scale of needs”**
>
> Rheumatologist, Toronto Western Hospital

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Source: KPMG interviews

Key III Tertiary clinic Community clinic

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Key findings

Improving collaboration between dermatology and rheumatology departments (1/2)

Improving the relationship between dermatology and rheumatology teams has been recognised as key in providing comprehensive and holistic care for patients with PsA. There are a number of models for improving collaboration between the two specialties which require different levels of resources and commitment from stakeholders

	Overview	Advantages	Challenges	Required level of commitment from stakeholders
Combined clinics	— Clinics during which both a rheumatologist and a dermatologist are present to assess skin and joint symptoms — They can also involve a single HCP if they are certified in both dermatology and rheumatology	— One–stop–shop for diagnosis and/or management — Comprehensive care through access to additional expertise — Potential savings to the healthcare system from the reduced number of appointments	— **Billing**: Challenges with receiving payment to both departments for the joint activity — **Scheduling**: Difficulties in finding the time and location for both specialties to meet — **Patient mix and volumes:** Not all PsA patients might require an input from both specialties. However, without the efficient use of both specialists' time, the combined clinic may not be financially sustainable	◕ **High**: Combined clinics require shared facilities and regular time commitment from both specialties
Multidisciplinary team meetings	— Meetings where patients are assessed retrospectively. These can involve dermatologists and rheumatologists as well as other specialists (e.g. gastroenterologists)	— Holistic approach to patient care with access to a range of specialists — Improved peer and student education — Different specialists can be involved, based on the case discussed	— **Reduced patient interaction:** Stakeholders do not interact with the patient directly — **Inconvenience for patients:** More appointments required if a patient needs to be assessed by another specialist	◑ **Medium**: Multidisciplinary team meetings require multiple team members to be available at the same time
Informal communication and knowledge sharing	— Knowledge is shared during seminars, conferences and ad hoc meetings — Technology is used to connect to other HCPs (e.g. online platforms, teleconferences)	— Improved access to other specialists — Dermatologists become more 'joint aware' and rheumatologists more 'skin aware'	— **Low level of interaction**: Less formalised way of collaboration which makes it more difficult to maintain the relationship. Recreating this model becomes particularly difficult once one of the specialists leaves	◔ **Low:** Informal communication means that there is no need for regular appointments. Use of technology (such as teleconferences) can further improve the ease of implementing this model

Source: KPMG interviews

Challenge
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Key findings

Improving collaboration between dermatology and rheumatology departments (2/2)

During our visits, we observed a number of combined rheumatology–dermatology clinics which differed in terms of their purpose, frequency and duration of the clinic as well as composition of the attending HCPs. These specific models have been developed to fit the needs of patients and clinicians at the given centre

Centre	Location	Purpose	Frequency	Patients per clinic	Attendance	Case study
BRIGHAM AND WOMEN'S HOSPITAL	Boston, US	— Diagnosis — Management	— Once–weekly — Three hours	20–30	— Rheumatologist — Dermatologist — Residents and students	Page 64
Toronto Western Hospital	Toronto, Canada	— Diagnosis — Management	— Once monthly — Half–a–day	20–25	— Rheumatologist — Dermatologist	Page 67
University of Lübeck	Lübeck, Germany	— Diagnosis — Management	— Once–monthly/driven by demand	Driven by demand	— Rheumatologist — Dermatologist — Students	Page 69
HOSPITAL ITALIANO de Buenos Aires	Buenos Aires, Argentina	— Diagnosis — Management	— Once–weekly — Three hours	10	— Rheumatologist — Dermatologist — Fellows	Page 72
Guy's and St Thomas' NHS Foundation Trust NHS	London, UK	— Management	— Once–weekly — 30 minutes	2–3	— Rheumatologist — Dermatologist	Page 75

Source: KPMG interviews
Note: Centres are listed in the order in which they were interviewed

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Key findings

Skin And Related Musculoskeletal Diseases (SARM) clinic (1/3)

BRIGHAM AND WOMEN'S HOSPITAL

Case study 1

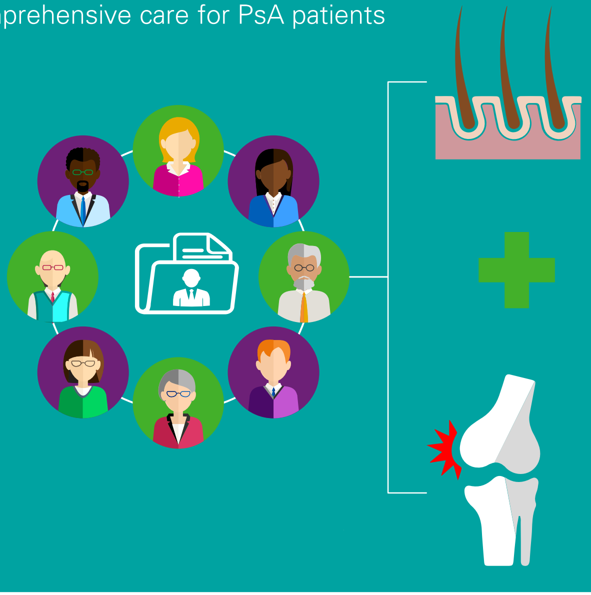
What is the SARM clinic?

Brigham and Women's Hospital offers a unique model of PsA care where a dermatologist and rheumatologist see patients together to provide care for skin and joint manifestations

What was the rationale behind its setup?

PsA patients present with both joint and skin symptoms therefore requiring the input of rheumatology and dermatology specialist teams. However, these teams often work in silos, even within the same hospital

The team at Brigham and Women's Hospital wanted to address this issue by setting up a combined clinic where the two specialties are brought together to provide comprehensive care for PsA patients



What are the key features of the clinic?

Frequency

The clinics run once–weekly for approximately three hours

Attendance

All faculty members, including a rheumatologist, dermatologists, students and researchers, attend the combined clinics

Patient numbers

During each session, roughly 20–30 patients attend between all providers

Challenge
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Key findings

Source: KPMG interviews

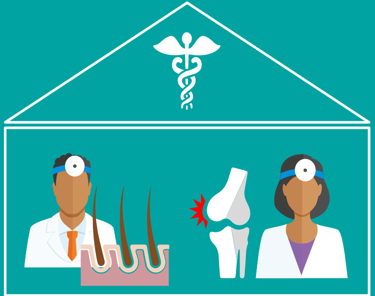
Skin And Related Musculoskeletal Diseases (SARM) clinic (2/3)

BRIGHAM AND WOMEN'S HOSPITAL

Case study 1

What are the benefits of the clinic?

One–stop–shop approach to diagnosis



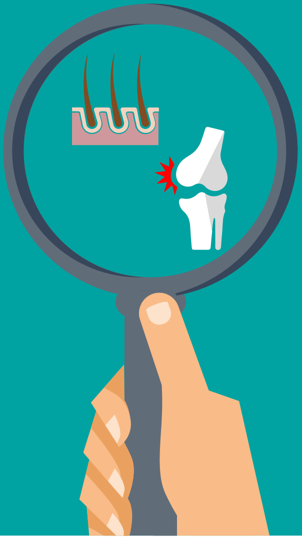
As both specialties are present during the appointment, PsA diagnosis can be made promptly and accurately, thereby improving patient experience as well as helping avoid irreversible joint damage

Education opportunities for staff and patients

The presence of both specialties allows doctors to learn from each other and provides good training opportunities for medical students

In addition, patients can learn about their disease and treatments from both a rheumatology and dermatology perspective

Monitoring of skin and joint symptoms



This multidisciplinary approach allows for continuous monitoring of skin and joint manifestations throughout the course of the disease

Recruitment for clinical trials

The clinic allows doctors to identify patients that fit the recruitment criteria for the PsA clinical trials they are involved in

Challenge
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Key findings

Source: KPMG interviews

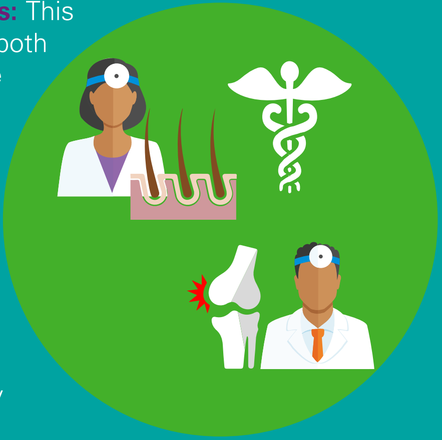
Skin And Related Musculoskeletal Diseases (SARM) clinic (3/3)

BRIGHAM AND WOMEN'S HOSPITAL

Case study 1

What are the challenges to replicating this model?

Both specialties: This model requires both specialties to be present during patient appointments. This might be challenging for private practices that employ dermatology or rheumatology specialists only

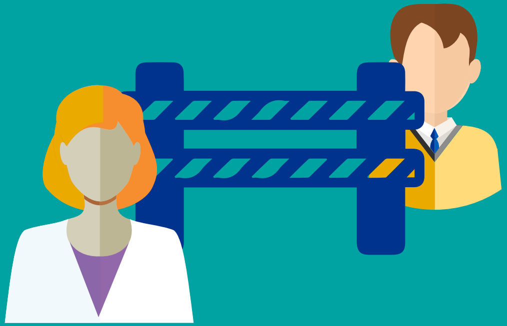


Patient mix: In addition, with a high volume of patients who do not need any input from a rheumatologist, it might be difficult to get the right ratio of specialists to make sure all rheumatologists are occupied

Scheduling: Scheduling of the combined clinic can be challenging as you need to get the right mix of patients present during the clinic (i.e. making sure that the patients who require the input of both specialists are scheduled)

What have you tried that did not work when setting up your clinic?

In the past, the centre tried having trainees from both specialties to assess the patient at first. This model did not work because they did not know each other and could not work together effectively



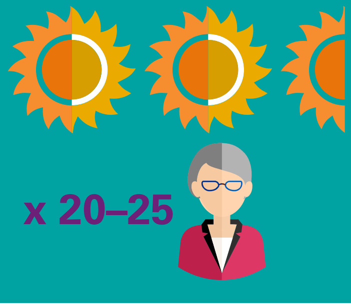
Source: KPMG interviews

The combined clinic at Toronto Western Hospital (1/2)

What is the combined clinic?

The combined clinic is a formal clinic attended by both rheumatologists and a dermatologist

It runs two half–days a month with 20–25 patients seen per session



What was the rationale behind the clinic's set up?

Virtual clinic: Initially, there was a virtual clinic between the rheumatology and dermatology department where practitioners would informally contact each other via phone/email, and visit each other's offices on an ad hoc basis

However, dermatology appointments tend to be shorter than the rheumatology ones as the skin review is less time consuming. That is why it was challenging for rheumatologists to see dermatology patients on an ad hoc basis

Combined clinic: The combined clinic was established to enable a formal two–way approach to the care of PsA that aims to enhance diagnostic accuracy and appropriate treatment choices

What are the key features of the combined clinic?

When the combined clinic began, patients were being referred to it directly. However, this proved challenging given that only some of the patients had both skin and joint symptoms. To address this issue, referrals to a rheumatologist are now examined to see if a combined clinic appointment is required

New patients attend the combined clinic if there is any suspicion of joint involvement, whereas patients who are already diagnosed are seen during the combined clinic if their previous treatments have failed or if input from both specialties is needed

Challenge
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Key findings

Source: KPMG interviews

The combined clinic at Toronto Western Hospital (2/2)

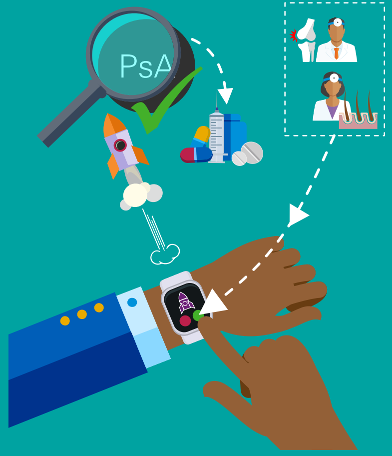
Toronto Western Hospital

Case study 2

What have been the benefits of the combined clinic?

Improved diagnosis

The presence of both specialties during the combined clinics leads to a prompt and correct diagnosis and faster initiation of the treatment



Better access to treatment

Where either skin or joint symptoms are severe enough, the practitioner of the respective specialty can prescribe biologics that the patient may not have access to otherwise. In addition, it allows them to choose biologics that are best suited to the full scale of the patient's needs

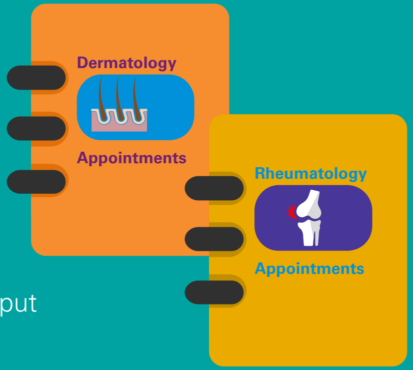
Improved satisfaction

Patients only have to attend one appointment which increases their overall experience

What are the challenges faced by the combined clinic?

Scheduling

Each department has its own appointment system which makes it difficult to schedule the combined clinic



Limited number of rooms

The number of available rooms limits throughput of the clinic

Burden on patients

Patients sometimes complain about having to go through many tests and fill in questionnaires which are intended for research purposes

What are the next steps for the combined clinic?

There are plans to introduce an app, allowing patients to fill in questionnaires at their own convenience

Challenge
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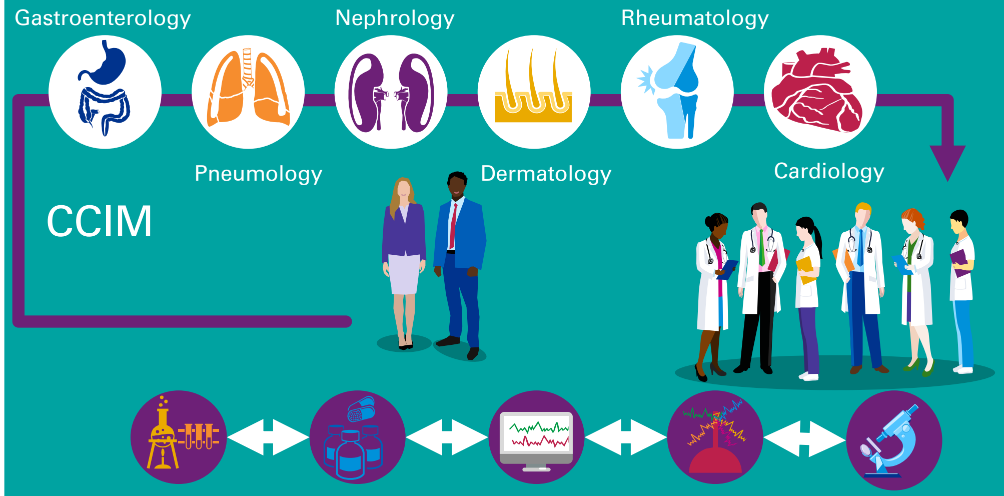
Key findings

Source: KPMG interviews

Multidisciplinary approach to PsA (1/3)

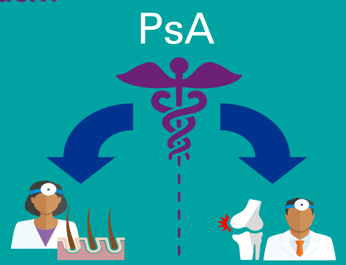
The overview

The Comprehensive Centre for Inflammation (CCIM) was established in 2013 at the University Hospital Schleswig–Holstein in Lübeck to provide an interdisciplinary approach to the treatment of inflammatory disorders, including PsA



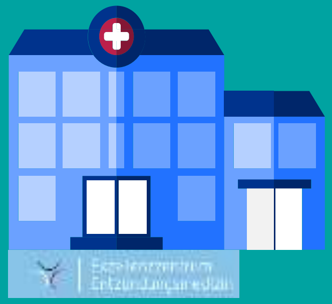
What was the rationale for this approach?

The management of PsA has traditionally been split across the two specialties, with dermatologists taking care of the skin symptoms and rheumatologists looking after the joint manifestations



However it is becoming increasingly clear that there is a need for multidisciplinary care that provides a holistic and consistent approach to the treatment of PsA

To address this issue, the CCIM was created to provide comprehensive and multidisciplinary care for PsA patients



Challenge
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Key findings

Source: KPMG interviews

Multidisciplinary approach to PsA (2/3)

What are the key features?

MDT meetings: At CCIM patients have access to multiple specialists in one place. More complex PsA cases are discussed during case conferences. During these one–hour long board meetings, physicians and researchers meet to discuss patient cases from a multidisciplinary perspective

The aim of these meetings is to make timely and correct diagnoses and treatment decisions, as well as to improve care delivery at the centre. These meetings can also be attended by specialists from other hospitals at the regional and national level

- **Weekly meetings:** These conferences are always attended by rheumatologists, dermatologists and gastroenterologists. Depending on the case discussed, other specialties, including paediatricians, nephrologists and urologists, might also be present
- **Monthly meetings:** These are attended by the broader team, including pathologists and microbiologists, and they are meant for discussions of any issues relating to patients and the clinic

Joint clinic: These are monthly combined outpatient clinics which are attended by dermatologists and rheumatologists, as well as junior doctors, to treat the most complex cases of PsA. During the joint clinics clinicians discuss cases and collectively make decisions regarding patients' diagnoses or readjustment of the current treatment. This helps to address the whole spectrum of patients' needs, thereby providing more individualised patient care

Challenge
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Key findings

Source: KPMG interviews

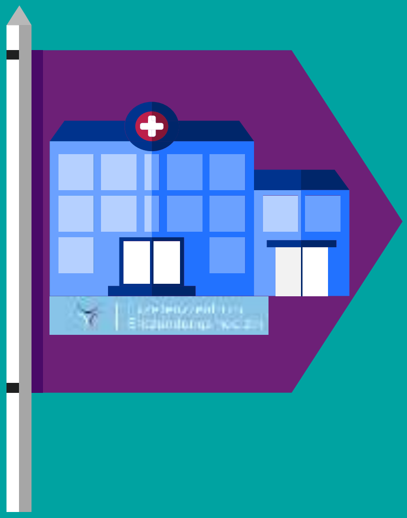
Multidisciplinary approach to PsA (3/3)

What are the challenges?

Funding: Although the University of Lübeck received a grant from the German Research Foundation to establish the interdisciplinary centre, the grant was only enough to cover approximately 10% of the initial costs. The centre therefore had to seek additional financial support

The interdisciplinary model of care was a success from a clinical and scientific perspective; however, its economic value has not been studied yet. In the future, the centre will try to analyse the long–term cost–effectiveness of this model of care

Awareness of the centre: When the centre was first established, it was challenging to make other hospitals and community centres aware of this highly specialised clinic and refer their patients to it. However, throughout the last two years the centre has proved its commitment to PsA and is now a well–regarded specialist centre both among HCPs and patients



What were the success factors?

Financial support:

A grant from the German Research Foundation (DFG), and operational and financial support from the university

Personal interest

Personal interest and dedication to the treatment of psoriasis and psoriatic arthritis

Networks and links to other centres: Support from colleagues, especially rheumatologists and gastroenterologists from the surrounding areas who referred their patients to the centre

Communicating value: Commitment of the doctors to communicate the value of an interdisciplinary model of care in inflammatory disorders through conferences, seminars and publications

Challenge
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Key findings

Source: KPMG interviews

Combined rheumatology and dermatology clinic (1/3)

HOSPITAL ITALIANO
de Buenos Aires

What is the combined clinic?

Hospital Italiano offers a combined clinic between rheumatology and dermatology specialty for PsA so that patients can have access to both specialist opinions within the same clinic

What are the key features of the clinic?

Frequency

The clinic takes place once weekly with each rheumatologist dedicating three hours to patients. Consultations for existing patients are 15 minutes but consultations for new patients may be up to 30 minutes

Attendance

During the combined clinic, there are four rheumatologists and one dermatologist, as well as dermatology and rheumatology fellows. However, there are plans to increase the dermatology presence so that the single dermatologist has more support within the clinic

Patient profile

Patients are usually referred to the combined clinic because either the dermatologist or the rheumatologist has doubts about the patient. For example, the skin condition may clear and yet the patient still has joint involvement

Challenge
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Key findings

Source: KPMG interviews

Combined rheumatology and dermatology clinic (2/3)

HOSPITAL ITALIANO
de Buenos Aires

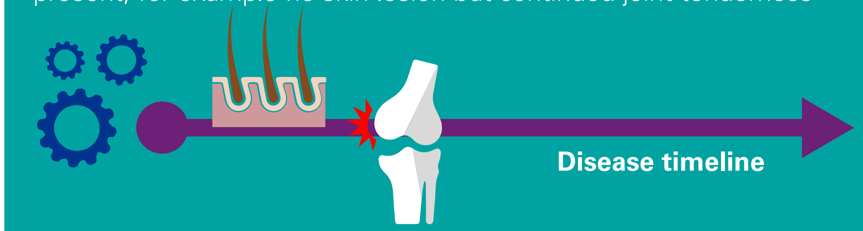
What are the benefits of the combined clinic?

One–stop–shop approach to diagnosis

As both specialties are present during the appointment, PsA diagnosis can be made promptly and accurately, thereby improving patient experience as well as helping avoid the irreversible joint damage. The specialists use the following tools and questionnaires with the patient to diagnose PsA as well as assess disease severity: The Psoriatic Arthritis Screening and Evaluation (PASE), The PsA Quality of Life (PsAQoL), Psoriasis Area Severity Index (PASI), Dermatology Life Quality Index (DLQI)

Monitoring of skin and joint symptoms

This approach allows for a continuous monitoring of skin and joint manifestations throughout the course of the disease so that both specialists can evaluate the changes in the patient. This is particularly useful in scenarios where one symptom has cleared but the other is still present, for example no skin lesion but continued joint tenderness

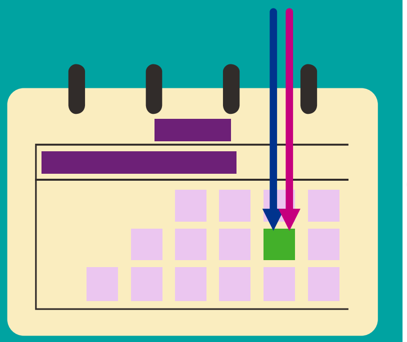


The diagnostic/assessment tools can also be used to document the changes in the patient’s status. For example, if methotrexate is used to clear a patient’s psoriasis then the PASI could be used to compare the patient’s skin condition before and after treatment

Patient–centric approach

The combined clinic allows for improved access to care as patients are able to access both specialists within the same forum without the delay time of waiting for a new appointment. Patient feedback suggests that this approach is highly patient–centric as concerns can be addressed immediately. The patient may also feel that his/her care is being prioritised by having two specialists involved

Patient education



The clinic provides a forum to share information on PsA with the patient and any family members. The centre produces its own information leaflets on PsA

One leaflet includes information that breaks down the disease into its symptoms, the parts of the body it affects and how to diagnose the disease. Another similar leaflet focuses on the treatment for PsA. This includes advice on the type of exercise routine to follow as well as listing the medical options of DMARs and biologics. Both leaflets use simple language and images to make the material accessible to all patients

Challenge
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Key findings

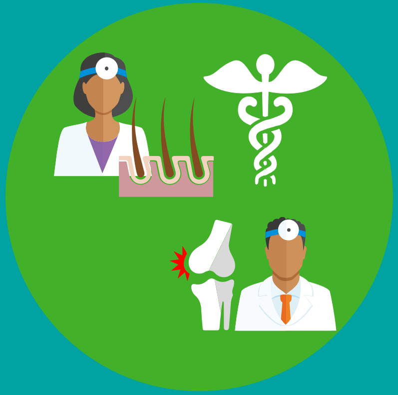
Source: KPMG interviews

Combined rheumatology and dermatology clinic (3/3)

HOSPITAL ITALIANO
de Buenos Aires

Case study 4

What are the challenges to replicating this model?



Both specialties: This model requires both specialties to be present during patient appointments. This might be challenging in centres where there is limited capacity in dermatology or rheumatology. Due to the high demand at Hospital Italiano, the team would like more dermatologists to be involved in the combined clinic. This would also shift the burden away from the sole dermatologist who is currently involved in the clinic

Collaboration: Collaboration between rheumatologists and dermatologists is essential. This may be more challenging in hospitals that have departments that work in silos or simply less contact between different specialties

Increasing demand: Having a successful combined clinic leads to high patient demand. This can create a challenge to find appointments for patients during a week when the clinics are only held one day a week

Challenge
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Key findings

Source: KPMG interviews

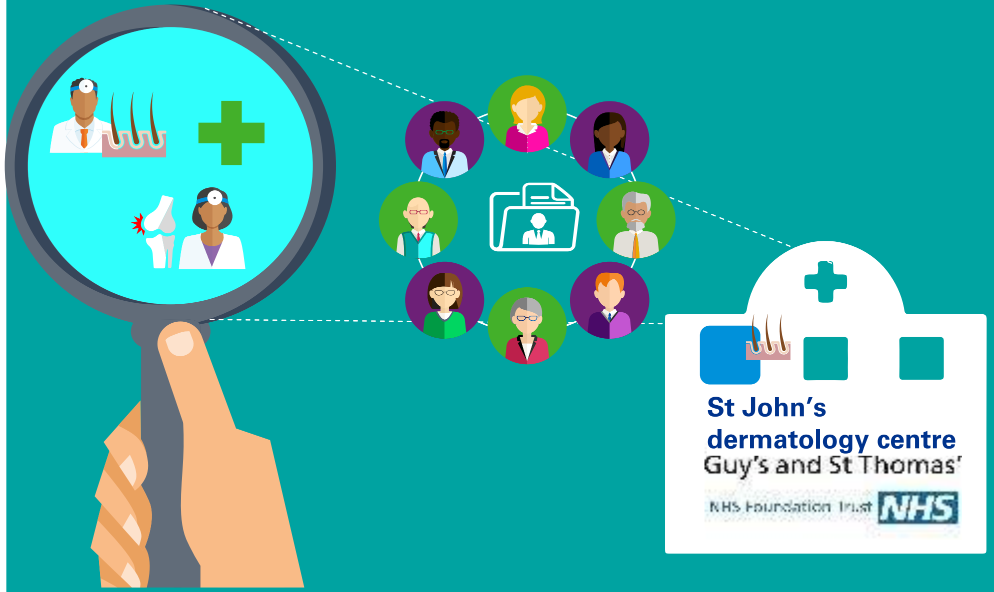
Combined clinic (1/3)

Guy's and St Thomas' NHS Foundation Trust NHS

Case study 5

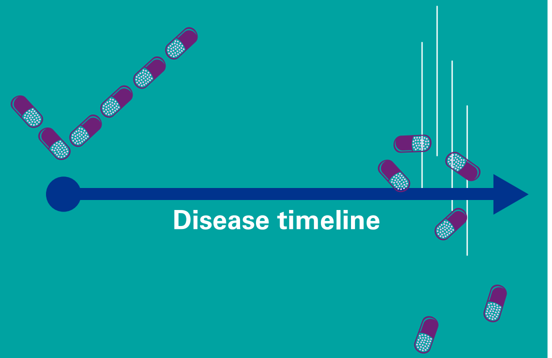
What is the combined clinic?

At Guy's and St Thomas' NHS Foundation trust, rheumatologists and dermatologists run a weekly combined clinic for PsA patients. The purpose of this is to improve the management of difficult–to–treat patients by having both specialists present at the same time



What was the rationale behind its set–up?

Despite the availability of multiple treatment options, not all patients respond to therapy and some may lose the initial response over time



These PsA patients require optimisation of their treatment with careful consideration of both skin and joint symptoms

However, when patients are seen by a rheumatologist and a dermatologist during different clinical slots, this leads to issues with communication between the specialties and inconsistent care. The combined clinic was set up to help in the management of complex cases of PsA that may require the real–time input of both specialties to provide better patient care

Challenge
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Key findings

Source: KPMG interviews

Combined clinic (2/3)

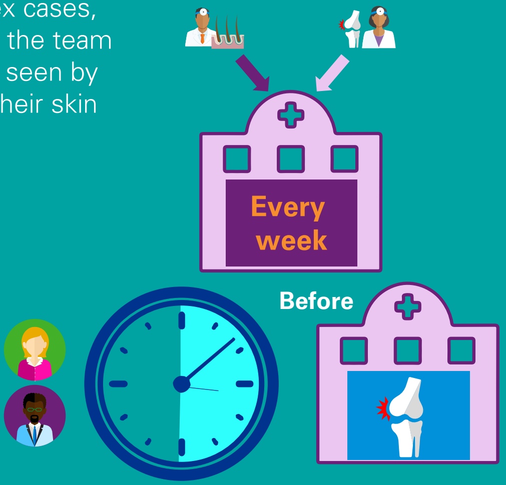
Guy's and St Thomas' NHS Foundation Trust NHS

Case study 5

What are the key features of the combined clinic?

The model:

The combined clinic takes place every week in a 30–minute slot before the rheumatology clinic starts. As the combined clinic is reserved for the reassessment of the most complex cases, only two to three patients are seen by the team during each clinic. Patients are usually seen by a dermatologist first who will assess their skin symptoms



Referrals

The combined clinic is run for patients who are already attending either rheumatology or dermatology at the hospital. Patients are referred from these departments to attend the combined clinic

Place in the pathway:

The clinic is intended for the management of PsA rather than for diagnosis, and most patients who attend will have already been diagnosed with PsA. Once the treatment decision has been made, patients are referred back to their original centre

What are the benefits of the combined clinic?

Improved collaboration and training opportunities

As the combined clinic takes place every week, the dermatologists and rheumatologists are constantly in touch and can discuss other patients in an ad hoc manner. The combined clinic provides training opportunities as rheumatologists and dermatologists can learn more about the other specialty

Better treatment decisions:

An internal audit of all combined clinics run between September 2013 and August 2015 showed that the majority of PsA patients had an active joint or skin disease which required an escalation or adjustment of their current treatment to treat symptoms or complications. In 80% of cases their treatment was changed or readjusted when they were seen in the combined clinic, thanks to the collaborative input of rheumatologists and dermatologists identifying treatments that could better address their symptoms. In addition, most patients attended the clinic only once, suggesting that the treatment change was successful in addressing their issues

Improved access to drugs:

Some treatments are only available for either psoriasis or arthritis so patients can access treatments they would not get if they were treated by just one specialist

Patient experience:

Doctors reported that some patients request to be referred to the PsA clinic because they have heard of the combined clinic from other patients or their doctors

Challenge
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Key findings

Source: KPMG interviews

Combined clinic (3/3)

Guy's and St Thomas' NHS Foundation Trust

Case study 5

What are the challenges associated with the combined clinic?

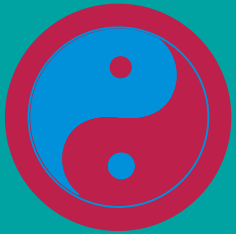
Billing: Since both specialties are present during the combined clinic, it can lead to issues with billing, as it can be a complicated process for both departments to be reimbursed for a joint activity. However, at Guy's and St Thomas', rheumatologists choose not to get paid for the half hour they use to go to the combined clinic, thereby avoiding this issue

Scheduling: It might be challenging to find the time and location for both specialties to meet. However, it was not the case here as the departments are located next to each other, and the dermatology and rheumatology clinics run during the same time slot

Collaboration: There are significant differences in how rheumatologists and dermatologists work, and although learning to understand each other is a long process, it is key for the combined clinic to work well. Rheumatologists emphasised how time is often of the essence for them, in order to treat the disease before arthritis can further develop. Dermatologists often take a more slow–paced approach to treating skin disorders, since there is less of a time–limit on managing the condition. Understanding, accepting and finding a way to work with these different approaches to care is a major challenge and important consideration in the running of a combined clinic

What would you recommend to other centres who would like to set up a combined clinic?

Start small: It is very difficult to set up a combined clinic if you do not have an established relationship with the other specialist. It should be built up organically as the relationship between the rheumatologist and dermatologist develops



Build a symbiotic relationship: Everyone should get something out of the collaborative approach – you can help and learn from each other

Know your responsibilities: The person who prescribes the treatment is critical. It is vital to know who looks after the patient following the combined clinic because they cannot be floating between the two specialties

What are the next steps?

The model is still evolving and clinicians are trying to find the most efficient way of running the combined clinics. Recently, following patient feedback, they moved the combined clinic to half an hour later as patients were having trouble travelling during rush hour due to their arthritis

Challenge
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Key findings

Source: KPMG interviews

Multidisciplinary approach to PsA (1/2)

The Prince of Wales Hospital, Hong Kong

Case study 6

What is an MTD approach?

The overview

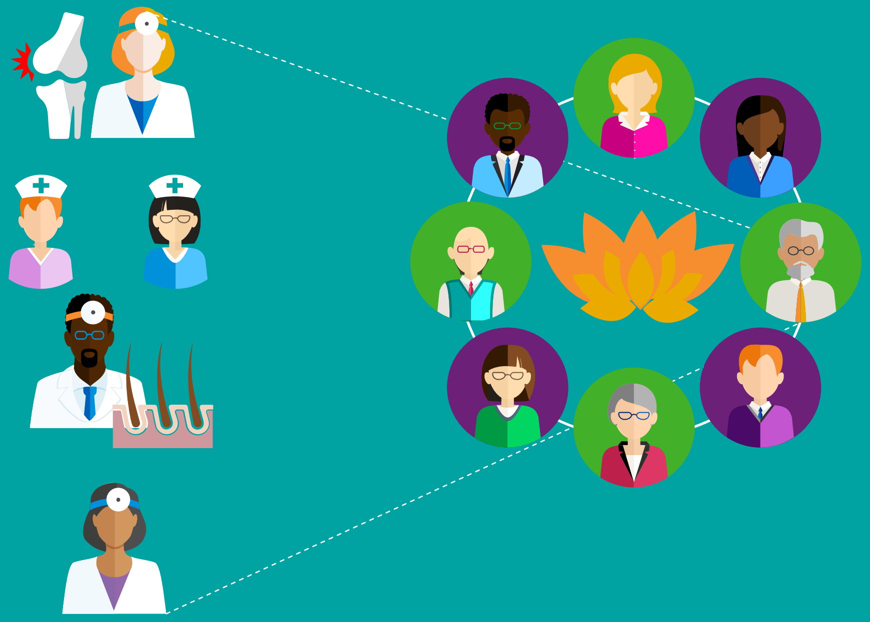
The rheumatology service at the Prince of Wales Hospital in Hong Kong offers multidisciplinary care involving rheumatologists and nurses as well as other specialists to provide comprehensive and patient–centred care

Who is the part of the MDT team?

- **Rheumatologists**: Rheumatologists are the core of the MDT. The leader of the team maintains the standard of care and conveys the vision and leadership to the team. Junior doctors can learn from their more experienced colleagues
- **Nurses**: Nurses assist doctors in disease and drug monitoring as well as patient education and counselling. A rheumatology nurse has set–up a nurse–led clinic for rheumatology patients
- **Dermatologists**: There is a good level of collaboration between the dermatology and rheumatology departments, using both formal channels (i.e. referral pathways) and informal networks (ad hoc communication)
- **Other specialists:** The team collaborates closely with other specialists who may be required to provide patient care, including radiologists and cardiologists

What was the rationale behind this set–up

Due to limited funding and lack of space within the hospital, there is currently no combined clinic during which PsA patients can be seen simultaneously by both specialists. However, the high level of collaboration and meetings across the MDT allows for knowledge sharing, and PsA patients can be examined for both skin and joint symptoms



Challenge
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Source: KPMG interviews

Multidisciplinary approach to PsA (2/2)

The Prince of Wales Hospital, Hong Kong

Case study 6

What are the challenges associated with this model?

There is a limited interaction with the patient and the multidisciplinary team cannot make decisions in real–time. It can also be more inconvenient for a patient who has to attend multiple appointments to be seen by both a rheumatologist and a dermatologist

What are the possible improvements?

Although there is a good level of interaction between dermatologists and rheumatologists, the collaboration could be further improved by creating a forum where these professionals could meet, e.g. during a combined clinic

The MDT could be strengthened by the presence of a physiotherapist or allied health teams (e.g. occupational therapy workers, social workers, etc.) who are specialised in rheumatoid diseases

In addition, PsA patients often have metabolic symptoms so having dieticians within the team could be very helpful as it would reduce the need for formal referrals

Vision of the multidisciplinary care at PWH

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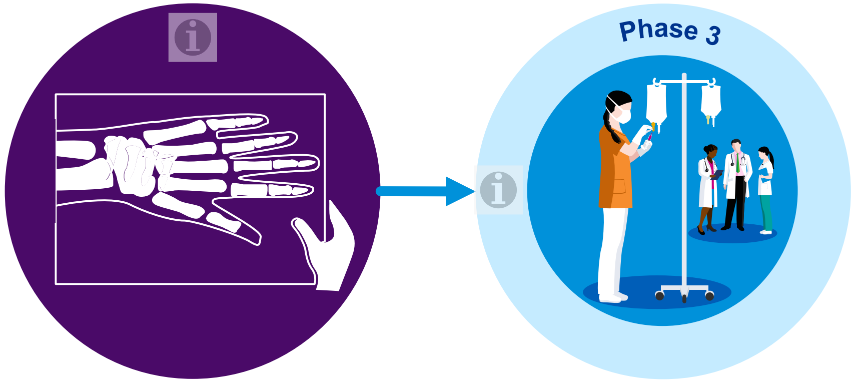
Source: KPMG interviews



Findings

Treatment initiation and management

- **Siloed approach to care in secondary, tertiary and community centres (2/2)**
- Gaps in clinical management
- Challenges associated with the use of biologics
- Lack of patient centricity

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Siloed approach to care: community centres

What is the challenge?

Limited access to other specialists

- Community–based dermatologists and rheumatologists work in silos, concentrating only on the treatment of skin or joint symptoms, respectively
- The lack of a collaborative approach can lead to inconsistent care and suboptimal outcomes

What are the causes?

Limited access to specialists

- Many community–based rheumatologists and dermatologists are not located within the same centre, preventing them from having regular meetings

Lack of networks

- Dermatologists and rheumatologists often deal with separate patient groups and do not have established relationships and networks

What can be done to address it?

Click on each number below to go to the relevant case study

Intervention	Overview	Key stakeholder(s)	Case studies
Development of networks and relationship between community–based centres	— Rheumatologists and dermatologists should establish good working relationships with each other, even if based at different centres — This can be enabled through the use of technology (teleconferences, online connectivity platforms) and face–to–face meetings (conferences, seminars)	— Dermatologists — Rheumatologists	1 Development of 'The Arthritis Program' at Southlake Hospital in Mississauga (Canada) which brings a range of specialists together 2 Developing the relationship between GPs/dermatologists and rheumatologists at the community centres in Ontario, Canada

> **You have to create an easy way of collaboration. It could be done through conferences or electronically. It is also important for a dermatologist to have a single point of contact**
>
> Rheumatologist, Brigham and Women's Hospital, Boston

Key III Tertiary clinic; Community clinic

Source: KPMG interviews

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The Arthritis Programme (TAP) (1/3)

Community clinics in Ontario, Canada

Case study 1

Context

During our trip to Toronto we visited the Southlake Regional Center in Newmarket where we spoke to Dr Thorne, Chief of the Division of Rheumatology, as well as Director of The Arthritis Program (TAP), an inter–professional outpatient programme for rheumatic disorders

In addition to the Arthritis Program, the centre is involved in other research initiatives, including:

- **SPARCC** (Spondyloarthritis Research Consortium of Canada): a research network led by Toronto Western which aims to address the genetic basis of susceptibility to the disease and develop outcomes to assess disease activity and structural damage, response to therapy, quality of life and disability
- **CATCH** (The Canadian Early Arthritis Cohort): a national, multicentre, observational, prospective cohort of patients with early inflammatory arthritis which aims to describe characteristics of Canadian patients with early arthritis
- **OBRI** (Ontario Best Practice Research Initiative): an initiative to improve the quality of care and health outcomes of arthritis patients by gathering long–term information on therapies, clinical practice and healthcare utilisation in the real world setting

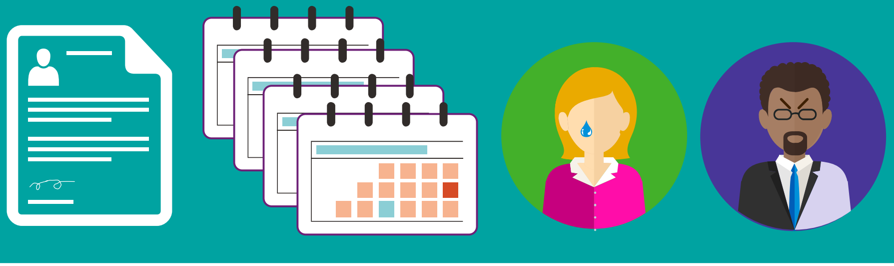
What is the Arthritis Programme?

TAP is a regional programme at Southlake which aims to provide early access to treatment for patients suffering from PsA and other inflammatory conditions [1]

Timeline of PsA and other inflammatory conditions

What was the rationale behind the programme?

When a referral from a GP is received by a specialist, it can take several months before the appointment, leaving the patient undiagnosed and without the appropriate treatment. The Early Arthritis Clinic (EAC) was created to decrease the delay in the diagnosis and treatment initiation and to help address the shortage and overloading of physicians [2]



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Sources: KPMG interviews; secondary research: 1: Southlake Regional Center (2015) http://www.southlakeregional.org/Default.aspx?cid=1779; accessed: 6th April 2016

The Arthritis Programme (TAP) (2/3)

Community clinics in Ontario, Canada

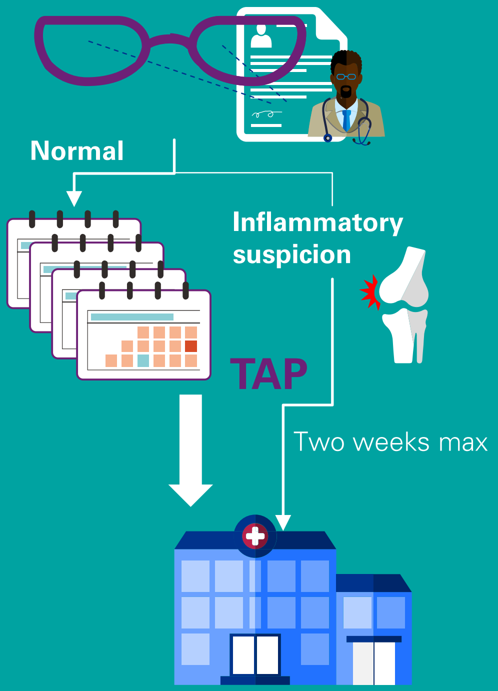
Case study 1

What are the key features of the programme?

Triaging: Referrals received from GPs are reviewed daily. Some cases are seen in a normal fashion which can represent months of waiting, whereas cases with inflammatory suspicion are sent to the TAP and seen within a couple of weeks

Team–based approach: Patient's first encounter is usually with an inter–professional team which consists of a pharmacist and physiotherapist, and an occupational therapist who can assess patient's joints. If the case proves to be more complex, the patient is seen by a rheumatologist on the same day. Once the diagnosis is made, patients are helped to get onto the correct treatment

Peer education: All team members are provided with training in rheumatology. In addition, pharmacists are trained in how to administer treatments



Close proximity of the HCPs: All HCPs, including rheumatologists, pharmacists, social workers and pool therapists, are present in the same location and patients can seamlessly rotate from one HCP to the next. They are also trained in rheumatology which means that they assess the patients are provide them with an adequate care and detailed education

Patient education: To complement the clinical practice, patients can enrol in one of four therapeutic education programs, including inflammatory arthritis, to develop coping skills to manage arthritis on a daily basis. Patients with complex issues can continue their journey to self–management by attending a chronic disease management group. There are several groups to choose from focusing on coping skills, nutrition or exercise. Each session builds on the material from the previous week. Patients can then transition to community self–management programmes, such as the partnership Southlake has with Newmarket Parks and Recreation [1]

> I took part in a three–week educational programme which was part of the TAP. Being in the company of other PsA and RA patients and being able to consult, learn and ask questions offered us the support and hope we needed early on. But, most importantly, we really felt that the professionals cared about our well–being
>
> **Patient, The Arthritis Program, Southlake Regional Center**

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Key findings

Source: KPMG interviews

The Arthritis Programme (TAP) (3/3)

Community clinics in Ontario, Canada

Case study 1

What have been the benefits of the programme?

Every year, approximately 10,000 patient visits are organised through TAP. The programme has increased the speed of diagnosis and initiation of the correct treatment whilst enhancing the adherence to care

In addition, the team–based approach to care has provided comprehensive care to PsA patients and reduced duplication among specialists

Furthermore, TAP is committed to research and is involved in a number of leading–edge projects that are paving the way in the field of PsA

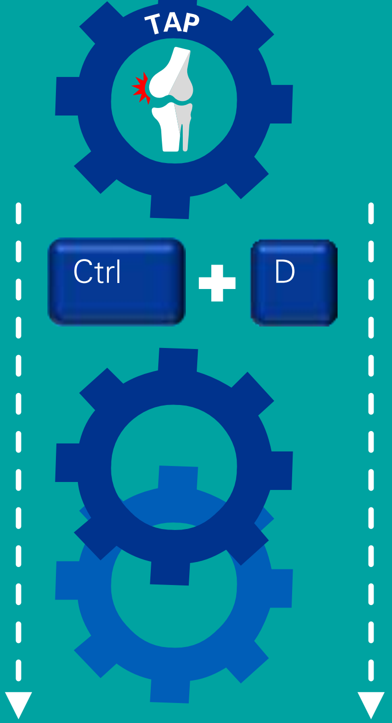
What are the challenges facing the initiatives?

Despite the success of this initiative, this model of care has not yet been replicated elsewhere. It requires involvement of a number of specialties and close collaboration among HCPs

In addition, TAP was created thanks to the grant provided from the Ontario Ministry of Health and Long–Term Care. Other centres might struggle with gaining sufficient funding for similar initiatives

What are the next steps?

To replicate this model in other disease areas



Source: KPMG interviews

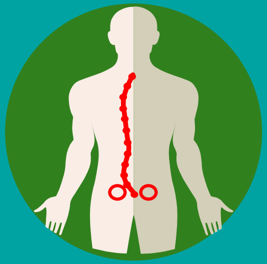
Developing the relationship between GPs/dermatologists and rheumatologists (1/2)

Community clinics in Ontario, Canada

Case study 2

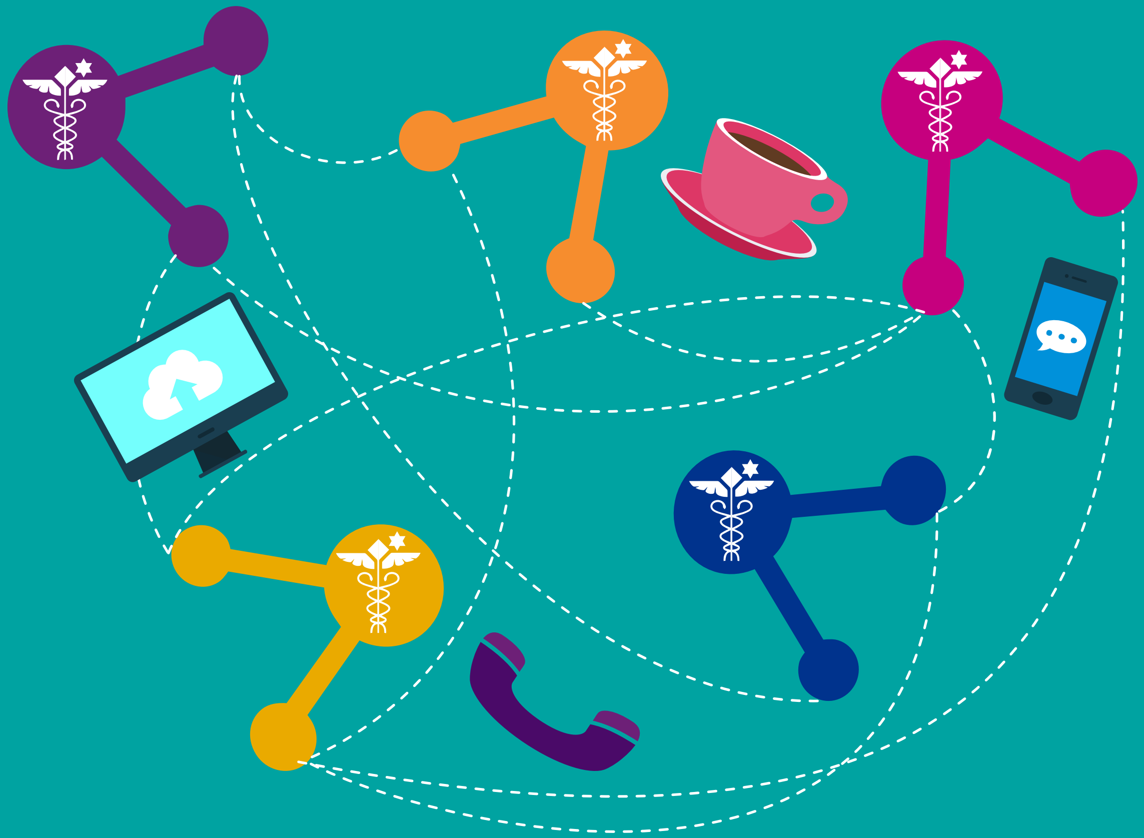
What is the challenge?

PsA is a heterogeneous disease affecting multiple system organs. Involvement of a single specialty is therefore not always sufficient for more complex cases, resulting in delays in the correct diagnosis, an inconsistent approach to treatment and suboptimal outcomes. However, for many centres, including community–based clinics, it is not always possible to run combined clinics with multiple specialties present at the same time



How can this be improved?

By developing informal networks and stronger relationship among specialties and leveraging technology



Source: KPMG interviews

Developing the relationship between GPs/dermatologists and rheumatologists (2/2)

What are the examples of initiatives to improve relationships among HCPs?

Improving awareness of PsA

Due to the limited knowledge of PsA among HCPs, many patients suffer from the disease for years before treatment is initiated. It is vital to educate GPs and dermatologists on the disease as they are best positioned to recognise early symptoms. This can be done through:

- **Online education:** Doctors can use an online platform to learn about recent advances while receiving the Continuous Medical Education (CME) credit
- **Grand rounds with GPs:** Sessions where specialists give presentations on recent advances in rheumatology to a group of GPs
- **Small–group sessions: I**nteractive sessions with GPs which can be sponsored by pharma companies

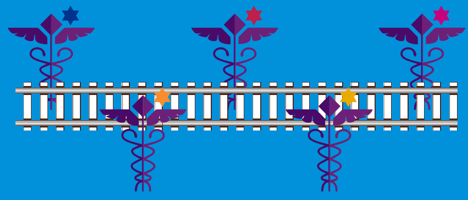
Communicating HCP’s interest in PsA

Clear communication of one’s interest in PsA (e.g. by including it on the business cards or in letterheads)

Informal networks …

Informal networks between rheumatologists and other specialists who are relevant to and interested in PsA, including (but not limited to) dermatologists, GPs, physiotherapists, occupational health specialists and psychologists

Seamless transition across specialties



To enable specialists to make the correct diagnosis and initiate treatment, they need to have access to up–to–date information on their patients’ medical history and test results. Specialists can ask referring doctors to fill in forms that contain information on:

- **Patient medical history:** information on vaccinations, allergies, other chronic disorders, use of certain medicines (e.g. warfarin)
- **Lab tests/scans:** tests including ESR (erythrocyte sedimentation rate test to detect inflammation), hepatitis screening, CRP (C–reactive protein) test, spine x–rays, SI (sacroiliac) joint x–rays

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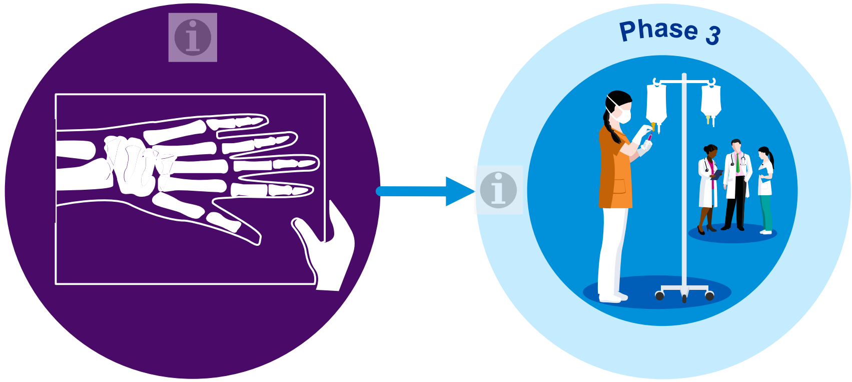
Source: KPMG interviews



Findings

Treatment initiation and management

- Siloed approach to care in secondary, tertiary and community centres
- **Gaps in clinical management**
- Challenges associated with the use of biologics
- Lack of patient centricity

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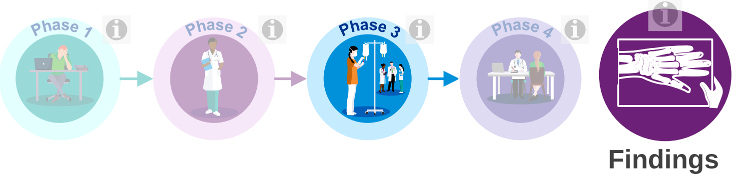
Gaps in clinical management



What is the challenge?

Gaps in clinical management of PsA

— Although many effective PsA therapies have been introduced over the last decade, many patients do not respond to their treatment or may lose the initial response over time [1]

What are the causes?

Inconsistent treatment

— Treatment decisions in PsA are often inconsistent, leading to wide variation in treatment quality and success

Lack of consensus on treatment outcomes

— The tools to measure disease activity in PsA are lacking and many of the existing ones have been adopted from other rheumatic and inflammatory disorders [2]

What can be done to address it?

Click on each number below to go to the relevant case study

Intervention	Overview	Key stakeholder(s)	Examples
Use of protocols and treatment algorithms	— Consistent use of protocols and treatment algorithms should be encouraged. In the past years, a number of PsA treatment clinical guidelines have been published, helping to build consensus around the management of PsA. These often share a number of common recommendations	— Rheumatologists — Dermatologists — GPs	① Examples of evidence–based treatment algorithms followed at the visited centres
Development and validation of new outcome measures in PsA	— There is a need to develop outcome measures that satisfy the needs of all stakeholders involved: patients, doctors and payers. These should also be easy to record in electronic databases	— Rheumatologists — Dermatologists — Payers — Patients	② Examples of outcome measures used at the visited centres

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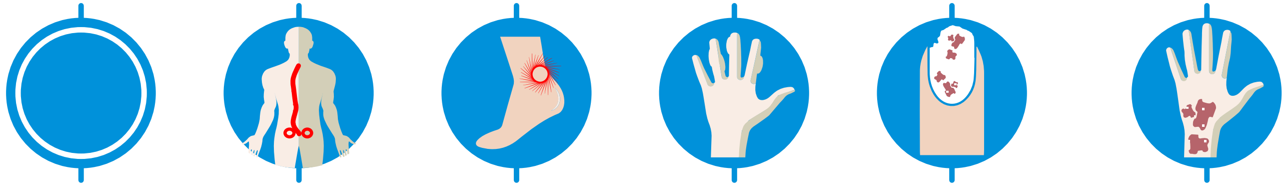
Sources: KPMG interviews; secondary research: 1: Mease, P.J., Armstrong A.W. (2014) Managing patients with psoriatic disease: the diagnosis and pharmacologic treatment of psoriatic arthritis in patients with psoriasis. Drugs. 74(4):423-41; 2: Betteridge, N. et al (2015) Promoting patient–centred care in psoriatic arthritis: a multidisciplinary European perspective on improving the patient experience. J Eur Acad Dermatol Venereol. Advance online publication

The centres we visited treat PsA according to the guidelines developed by GRAPPA and EULAR

The majority of visited centres utilised GRAPPA or European League Against Rheumatism (EULAR) guidelines for the treatment of PsA, whereas some modified the guidelines based on the availability of treatments and affordability (e.g. Cape Town). Although the guidelines differ in terms of complexity, they share a number of common recommendations: PsA treatment should be initiated with NSAIDs and DMARDs, with biologic therapies used in later lines of therapy



	GRAPPA(1)						**EULAR(2)**
	Peripheral	**Axial disease**	**Enthesitis**	**Dactylitis**	**Nail**	**Skin**	
First line	— NSAIDs — DMARDs	— NSAIDs — Physiotherapy + NSAIDs	— Physiotherapy — NSAIDs	— Corticosteroid injections — NSAIDS	— Biologics — Topicals	— Topicals	— NSAIDs +/- glucocorticosteroid injections — DMARDs (in case of adverse prognostic factors)
Second line	— Biologics	— Biologics	— Biologics	— DMARDs	— Biologics	— Phototx/ DMARD	— DMARDs — Biologics can be considered for patients with enthesitis and axial disease
Third line	— Switch biologic	— Switch biologic	— Switch biologic	— Biologics	— Switch biologic	— Biologic	— Switch DMARD (arthritis without adverse prognostic factors) — Biologic (+/– DMARD) (arthritis with adverse prognostic factors)
Fourth line				— Switch biologic		— Switch biologic	— Switch biologic

Sources: KPMG interviews; secondary research: 1: Coates LC, et al. (2016) Group for research and assessment of psoriasis and psoriatic arthritis: Treatment recommendations for psoriatic arthritis 2015. Arthritis Rheumatol. 2016 Jan 8. doi: 10.1002/art.39573. [Epub ahead of print]; 2: Gossec, L. et al (2015) European League Against Rheumatism (EULAR) recommendations for the management of psoriatic arthritis with pharmacological therapies: 2015 update. Ann Rheum Dis. 0:1–12

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Ideally, patients should have their treatment adjusted as needed to achieve the goals of therapy

The interviewed stakeholders agreed that in PsA, as well as in other rheumatic conditions, treat–to–target approach should be used where the target is defined as disease remission or low/minimum disease activity. However, due to the heterogeneous nature of PsA and multisystem involvement, there is currently no consensus on how to measure disease activity to identify those who might be sub–optimally treated

Minimal disease activity (MDA) criteria in psoriatic arthritis [1]

A patient is classified as having 'minimal disease activity' when achieving five out of seven following criteria:

- Tender joint count ≤ 1
- Swollen joint count ≤ 1
- PASI <1 or BSA ≤ 3
- Patient pain visual analogue score ≤ 15
- Patient global disease activity visual analogue score ≤ 20
- HAQ ≤ 0.5
- Tender entheseal points ≤ 1

- PsA is a complex disease with various manifestations including involvement of peripheral and axial joints, skin and nails, enthesitis and dactylitis
- All these clinical features should be considered when assessing disease activity to identify those who are sub–optimally treated and might require treatment optimisation
- Remission criteria and composite activity indexes (such as the disease activity score (DAS–28 joints) developed for rheumatoid arthritis have been used in PsA (e.g. at Guy's and St Thomas' Hospital in London); however, they do not include some unique manifestations of PsA
- In 2010, GRAPPA endorsed the Minimum Disease Activity (MDA) criteria, as a possible target of treatment for patients with PsA that encompasses most disease domains [1]
- It is anticipated that simpler and more practical measures will evolve that allow for precise evaluation of disease activity and patient's response to therapy

> **“From the patient point of view, it is complete remission and lack of inflammation in our body that should remain the ultimate treatment target in PsA”**
>
> Patient Research Partner, GRAPPA

> **“There is a need to develop new measures of disease activity that can satisfy the needs of all stakeholders involved: patients, doctors and payers”**
>
> Rheumatologist–dermatologist, Tufts Medical Centre, Boston

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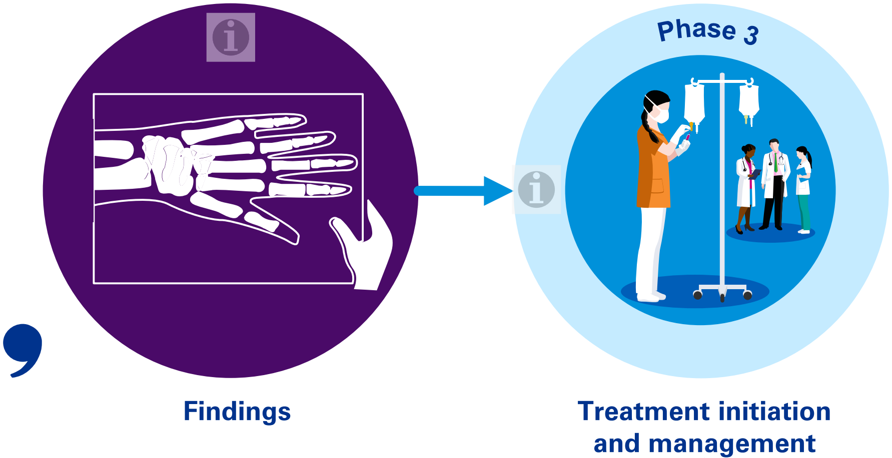
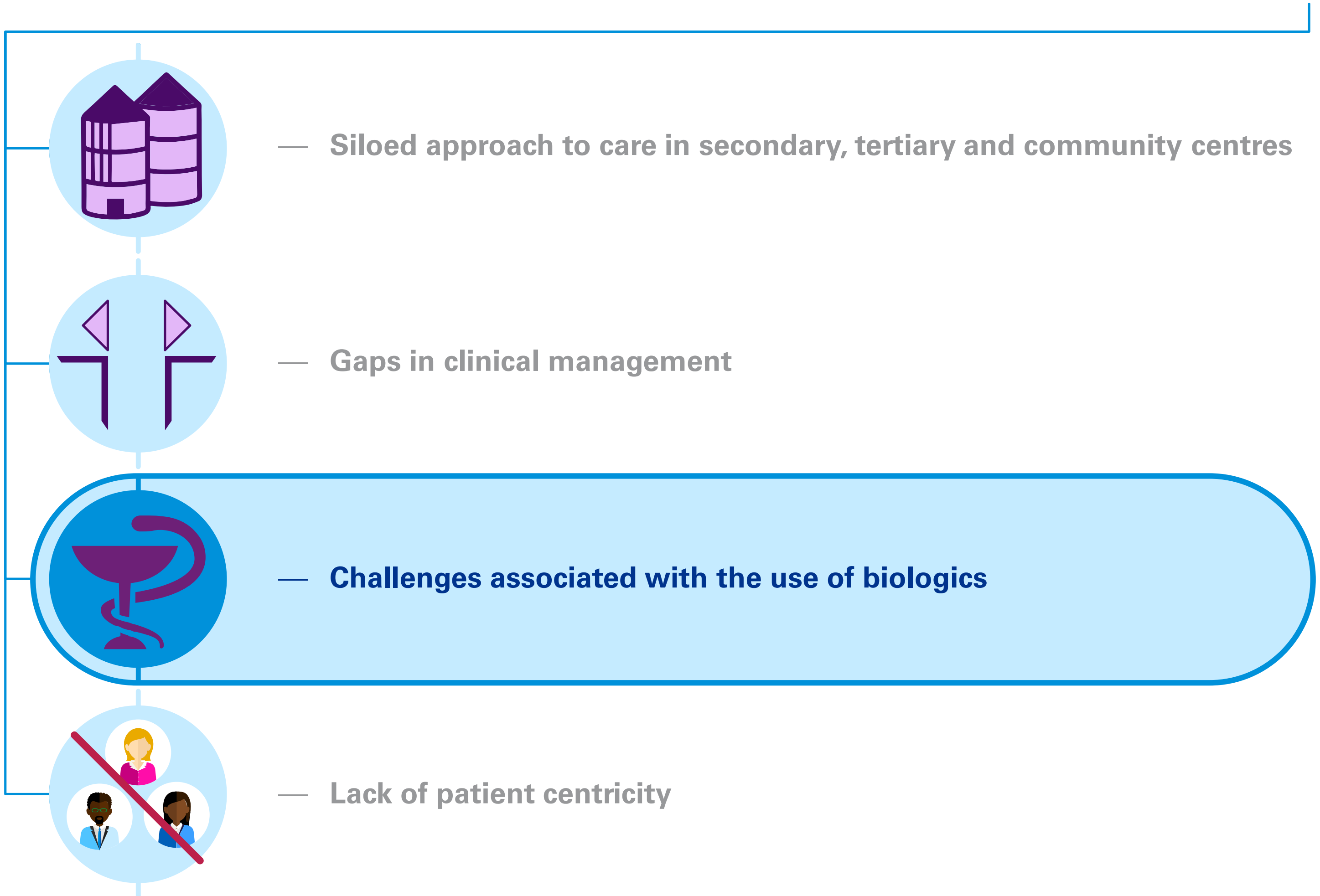
Sources: KPMG interviews; secondary research: 1: Coates LC, Fransen J, Helliwell PS. (2010) Defining minimal disease activity in psoriatic arthritis: A proposed objective target for treatment. Ann Rheum Dis;69:48-53

> Biologics are strictly controlled by the government and it creates a lot of social problems and feelings of isolation among patients who do not have access to these therapies
>
> Chairman, PsA patient association, Hong Kong





— Siloed approach to care in secondary, tertiary and community centres

— Gaps in clinical management

— **Challenges associated with the use of biologics**

— Lack of patient centricity

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Challenges associated with the use of biologics

What is the challenge?

Challenges associated with the use of biologics

— Although many effective treatment options are available for PsA, access to these therapies can be reduced or delayed for some patients

— There is also some evidence that PsA patients are undertreated as up to 59% of PsA patients are not given any medication for their symptoms or receive topical therapy only [1]

What are the causes?

Cost of biologics

— The cost of biologics has had a significant impact on limited health care resources, requiring decision makers and payers to increase their scrutiny with regards to reimbursement.[2] For instance, reimbursement of biologics in the UK tends to be limited to patients who have failed at least two DMARD treatments [3]

Higher burden on HCPs and patients

— Use of biologic therapies can place additional burden on HCPs (such as the need for extra check–ups and vaccinations) and additional nursing staff may be required. In can also be more burdensome for patients (e.g. physical preparation for self–injections)

What can be done to address it?

Click on each number below to go to the relevant case study

Intervention	Overview	Key stakeholder(s)	Case studies
Enrolment of patients into clinical trials	— Patients with severe disease can be enrolled into clinical trials to get access to newer and potentially more effective treatment options	— Rheumatologists — Researchers — Patients	1 PsA Research Clinic at the Prince of Wales Hospital, Hong Kong (III)
Development of relationships with commissioners	— Hospitals should develop relationships with commissioners which can help create alternative care pathways and improved reimbursement	— Rheumatologists — Dermatologists	

Key III Tertiary clinic — Community clinic

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Key findings

Sources: KPMG interviews; secondary research: 1: Lebwohl, M.G., Bachelez, H., Barker, J. et al (2014) Patient perspectives in the management of psoriasis: results from the population-based Multinational Assessment of Psoriasis and Psoriatic Arthritis Survey. J Am Acad Dermatol.; 70:871–881.e30; 2: Lee, S., et al. (2010) The burden of psoriatic arthritis: a literature review from a global health systems perspective. P.T.; 35(12): 680–689; 3: NICE (2010) Etanercept, infliximab and adalimumab for the treatment of psoriatic arthritis. TA199

PsA research clinic (1/3)

The Prince of Wales Hospital, Hong Kong

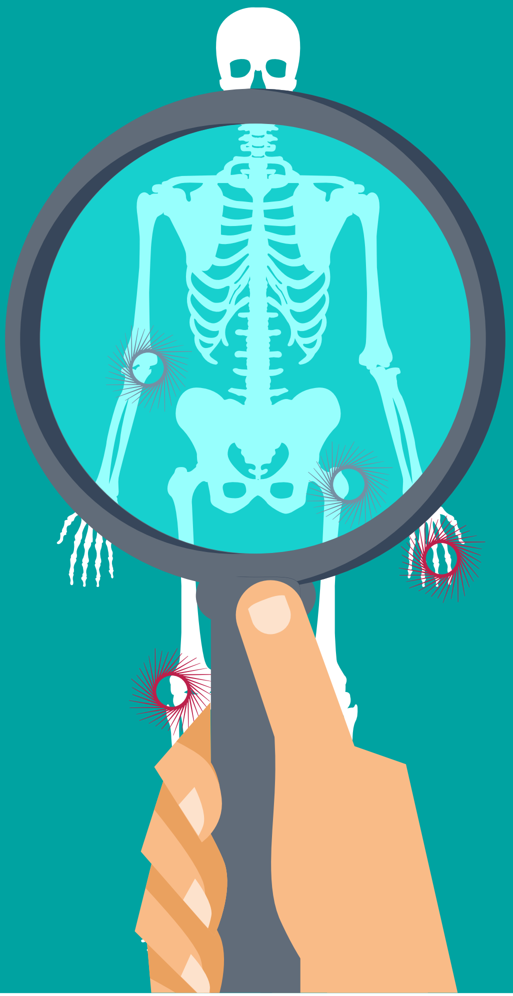
Case study 1

Overview

Researchers at the Prince of Wales Hospital (PWH) in Hong Kong are investigating whether strategies aimed at remission can prevent bone loss and progression of atherosclerosis as both of these conditions may be associated with PsA [1,2]

These research activities have been incorporated into the clinical setting so that patients who fulfil the enrolment criteria can attend the research clinic rather than the routine clinic and receive better care

The research clinic incorporates a two–year, protocol–driven programme after which patients return to routine care. Out of the 485 patients treated at the hospital, 109 PsA patients are currently followed up on in the research clinic

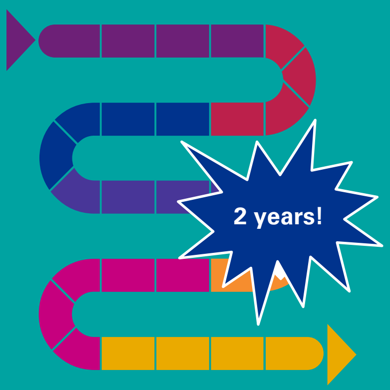


What was the rationale behind its set–up?

The rheumatology service at the PWH is facing challenges in providing quality care to its patients. With limited resources and escalating demand for the service, the waiting times for an initial appointment with the specialist can reach two years. Therefore, the team is not always able to provide early diagnosis and use the treat–to–target approach (where the treatment goal is defined as remission or low disease activity, and treatment is adjusted if the goal has not been reached)

In addition, as PWH is a university clinic, the clinicians would like to conduct research which could be published in high–impact journals

Therefore, the research clinic has been set up to incorporate research into the clinical service. The clinic provides a high quality service while conducting research on chronic inflammation in PsA



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Key findings

Sources: KPMG interviews; secondary research: 1: Zhu, T., et al (2015) Density, structure, and strength of the distal radius in patients with psoriatic arthritis: the role of inflammation and cardiovascular risk factors. Osteoporos Int. 26(1):261-72; 2: Tam, L.-S., et al (2008) Cardiovascular risk profile of patients with psoriatic arthritis compared to controls—the role of inflammation. Rheumatology. 47 (5): 718-723

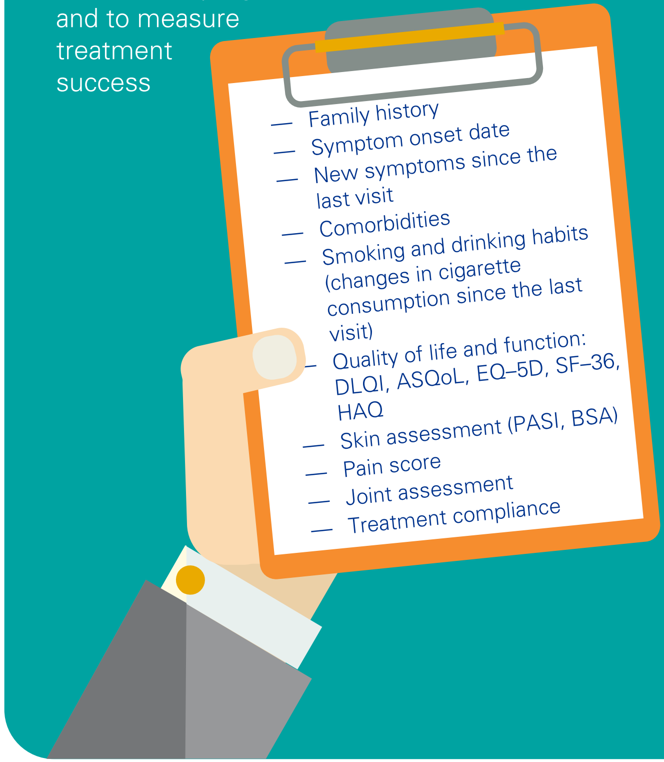
PsA research clinic (2/3)

The Prince of Wales Hospital, Hong Kong

What are the key features of the PsA research clinic?

Initial assessment

During the first visit, patients are given a detailed questionnaire to fill in. The questionnaire from the first visit is kept as a baseline which is then used to monitor the progression of the disease and to measure treatment success

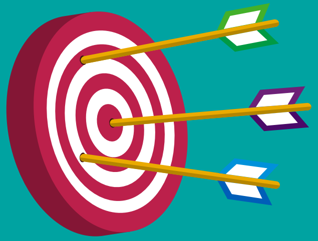


- Family history
- Symptom onset date
- New symptoms since the last visit
- Comorbidities
- Smoking and drinking habits (changes in cigarette consumption since the last visit)
- Quality of life and function: DLQI, ASQoL, EQ–5D, SF–36, HAQ
- Skin assessment (PASI, BSA)
- Pain score
- Joint assessment
- Treatment compliance

Treatment management

In the research clinic, physicians assess disease activity and use the treat–to–target approach to PsA care with minimum disease activity (MDA) as the treatment target. If patients do not reach the target, their treatment is either optimised or changed. In the routine clinic, the treat–to–target approach is not normally used due to infrequent and short appointments

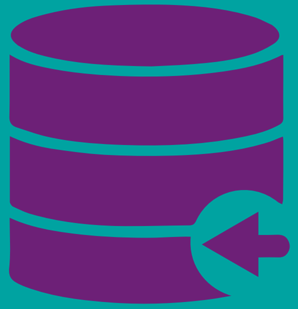
As the research focus is on atherosclerosis and osteoporosis, the key outcomes include cardiovascular comorbidities and bone loss



Follow–up appointments and monitoring

During the appointments, PsA patients are first seen by nurses who provide education and counselling and perform disease and drug monitoring. Following the appointment with the nurse, patients are seen by a rheumatologist

The research clinic is supported by an electronic database which enables researchers to collect and store all patient data. It also provides monthly updates on the progress of recruitment



Challenge
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Key findings

Source: KPMG interviews

PsA research clinic (3/3)

The Prince of Wales Hospital, Hong Kong

Case study 1

What are the benefits of the research clinic to patients?

Shorter waiting times

Due to the limited number of rheumatologists, it can take up to two years for a PsA patient to be seen for their initial assessment. However, patients in the research clinic can be seen within two weeks

Earlier access to biologics

In Hong Kong, there is very limited access to biologics. Patients need to have failed at least three DMARD therapies and have at least four tender or swollen joints before they are eligible for biological treatment

Enrolment in these studies provides early access to treatments that would otherwise be unavailable for many patients. This is beneficial to patients since early use of biologic therapies can prevent the accumulation of joint damage

Improved care and patient–centricity

In the research clinic, the rheumatology team can provide a more holistic approach to patients' care. With longer appointment times (30–45 minutes each), they can perform a full check of symptoms, measure patients' quality of life and screen for comorbidities

In addition, the patient's perception of the provider–patient interaction is measured in order to improve the quality of that interaction and provide a more patient–centric approach to care

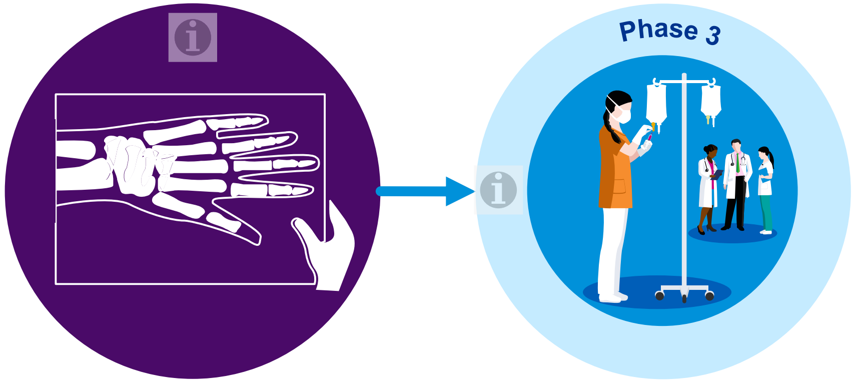
What are the challenges associated with the research clinic?

Not all PsA patients are eligible for the study (e.g. if they do not have active joint disease) and therefore cannot attend the research clinic, which means they receive a lower quality of care. In addition, patients who complete the programme and return to routine care might not have the same access to treatment as before

Challenge
Home
Key findings

Source: KPMG interviews

> **To deliver optimal PsA treatment you have to educate and engage patients in their care**
>
> Rheumatologist, University Hospital
> Schleswig–Holstein, Lübeck



Findings

Treatment initiation and management

- Siloed approach to care in secondary, tertiary and community centres
- Gaps in clinical management
- Challenges associated with the use of biologics
- **Lack of patient centricity**

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Lack of patient centricity

What is the challenge?

Lack of patient centricity

- As patients become more engaged in healthcare, they want to be empowered to manage their own health. However, many centres could do more to be truly patient–centric
- Lack of patient–centricity can lead to poorer patient experience. A recent survey conducted by the US National Psoriasis Foundation on more than 5,000 PsA patients revealed that approximately 50% of PsA patients were not satisfied with their treatment [1]

What are the causes?

Limited communication

- Insufficient communication between patients and doctors can lead to a mismatch in expectations with regards to the treatment goals

Low level of patient education

- Due to limited resources, HCPs often fail to provide sufficient education to their patients. However, a higher level of patient knowledge is associated with greater satisfaction with care [2]

Low engagement

- Similarly, patients are often not included in the decision–making process despite the fact that patients who are actively involved in their care demonstrate greater satisfaction with treatment

What can be done to address it?

Click on each number below to go to the relevant case study

Intervention	Overview	Key stakeholder(s)	Case studies
Improved communication between HCPs and patients and engagement of patients in their care	— Communication between HCPs and patients should be improved to understand patients' concerns and align expectations and goals — Patients should be actively engaged in their care	— HCPs — Patients	1 Pregnancy clinics at Guy's and St Thomas' hospital in London, UK (III)
Development of educational programmes for patients	— PsA patients should be educated on the disease, treatment options, their risks and benefits. A structured programme of education should be considered to ensure patients receive adequate and consistent information	— HCPs — Patients	2 Patient centricity at Toronto Western Hospital, Canada (III)
Collaboration with patient associations	— Clinicians should engage with patient associations as these can provide additional support for patients	— HCPs — Patients	
Patient education by medical office staff	— As clinicians and nurses often do not have enough time to provide patients with detailed education, certain types of educational programmes can be delivered by trained medical office staff (e.g. medical assistants) at the point–of–care	— Medical office staff — Patients	

Key III Tertiary clinic 🏠 Community clinic

Sources: KPMG interviews; secondary research: 1 Armstrong, A.W., et al (2013) Undertreatment, treatment trends, and treatment dissatisfaction among patients with psoriasis and psoriatic arthritis in the United States: findings from the National Psoriasis Foundation surveys, 2003–2011. JAMA Dermatol.; 149(10):1180–5; 2: Leung Y., et al. (2009). Involvement, satisfaction and unmet health care needs in patients with psoriatic arthritis. Rheumatology. 48(1):53–6

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Key findings

Pregnancy clinics (1/2)

Guy's and St Thomas' NHS Foundation Trust NHS

Case study 1

Overview

The advanced nurse specialist at Guy's and St Thomas' runs formalised clinics for patients with rheumatic diseases who are considering pregnancy. These clinics have been set–up for female patients with PsA as well as their partners and they aim to help patients understand the implications of the disease and therapies on pregnancy, and choose the appropriate actions

What is the rationale for having pregnancy clinics?

PsA often affects women during their childbearing years. Although the arthritis itself can temporarily improve for women during their pregnancy, some of the treatments for PsA may be associated with birth defects [2]. In addition, taking care of a child can be more difficult for patients suffering from joint disease than for healthy parents

The pregnancy clinics have been set up at Guy's and St Thomas' as it can be helpful for patients to have discussions with healthcare professionals about pregnancy and potential treatment alterations several months before trying to conceive

Challenge
Home
Key findings

Sources: KPMG interviews; secondary research; 1: Krause, M.L.,et al (2014) Use of DMARDs and biologics during pregnancy and lactation in rheumatoid arthritis: what the rheumatologist needs to know. Ther Adv Musculoskelet Dis. 2014 Oct; 6(5): 169–184; 2: Kurizky. P.S., et al (2013)Treatment of psoriasis and psoriatic arthritis during pregnancy and breastfeeding. An Bras Dermatol. 90(3):367-75

Pregnancy clinics (2/2)

Guy's and St Thomas' NHS Foundation Trust NHS

Case study 1

What are the key features of the pregnancy clinics?

Pre–pregnancy counselling

To provide pre–pregnancy counselling on the risks and appropriate timing of pregnancy in PsA patients who often have complex diseases and are taking multiple medications, some of which can be teratogenic

Follow–up during pregnancy

To follow patients through their pregnancies, help differentiate disease from pregnancy manifestations and provide advice on the safest therapeutic interventions

Follow–up after childbirth

To follow patients for three months post childbirth to ensure continuity of care and prompt treatment of any potential flares of PsA

Education

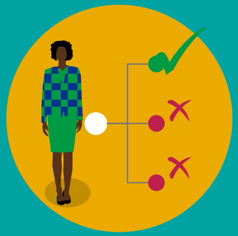
Patients are more aware of the implications of their disease and treatments for both the mother and child

Advice

The nurse develops a personalised treatment plan and provides advice to patients and families of patients who are considering or going through pregnancy

Better–informed decisions

Improved patient education coupled with advice from specialised nurses can lead to better informed decisions and improved outcomes for both parents and their future children



Challenge
Home
Key findings

Source: KPMG interviews

Patient Centricity: Advisory Committee and Newsletter (1/3)

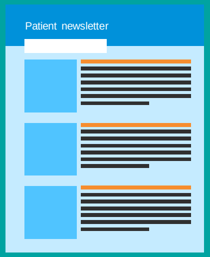
Toronto Western Hospital

Case study 2

How is the clinic patient–centric?

Toronto Western Hospital has a number of initiatives to promote patient–centricity, including a patient newsletter, patient advisory committee and an annual patient education symposium

Patient newsletter



Patient advisory committee

Annual patient education symposium

> Ordinarily everything is being done to us or for us, the patients, but we usually have little say in the process. I believe patients are very much an under–used resource in the planning and delivery of healthcare. Ever since the Patient Advisory Committee was set up at Toronto Western Hospital the doctors have been listening to us and have incorporated some of our suggestions in the patient newsletter and the patient educational symposium as well as in some of the research. I believe the results will speak for themselves, i.e. better informed patients, better informed research, better outcomes, etc.

Member of the Patient Advisory Committee, Toronto Western Hospital

What was the rationale behind the centre becoming more patient–centric?

Until a few years ago communication between physicians and patients was very limited. However, it was recognised that improving patient–centricity had a number of beneficial outcomes:

- Patients are more likely to own their disease and treatment if they have a say in how it is managed and if they feel their opinion matters
- Keeping patients informed reduces stress and uncertainty when undergoing treatment
- Patient–centricity and the patient advisory committee have become important elements in scientific and medical education grant requests

Challenge
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Key findings

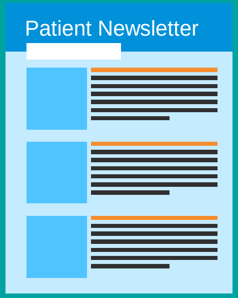
Source: KPMG interviews

Patient-centricity: advisory committee and newsletter (2/3)

Toronto Western Hospital

Case study 2

What are the key features of their patient–centricity initiatives?



Patient educational symposium: An annual event for PsA patients and their families. During the symposium, PsA experts from the University of Toronto educate patients on the disease and its outcomes, as well as recent advances in PsA treatment. Patients also have the opportunity to ask questions during a Q&A session with the experts

Patient newsletter: Released twice a year, the newsletter is intended for new and current PsA patients at the hospital. The newsletter comprises a brief overview of the disease, the history of the clinic, current research projects and future initiatives. It also guides patients to resources where they can find more information on the disease, and provides contact details of the PsA Program

Note: Copy of the Patient Newsletter can be found in the appendix (pages: 178 – 184)

The patient advisory committee: The patient advisory committee represents PsA patients in any area where patients’ interests are involved. The committee helps medical staff review the patient newsletter, write lay summaries for grant applications and plan topics for the annual patient education symposium. In addition, members of the committee participate in research and conference work where patient representation is required. The committee comprises six or seven patients who meet with the practitioners every three months. Membership is on a voluntary basis, and members are from different social and ethnic backgrounds

What are the challenges facing the initiative?

The key challenges are associated with the time required by medical staff to participate in these initiatives

Challenge
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Key findings

Source: KPMG interviews

These interventions can lead to a number of potential benefits (1/2)

During our site visits, we asked the interviewed clinicians to highlight the potential benefits that may be achieved through the implementation of interventions discussed. Although the centres we visited do not have formal systems in place that allow the impact to be measured, most of them agreed on the benefits that can be achieved

Intervention	Clinical benefits					Economic benefits		Patient experience	
	Improved time to referral/ diagnosis	Improved disease control	Improved adherence	Adequate control of comorbidities	Improved QoL	Fewer hospital admissions	Reduced productivity loses	Improved empowerment	Increased convenience
Challenge: Lack of collaboration between dermatology and rheumatology departments									
Improved coordination of dermatology and rheumatology services		✓		✓	✓	✓	✓		✓
Challenge: Siloed approach to care: community centres									
Development of networks and relationship between community–based centres		✓		✓	✓	✓	✓		✓

Source: KPMG interviews

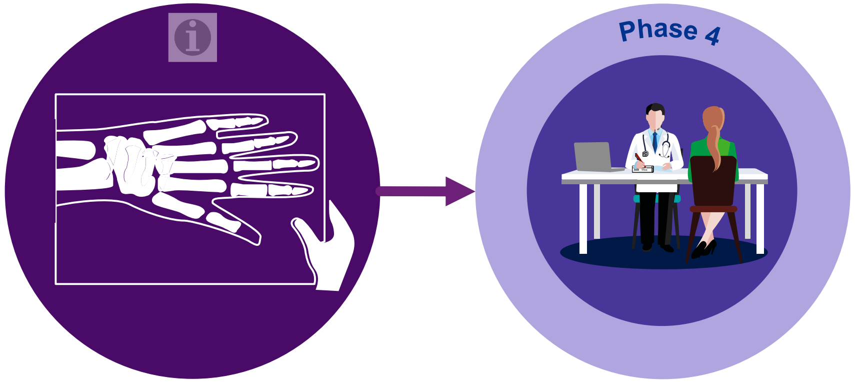
Challenge
Home
Key findings

These interventions can lead to a number of potential benefits (2/2)

Intervention	Clinical benefits					Economic benefits		Patient experience	
	Improved time to referral/ diagnosis	Improved disease control	Improved adherence	Adequate control of comorbidities	Improved QoL	Fewer hospital admissions	Reduced productivity loses	Improved empowerment	Increased convenience
Challenge: Gaps in clinical management of PsA									
Use of protocols and treatment algorithms		✓		✓	✓	✓	✓		
Development and validation of new outcome measures		✓				✓	✓		
Challenges associated with the use of biologics									
Enrolment of patients into clinical trials		✓		✓	✓	✓			
Development of relationships with commissioners									
Challenge: Lack of patient centricity									
Improved communication and engagement of patients in their care			✓	✓	✓			✓	
Development of educational programmes for patients			✓	✓	✓			✓	
Collaboration with patient associations			✓	✓	✓			✓	
Patient education by medical office staff			✓	✓	✓			✓	

Challenge
Home
Key findings

Source: KPMG interviews



Findings

Follow–up

— **Inadequate management of comorbidities**

— Lack of follow–up

> **Comorbidities are a much bigger issue in PsA than in other diseases, including RA. Here you have a whole range of possible comorbidities which can cause serious problems for patients. You have to be able to identify them early if you want to provide good care for your patients**
>
> Rheumatologist, Guy's and St Thomas' NHS Foundation Trust, London

Inadequate treatment of comorbidities

What is the challenge?

Inadequate treatment of comorbidities

- Patients with PsA have a high risk of comorbidities, including hypertension, cardiovascular diseases, diabetes and gastrointestinal disorders.[1] Cardiovascular risk is known to be responsible for 20–56% of deaths in patients with PsA [2]
- These can be overlooked by clinicians who focus solely on treating cutaneous and joint manifestations of PsA, leading to suboptimal outcomes

What are the causes?

Limited awareness

- The awareness of comorbidities associated with PsA is low among non–rheumatologists [3]

Lack of resources and networks

- Clinicians at many centres face challenges with a lack of time and resources to adequately monitor PsA comorbidities
- They may also have limited access to other specialties required to initiate the adequate therapy

What can be done to address it?

Click on each number below to go to the relevant case study

Intervention	Overview	Key stakeholder(s)	Case studies
Peer and patient education	— Healthcare providers should be educated on the impact of PsA on daily life, comorbidities and the long–term outcomes of PsA — Patients should be provided with timely education on the risk of developing comorbidities, especially in relation to the cardiovascular risk	— Rheumatologists — Academic societies — PAGs — Patients	1 Role of nurse specialist in monitoring patients at Guy's and St Thomas Hospital in London, UK 2 Nurse–led clinics at the Prince of Wales Hospital, Hong Kong III
Nurse–led clinics	— Nurse–led clinics should be considered for monitoring of patient's comorbidities if time constraints mean that treating rheumatologists are unable to do so	— Nurses	

Key III Tertiary clinic; Community clinic

> **We need to take better care of comorbidities. This is something that we are all aware of but have not worked on systematically. The management of comorbidities should be more standardised**
>
> Rheumatologist, Hospital Italiano de Buenos Aires, Buenos Aires

Sources: KPMG interviews; secondary research; 1: Ogdie, A., et al (2015) Recognizing and managing comorbidities in psoriatic arthritis. Curr Opin Rheumatol. 27(2):118-26; 2: Betteridge, N. et al (2015) Promoting patient-centred care in psoriatic arthritis: a multidisciplinary European perspective on improving the patient experience J Eur Acad Dermatol Venereol, advance online publication; 3: Helliwell, P., Coates, Chandran, V. et al. (2014) Qualifying unmet needs and improving standards of care in psoriatic arthritis Arthritis Care Res (Hoboken); 66: 1759-66

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Key findings

Nurse-led clinics for newly diagnosed patients (1/2)

Guy's and St Thomas' NHS Foundation Trust NHS

Case study 1

Overview

Guy's and St Thomas' centre focuses the time of the nurse team on activities where their skills can make the most impact, to avoid her performing jobs where other healthcare professionals could substitute. This includes running clinics for newly diagnosed patients with PsA which is supported by a telephone helpline

What was the rationale behind the clinic?

The clinic for newly diagnosed patients was established to support people with this new diagnosis and help them develop better coping strategies. This is especially important as the centre does not have a dedicated psychologist. In addition, the clinic was meant to improve their understanding of the disease, therapeutic options and treatment goals

What are the key features of the clinic?

Place in the pathway

Patients are referred to a rheumatology nurse specialist when a diagnosis has been made by their consultant rheumatologist and their treatment has been agreed. At the start of the treatment, patients are seen once a month which becomes less frequent as their condition stabilises

Dose escalation

The advanced nurse practitioner at the centre is responsible for altering the dose to help patients reach the treatment outcome, i.e. remission or low disease activity on the DAS 28 scoring system or MDA

Patient education

The nurse provides a detailed explanation of the diagnosis and treatment which is supported by written materials that patients can take home. During the clinic, she also provides patients with information before they start any drug therapy so they are fully informed and engaged in their treatment

Telephone helpline

The clinic is supported by a telephone helpline service where patients can leave a message and the nurse will get back to them, typically within 24 hours. The voicemail system allows the nurse to read patients' medical records and, if required, obtain advice from other specialists prior to speaking with patients. In addition, the phone line is documented and linked to patients' electronic medical records which ensures that all information is captured and stored

Challenge
Home
Key findings

Source: KPMG interviews

Nurse-led clinics for newly diagnosed patients (2/2)

Guy's and St Thomas' NHS Foundation Trust NHS

Case study 1

What are the benefits of the nurse–led clinic?

Improved patient education: The clinic is key in providing patient education. The centre used to have problems with patients refusing to take dose increases or have their treatment changed. Up to 35% of all patients were reluctant to an increased dose of their treatment. Within six years following the clinic set–up, the percentage of patients reluctant to dose increase dropped to 8%

Better relationship with the patient: Nurses tend to be more empathetic than doctors and develop better relationships with patients which is important to ensure that the patients are fully engaged in their treatment. Nurses are also good at handling patients' health beliefs and can help them develop better coping strategies

Follow–up and management of comorbidities: During the clinic, the nurse monitors the safety and effectiveness of PsA treatments. In addition, she helps manage patients' comorbidities

What are the next steps?

The centre is planning to create a more formalised nurse–led clinic for patients further along the patient pathway

Challenge
Home
Key findings

Source: KPMG interviews

Nurse-led clinics (1/2)

The Prince of Wales Hospital, Hong Kong

Case study 2

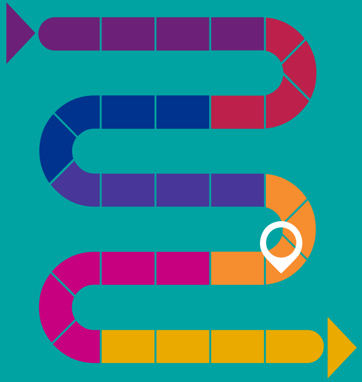
Overview

In the Hong Kong health system the Hospital Authority, the national entity responsible for health care, utilises nurse specialists in the outpatient hospital system [1]

At the Prince of Wales Hospital, the rheumatology nurse assists doctors with screening early arthritis patients, monitoring disease activity and adverse reactions, and management of long–term comorbidities. Most of these activities are carried out at a nurse–led clinic which was set up in 2013

Hospital Authority

What was the rationale for setting up the clinic?



Due to the limited number of rheumatologists, the waiting time to see a specialist can be relatively long (approximately six months). The nurse–led clinic was set up to enable patients to talk to specialised healthcare professionals and obtain advice in between appointments with rheumatologists

What are the key features of the clinic?

Patients are typically referred to the nurse–led clinic by a rheumatologists or by dermatologists. Consultations normally last 30–45 minutes and the waiting time for an appointment is 12 weeks

During the clinics, the rheumatology nurse supports the clinical team in a number of key activities along the patient pathway, including:

- **Treatments:** Administration of infusions and patient education on administering sub–cutaneous injections
- **Disease activity assessment**: Monitoring of the disease including skin assessment, joint count, X–ray scans
- **Drug monitoring**: Monitoring of compliance to the treatment and adverse effects
- **Patient education and support**: The nurse–led clinics are key in providing education and counselling to patients. During these clinics patients are educated on the disease, its treatment and its side effects, on how to administer self–injections, and pregnancy advice. In addition, patients are provided with details of support groups which they are encouraged to join
- **Screening for comorbidities**: Annual assessment of cardiovascular risk

The clinic is also supported by a nurse–led rheumatology hotline which is open during work hours on Monday to Friday. The line allows patients to call with any issues associated with the disease or treatment

Challenge
Home
Key findings

Sources: KPMG interviews; secondary research: 1. Sheer, B., Wong, F. (2008). The development of advanced nursing practice globally. Journal of Nursing Scholarship, 40(3),204–211

Nurse-led clinics (2/2)

The Prince of Wales Hospital, Hong Kong

What are the benefits of a nurse–led clinic and rheumatology helpline?

- **Patient–centric care:** Improved relationship between patients and HCPs
- **Shorter waiting time:** The waiting time to see an HCP at PWH was reduced from six to three months
- **Link to the PsA patient group:** The nurse encourages patients to join the PsA patient group to receive additional support
- **Improved monitoring:** Monitoring of the treatment efficacy and its adverse effects as well as regular screening for comorbidities
- **Reduced hospital admissions:** Fewer unnecessary hospital visits due to active disease and mild infections

What are the challenges of a nurse–led clinic?

There is only one rheumatology nurse at the hospital, leading to a heavy workload and long waiting times for appointments. It usually takes approximately three months to schedule an appointment with the nurse but it can be longer for newly diagnosed PsA patients

What are the next steps?

Because PsA patients tend to have metabolic complications and can have problems with weight, the nurses would like to start providing dietary advice to see if they improve compared to those who receive no education on their diet

Brochure of a PsA patient group

> **Providing adequate patient support and education is very important because it opens their minds to accepting the disease and living normal lives**
>
> Nurse, Prince of Wales Hospital, Hong Kong

Challenge
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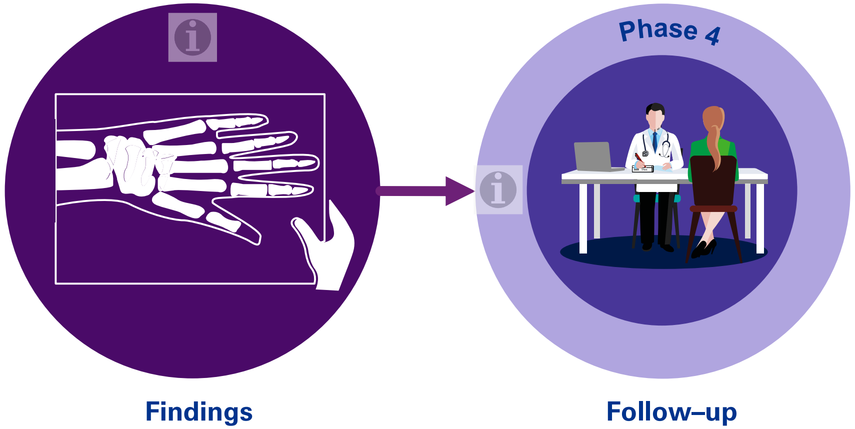
Key findings

Source: KPMG interviews



— Inadequate management of comorbidities

— **Lack of regular follow–up**

Home

Key findings

Lack of regular follow-up

What is the challenge?

Lack of follow–up

- In current practice some patients may not be followed up after their initial consultation
- The lack of regular monitoring means that patients' conditions are not assessed adequately and treatment cannot be optimised, even if the disease progresses

What are the causes?

Lack of systems to monitor patients

- Limited use of electronic databases makes it challenging to identify patients with whom an appointment should be scheduled

Limited awareness and stigmatisation

- Patients may not be aware of the need for regular assessments and not report to their doctor. This can be further exacerbated by the difficulty that patients with psoriasis may have in describing the impact of their disease on their lives

What can be done to address it?

Click on each number below to go to the relevant case study

Intervention	Overview	Key stakeholder(s)	Case studies
Regular monitoring	— Objective, regular and comprehensive assessment of the clinical symptoms of PsA should be performed and appropriate interventions instituted — The psychological, social and physical impact of the disease should also be monitored. There are a number of measures of function and disability that have been validated in PsA	— Rheumatologists — Nurses — GPs — Dermatologists — Patients	Electronic databases, registries and cohorts at: 1 Brigham and Women's Hospital in the US 2 Toronto Western Hospital in Canada 3 University Hospital Schleswig–Holstein in Lübeck, Germany 4 Hospital Italiano de Buenos Aires 5 Guy's and St Thomas Hospital in London, UK III
Use of databases and EMRs	— Electronic patient databases should be set–up as they enable clinicians to capture detailed data and make better informed decisions	— Rheumatologists — Nurses — GPs — Dermatologists — Patients	
Patient education	— Patients should be educated on the need for regular assessments	— Rheumatologists — Nurses — GPs — Dermatologists — Patients	

Key III Tertiary clinic · Community clinic

Source: KPMG interviews

Home
Key findings

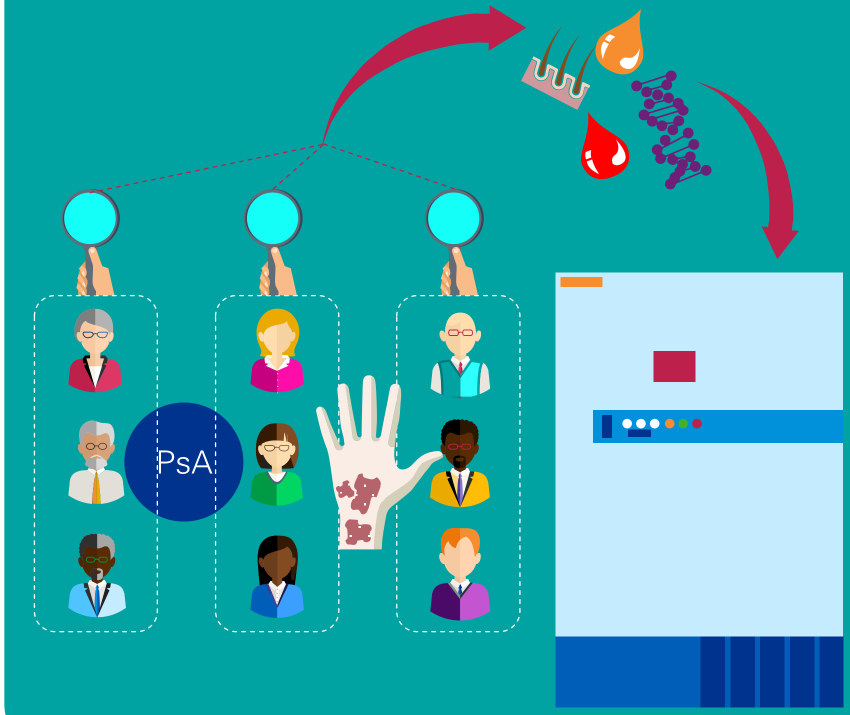
Brigham Cohort for Psoriasis and Psoriatic Arthritis (COPPAR) (1/2)

BRIGHAM AND WOMEN'S HOSPITAL

What is COPPAR?

COPPAR (Cohort for Psoriasis and Psoriatic Arthritis) is a cohort of psoriasis and PsA patients attending Brigham and Women's Hospital

The aim of COPPAR is to carefully phenotype psoriasis and PsA patients, and to develop a biorepository for their specimens (e.g. peripheral blood, plasma, serum, DNA, RNA, skin)



What is the rationale for setting up the cohort?

The cohort collects detailed information on psoriasis and PsA patients treated at the centre in order to:

— Identify predictors of treatment failure and response, and to characterise treatment transitions

— Determine predictors of PsA among patients presenting with psoriasis

— Characterise health services utilisation and quality of life of patients with PsA and psoriasis

— Assess relevant subgroups of patients with specific phenotypes, including non–plaque disease (e.g. nail disease, genital, inverse)

Source: KPMG interviews

Brigham Cohort for Psoriasis and Psoriatic Arthritis (COPPAR) (2/2)

BRIGHAM AND WOMEN'S HOSPITAL

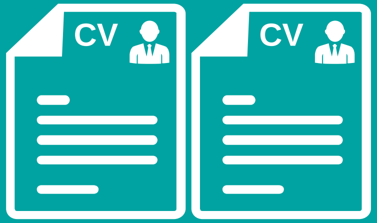
Case study 1

What are the key features of the cohort?

The infrastructure

COPPAR is a single–centre cohort with a large clinical caseload, dedicated dermatology–rheumatology practice, EMRs and existing biorepository. COPPAR is also based on the infrastructure already developed for a rheumatoid arthritis registry (Brigham and Women's Rheumatoid Arthritis Sequential Study, BRASS)

Clinical and scientific expertise



Investigators involved in the registry have strong backgrounds in relevant areas such as clinical care of psoriasis and PsA, biobanking, comparative effectiveness, pharmacoepidemiology and novel outcomes measures

Comparative effectiveness and biomarker research

At the centre, patients are treated with various treatments which allows clinicians to run non–randomised comparative effectiveness studies on these therapies

Prospective studies

Investigators have the ability to re–contact patients for additional prospective studies (e.g. clinical trials, biomarker research)

What are the next steps for the cohort?

- Enrol new prospective cohorts of psoriasis and PsA starting January 2016
- Collect and bank blood, skin and other biospecimens from patients
- Prospectively follow up on as many psoriasis and PsA patients as possible (the goal is 1,000 split equally between psoriasis and PsA)
- Seek adequate funds for more aggressive enrolment and biobanking

Challenge
Home
Key findings

Source: KPMG interviews

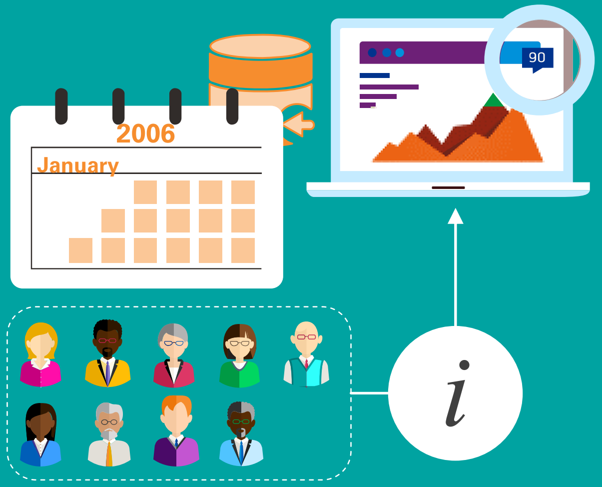
PsA and psoriasis databases (1/2)

Toronto Western Hospital

What are the PsA and psoriasis databases?

The PsA database was started in 1978 by Dr Gladman with the aim of monitoring and tracking changes to the disease over time [1]

In 2006 a psoriasis database was also set up to collect and store information from psoriasis patients

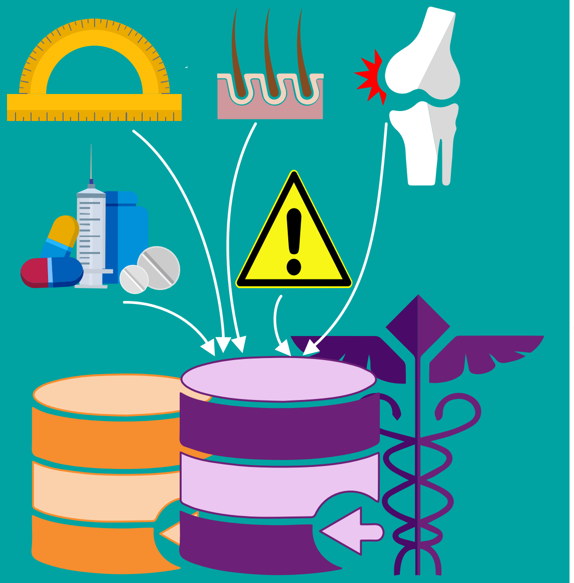


What was the rationale behind their set–up?

Dr Gladman was invited by a dermatology colleague to examine patients presenting with joint problems at the latter's clinic.
Dr Gladman realised that PsA was presenting in a noticeably different way than outlined in her training. She then endeavoured to conduct research on the condition. This led her to set up a database and clinic at Women's College, eventually moving to Toronto Western Hospital and taking on another rheumatologist as well as trainees

What are the key features of the databases?

The databases store more information than general registries, most notably detailed information on treatment side effects, treatments prescribed to patients, lab tests that have been completed, the granular phenotype of PsA, whether there is spinal involvement, level of skin disease, nail lesions and joint count



Sources: KPMG interviews; secondary research: 1. Gladman, D., et al (2005) Psoriatic arthritis clinical registries and genomics Ann Rheum Dis 2005; 64: ii103-ii105 doi:10.1136/ard.2004.030973

PsA and psoriasis databases (2/2)

Toronto Western Hospital

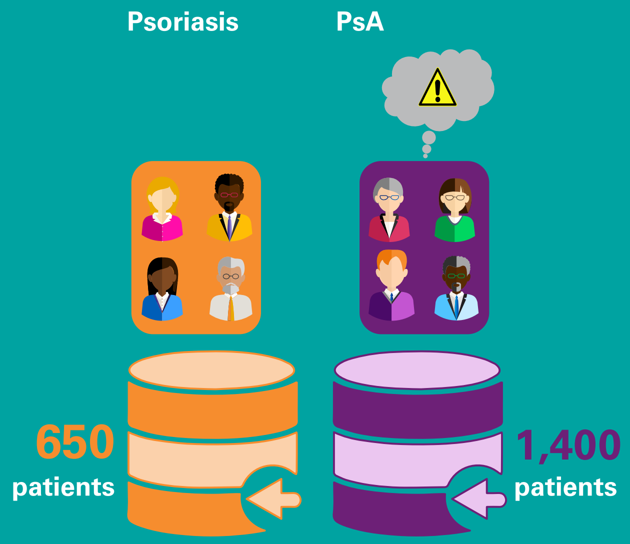
Case study 2

What are the benefits of the databases?

Storing over 38 years of patients' information has helped improve understanding of patterns of the disease and its progression, comorbidities and risk factors, as well as the efficacy and safety effects of various treatments [1]

What are the challenges faced by the databases?

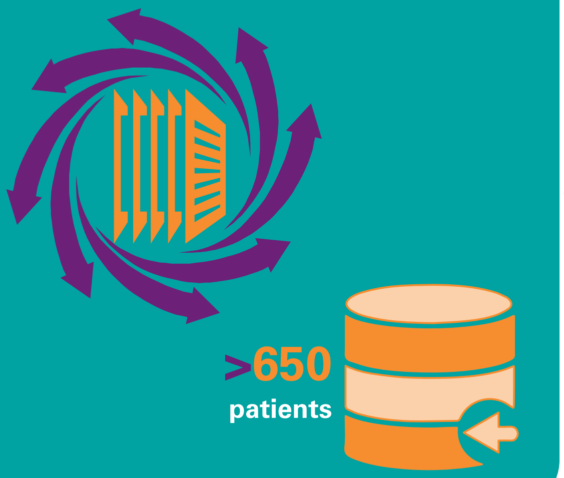
There are challenges associated with patient retention for the psoriasis database due to psoriasis patients not considering their disease a problem in the same way that PsA patients do. The number of patients on the psoriasis database is now less than half that of the PsA database (650 versus 1,400 respectively)



What are the next steps for the databases?

The database fields have evolved over the years to divest those where the validity could not always be assured, or where technical difficulties associated with collecting data outweighed the insight that was being gained, e.g. grip strength, back assessment by measuring three segments, etc.

The data fields collected will continue evolving and attempts will be made to increase patient numbers on the psoriasis database



Challenge
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Key findings

Sources: KPMG interviews; secondary research: 1: Gladman, D., Chandran, V. (2011) Observational cohort studies: lessons learnt from the University of Toronto Psoriatic Arthritis Program Rheumatology; 50: 25–31

PsoBest: German registry for psoriasis and psoriatic arthritis (1/2)

University of Lübeck

Case study 3

What is the PsoBest registry?

The PsoBest registry is a German nationwide registry set up to gather information about psoriasis and PsA patients

The aim of the registry is to evaluate the long–term efficacy and safety effects, and patient–reported outcomes in moderate to severe psoriasis and PsA patients treated with conventional systemic therapy or biologics

The registry was commissioned by the German Society of Dermatology and the Professional Association of German Dermatologists

What are the key features of the registry?

- **Study design:** Prospective cohort study
- **Study start**: January 2008 (the duration of the registry is at least 14 years)
- **Current patient numbers:** 4,500 psoriasis and PsA patients from 750 centres across Germany (the initial enrolment target of 3,500 has been exceeded)
- **Inclusion criteria**: Adult patients with moderate to severe psoriasis or psoriatic arthritis when treatment with a conventional systemic agent or biologic is started for the first time
- **Follow–up per patient**: Approximately 10 years
- **Case reports:** Standardised physician and patient case report forms are filled in every three to six months. The case reports collect detailed information on:
    - Treatments: Past and current systemic and biologic therapies
    - Efficacy outcomes: Psoriasis area severity index (PASI), Psoriatic Arthritic Response Criteria (PsARC), Disease Activity Score 28 (DAS 28), American College of Rheumatology score (ACR20)
    - Safety outcomes: Adverse and serious adverse events
    - Patient quality of life: Dermatology life quality index (DLQI), EuroQol questionnaire (EQ–5D)
    - Patient–reported outcomes: Health Assessment Questionnaire (HAQ)

Challenge
Home
Key findings

Source: KPMG interviews

PsoBest: German registry for psoriasis and psoriatic arthritis (2/2)

University of Lübeck

Case study 3

What are the expected benefits of the registry?

This national registry is intended to collect data useful for better planning and regulation of healthcare delivery at a national level. The registry is expected to have a number of benefits for patients and participating centres:

- It will further the understanding of psoriasis and PsA by gathering data on comorbidities, risk factors, and disease progression
- It will enable clinicians to compare the real–world efficacy and safety effects of multiple therapies
- It will help participating centres record disease characteristics and treatment outcomes, and track the disease progression, allowing clinicians to make better and more informed clinical decisions for individual patients

What are the challenges associated with setting up a national registry?

Motivating centres to participate and controlling data completeness are the two major challenges associated with creating a nation–wide registry. However, these challenges can be addressed by providing incentives for centres to take part in the registry and setting–up a vigilance committee to ensure completeness and consistency of data collected

Challenge
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Key findings

Source: KPMG interviews

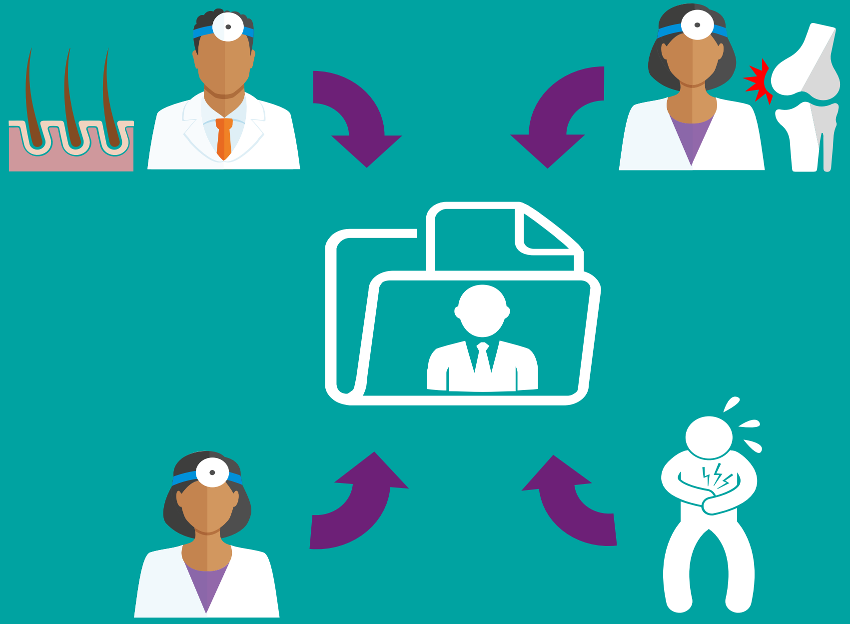
Electronic medical records system (1/3)

HOSPITAL ITALIANO
de Buenos Aires

Case study 4

What is the electronic medical records (EMR) system?

The EMR system links the hospital's network with peripheral centres, enabling it to be used throughout Hospital Italiano as well as in San Justo (a secondary hospital) and all the peripheral centres belonging to the same health maintenance organisation (HMO). Both specialists and GPs belong to this network. Therefore, this computerised system enables specialists, GPs and patients themselves to have access to relevant patient information



What is the rationale for the EMR system?

PsA care relies on the expertise of both rheumatology and dermatology. Whilst the EMR system is not designed for just one disease, the fact that all specialists and GPs can have access to it facilitates **specialty knowledge sharing in PsA**

Giving GPs access to the EMR system also enables them to talk through test results with patients. Sometimes patients may have close relationships with their GPs and therefore respond more positively to the same messages delivered by their GPs rather than a specialist

The EMR system was **generated in house** through the leadership of the vice–president of Hospital Italiano. Generating the system in house enabled the centre to customise it to meet the needs of the staff within the HMO [1]

By holding **focus groups and interviews with physicians** from different specialties within the HMO, the centre was able to create an EMR system that reflected the needs of everyone at the hospital

Another ultimate aim of the EMR system is to make it **easier to track and confirm appointments.** Patients are still able to contact administrative staff for information but the EMR system provides an online system where appointments can easily be tracked

Challenge
Home
Key findings

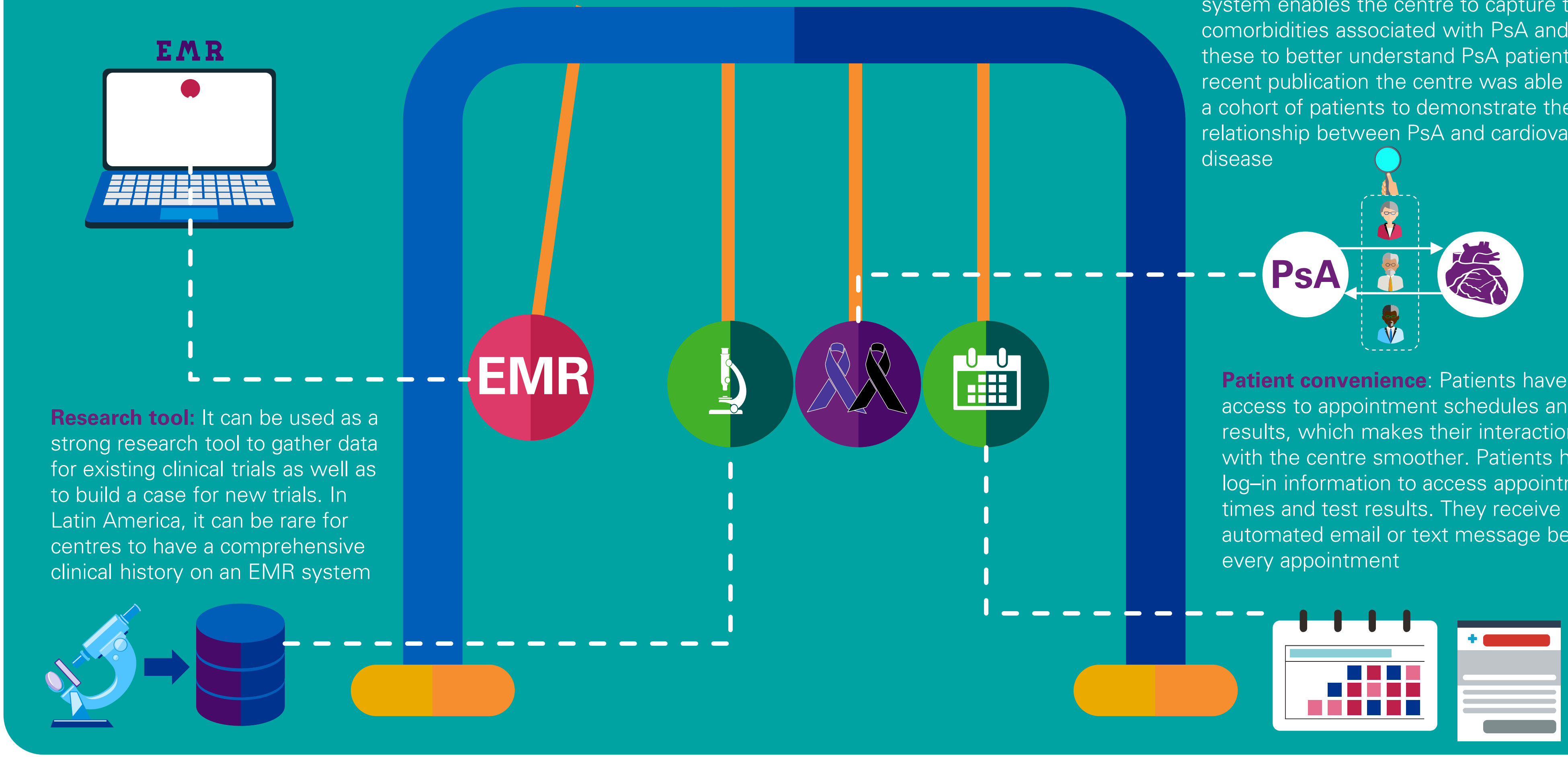
Source: KPMG interviews

Electronic medical records system (2/3)

HOSPITAL ITALIANO
de Buenos Aires

Case study 4

What is the impact of the EMR system?



Research tool: It can be used as a strong research tool to gather data for existing clinical trials as well as to build a case for new trials. In Latin America, it can be rare for centres to have a comprehensive clinical history on an EMR system

Monitoring of comorbidities: The EMR system enables the centre to capture the comorbidities associated with PsA and use these to better understand PsA patients. In a recent publication the centre was able to use a cohort of patients to demonstrate the relationship between PsA and cardiovascular disease

Patient convenience: Patients have easy access to appointment schedules and test results, which makes their interactions with the centre smoother. Patients have log–in information to access appointment times and test results. They receive an automated email or text message before every appointment

Source: KPMG interviews

Electronic medical records system (3/3)

HOSPITAL ITALIANO
de Buenos Aires

Case study 4

What are the challenges of replicating this model?

Buy–in from all stakeholders: The doctors who initiated the EMR system had to get buy–in from key stakeholders at all the hospitals and health centres within the HMO. This is particularly challenging where a centre seeks to implement an EMR system in multiple hospitals, but ultimately may enable more consistent care

The centre worked on developing the EMR system for about a year and a half (2000–2002) before testing the proof of concept first with GPs in the peripheral centres, and then with specialists. This slow change management was key to implementing the EMR system

Patients' perception: The centre feared that patients may not be receptive to a computerised system, which could be seen as impersonal (this proved not to be the case). It may also be challenging to engage older doctors or patients who are less comfortable with technology. At Hospital Italiano older patients may be contacted via phone so they feel more supported and not forced to rely purely on the EMR system

Consistency: Ensuring consistency of the information represented seems to be a key factor in making an EMR system relevant to end users. Hospital Italiano uses colour coding and a system that does not accept abbreviations to ensure that patient information is clear and easy to read for all medical specialties, GPs and patients

Challenge
Home
Key findings

Source: KPMG interviews

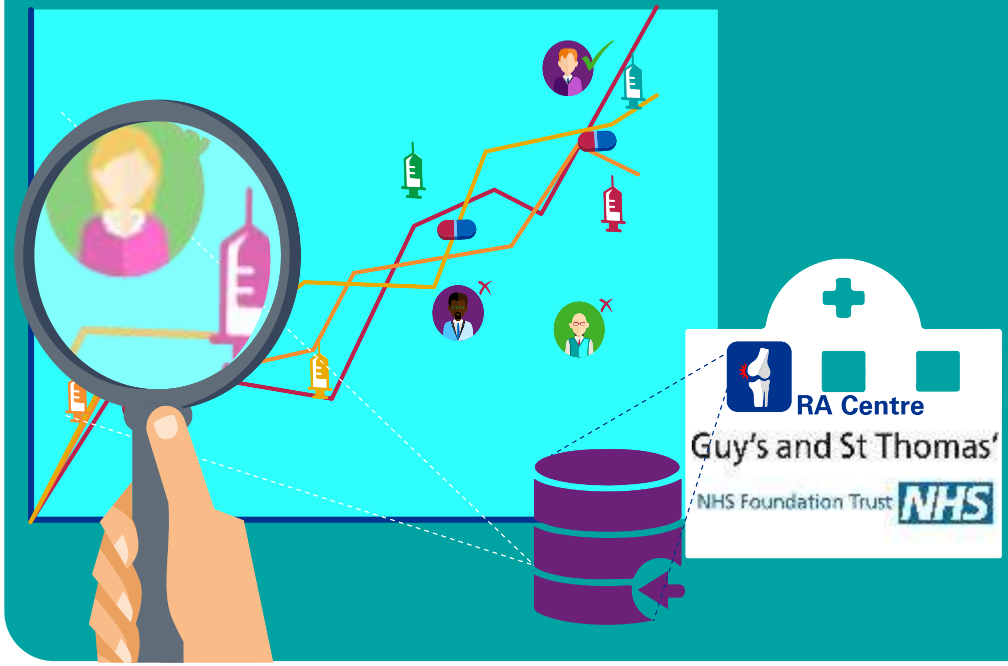
Inflammatory diseases database (1/2)

Guy's and St Thomas' NHS Foundation Trust NHS

Case study 5

Overview

Clinicians at the Guy's and St Thomas' place an emphasis on routine data monitoring for continuous quality improvement which led to the installation of an electronic database in 2006. The database allows the centre to collect data on patients with inflammatory diseases (including PsA), their treatments and clinical outcomes. Collection and analysis of the clinical data was enabled by the employment of a data manager by the centre



What is the rationale behind the database?

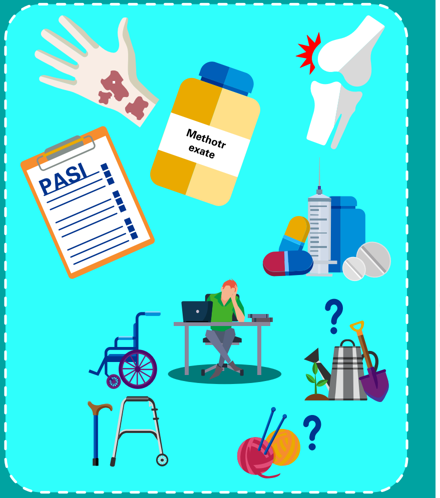
The IT systems at Guy's and St Thomas' Hospital allow for collection of patient data; however, as the system is quite old, it cannot be updated to suit the needs of the centre. The centre has therefore set up its own database which allows clinicians to collect clinical data on patients suffering from inflammatory diseases

What are the key features of the database?

Number of patients: Since 2006, 4428 visits by 818 PsA patients on database. 537 patients seen in the 15 months

Data collected: Clinical data collected includes information on patient treatments, joint and skin symptoms (68/66 joint count and DLQI/PASI more recently), the health assessment questionnaire (HAQ). Clinicians are also interested in quality of life measures and the centre is one of the few places collecting data on EQ–5D. The centre is now collecting data to assess minimal disease activity

Long follow–up: As the database was set up in 2006, with most PsA patient data form 2009, it contains long–term data on the PsA patients treated at the centre



Source: KPMG interviews

Inflammatory diseases database (2/2)

Guy's and St Thomas' NHS Foundation Trust NHS

Case study 5

What are the benefits of the database?

Better clinical decisions and research tool

The database allows the centre to capture detailed patient data, including the comorbidities associated with PsA, and use these to better understand PsA patients and make better–informed decisions. The electronic database can also be used as a strong research tool to study PsA

Quality improvement

Gathering patients' clinical data on the database allows for annual audits and reviews which facilitate assessment of the quality of services and enable introduction of improvements

What are the challenges associated with maintaining and using the database?

Burden on clinicians:

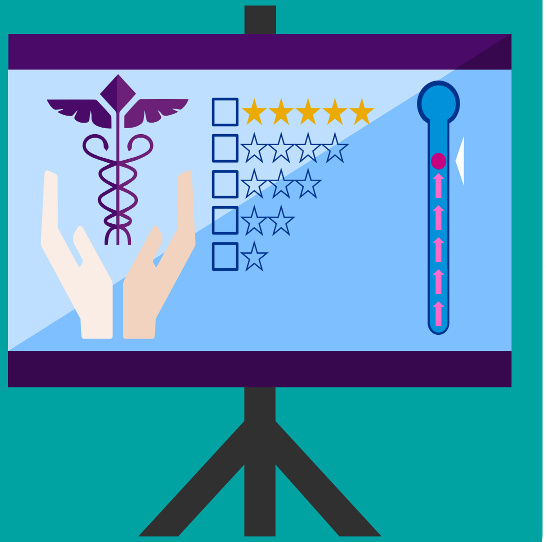
The database has to be updated by clinicians during each patient visit which can be challenging due to the short appointment times

Amount of data collected:

It can be challenging to analyse all the data that is collected; however, having a dedicated person to maintain the database and conduct the analysis helps with this issue

What are the next steps?

The centre has done a lot of analysis on rheumatoid arthritis patients to help demonstrate the effectiveness of their care at the centre; however, this has not yet been done for PsA patients. The next step will be to conduct detailed analysis of PsA patient population with the data that has already been collected



Challenge
Home
Key findings

Source: KPMG interviews

These interventions can lead to a number of potential benefits

During our site visits, we asked the interviewed clinicians to highlight the potential benefits that may be achieved through the implementation of interventions discussed. Although the centres we visited do not have formal systems in place that allow the impact to be measured, most of them agreed on the benefits that can be achieved

Intervention	Clinical benefits					Economic benefits		Patient experience	
	Improved time to referral/ diagnosis	Improved disease control	Improved adherence	Adequate control of comorbidities	Improved QoL	Fewer hospital admissions	Reduced productivity loses	Improved empowerment	Increased convenience:
Challenge: Inadequate treatment of comorbidities									
Peer education				✓	✓	✓	✓		
Nurse–led clinics				✓	✓	✓	✓		✓
Challenge: Lack of follow–up									
Regular monitoring		✓		✓					
Use of databases		✓		✓				✓	✓
Patient education			✓					✓	

Challenge
Home
Key findings

Source: KPMG interviews

The stakeholders identified several priority actions that could improve PsA care

During the interviews, we discussed a number of interventions that could improve the awareness of PsA among non–rheumatologists and patients, increase the diagnosis rate and lead to a more consistent care. We also asked about the priority actions and recommendations of how to 'formalise' PsA care

"First thing is to improve awareness. Provide better education for patients and doctors, including both GPs and secondary–care doctors"

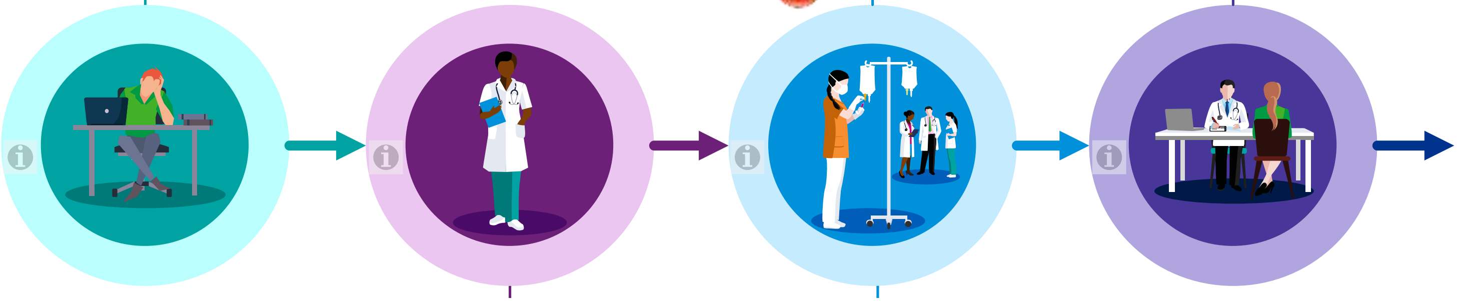
Dermatologist, Brigham and Women's Hospital, Boston

"I would advise other colleagues to set up a clinic where they can just focus on patients with PsA. This would make it easier for HCPs to concentrate on the various disease domains, so that a protocol–driven, treat–to–target approach is more feasible"

Rheumatologist, Prince of Wales Hospital, Hong Kong

"I would advise people to use a database. It allows us to learn from the patients we are treating and enables to determine whether we are following treatment recommendations. It is also easier to follow a treat–to–target approach if one collects the items in a standard way and prospectively"

Rheumatologist, Toronto Western Hospital



Pre–diagnosis

Referral and diagnosis

Treatment initiation and management

Follow–up

"Improve PsA diagnosis rate by sharing information on the key steps to making the correct diagnosis"

Rheumatologist, Groote Schuur Hospital, Cape Town

"Continue to increase collaboration between dermatology and rheumatology to improve care of PsA patients"

Rheumatologist, Groote Schuur Hospital, Cape Town

"If one can have combined clinics it is very helpful. But in the absence of a clinic, one needs to collaborate closely with a dermatologist so there can be a 'virtual clinic' which is what we had in Toronto before the combined clinic was established"

Rheumatologist, Toronto Western Hospital

Challenge

Home

Key findings

Source: KPMG interviews

Click on each flag to go to the section

List of centres visited by the KPMG team

1 **US**
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Brigham and Women's Hospital
January 2016
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2 **Canada**
TORONTO
Toronto Western Hospital
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4 **Argentina**
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5 **South Africa**
CAPE TOWN
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6 **UK**
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Key findings

Brigham and Women's Hospital

BRIGHAM AND WOMEN'S HOSPITAL

Boston, US

Click on each circle to go to the sub–section

Home

Key findings

Overview of the Centre for Skin and Related Musculoskeletal Diseases (SARM)

BRIGHAM AND WOMEN'S HOSPITAL

- The Centre for Skin and Related Musculoskeletal Diseases (SARM) at Brigham and Women's Hospital was established in 2003 as a referral centre. The team is led by Dr Joseph F. Merola and Dr Elinor Mody
- SARM is an academic centre where physicians have developed an innovative two–way approach to the care of skin and joint diseases (including PsA) that aims to enhance diagnostic accuracy and appropriate treatment choices

Core PsA team

2 **dermatologists** (including one trained in rheumatology)

2 **fellows** (including one derm–rheum fellow and one rheumatology fellow)

1 **rheumatologist**

4 **residents**

5 **nurses**

Several **researchers**

Patient pool

30–40 PsA patients

in the combined clinic each week

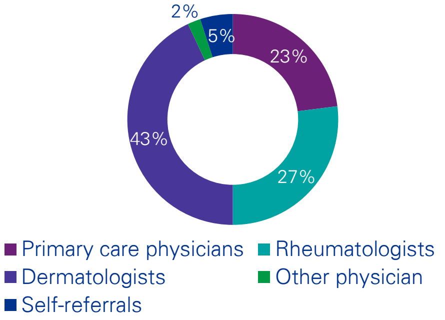
Weekly combined clinic (SARM clinic)

Catchment area

Regional (Maine, New Hampshire, Massachusetts, Rhode Island, Connecticut, Vermont)

- **Combined clinic**
- **Multi–disciplinary approach**
- **Clinical/ translational research**
- **Education and training**
- **Clinical trial unit**
- **Access to new therapies**

Sources of referrals[1]



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Key findings

Sources: KPMG interviews; secondary research: Velez, N.F., et al (2012) Management of psoriasis and psoriatic arthritis in a combined dermatology and rheumatology clinic Arch Dermatol Res. 2012 Jan; 304(1): 7–13

Within the clinic, there are numerous elements that improve PsA care (1/2)

BRIGHAM AND WOMEN'S HOSPITAL

What are the key strengths of the centre?

Multidisciplinary approach/ combined clinic

Overview

The centre offers a unique model of PsA care where patients are seen by both a dermatology and rheumatology specialist who work synchronously to evaluate their patients together

Why is this a strength? This model enables improved collaboration to:

- Improve the rate and consistency of PsA diagnosis
- Improve treatment by addressing both skin and joint symptoms
- Improve patient satisfaction with a one–stop clinic
- Provide unique training opportunities for staff to work across dermatology and rheumatology specialties

How does it work? SARM was set up to bring a multidisciplinary approach to the care PsA patients receive. The half–day clinic takes place every week with all faculty members present to provide comprehensive care for both skin and joint manifestations

◆

Education and training

Overview

There is a strong focus on bi–directional education where specialists can learn from each other but also where patients can learn from the HCPs responsible for their care. The centre also trains medical students from both specialties as well as numerous residents and joint fellows

Why is this a strength? Training sessions and education of HCPs and patients:

- Enable both specialties to recognise symptoms of the other and know when to refer patents
- Enable patients to become involved in the management of their own disease which increases their satisfaction

How does it work? The peer education is achieved by focusing on collaboration and dialogue between rheumatologists and dermatologists. All team members share the same office which further facilitates discussion between the two specialties. Patients are educated on their disease during the combined clinic which enables them to get a better understanding of the disease and treatment, from both a skin and joint perspective

◆

Home

Key findings

Source: KPMG interviews

Within the clinic, there are numerous elements that improve PsA care (2/2)

What are the key strengths of the centre? (cont)

Availability of the latest therapies

Overview

PsA patients get access to the latest therapies and interventions (e.g. advanced diagnostic radiology services) that may not yet be available at other clinics. In addition, the centre offers a quicker transition to systemic disease–modifying therapies

Why is this a strength? Although some symptoms of PsA can be managed with anti–inflammatory and topical medications, some patients may benefit from systemic treatment. There is some evidence that suggests that in many clinics PsA patients are undertreated [1]

How does it work? Because of the multidisciplinary experience and expertise at the centre, the clinicians are familiar and comfortable with using the latest treatments

◆

Clinical trials unit

Overview

The centre has a clinical trials unit that provides novel therapies to PsA patients who have failed other treatment modalities

Why is this a strength? There are many effective treatment options available for PsA but not all patients respond to the treatment, while others may lose their initial response over time.[2] Therefore, it is key to identify those patients who might benefit from investigational new drugs and enrol them in clinical studies that offer access to these treatments

How does it work? The seamless transition to clinical trials is enabled by the close proximity of SARM to the clinical trials unit, as well as good collaboration between clinicians and clinical trial investigators

◆

Development of tools to increase awareness and referral ('as easy as PSA', PASE)

Overview

The team at Brigham and Women's Hospital built a screening tool for PsA called PASE to enable dermatologists and other HCPs to recognise early symptoms. They have also developed a simple awareness tool ('As easy as PSA') to recognise key symptoms associated with PsA (**P**ain, **S**welling or **S**tiffness, **A**xial disease). This awareness tool is being validated as a possible screening tool for PsA

Why is this a strength? To increase awareness, referrals and diagnosis of PsA patients

How does it work? Development of these tools was possible by involving a team of dermatologists, rheumatologists and patient focus groups

◆

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Key findings

Sources: KPMG interviews; secondary research: 1: Kerkhof, P.C., et al (2015) Physician perspectives in the management of psoriasis and psoriatic arthritis: results from the population-based multinational assessment of psoriasis and psoriatic arthritis survey J Eur Acad Dermatol Venereol; 29(10): 2002–10; 2: Boehncke, W.H., Menter, A. (2013) Burden of disease: psoriasis and psoriatic arthritis Am J Clin Dermatol; 14(5): 377–88

These elements have improved patient outcomes

How have these elements improved patient outcomes?

In 2012, the centre published a retrospective chart review that assessed whether the creation of combined rheumatology–dermatology clinics had resulted in changes in diagnosis and treatment decisions.[1] The results of the study suggest that the combined clinic may facilitate the diagnosis of joint disease and can offer a more comprehensible treatment approach for PsA patients. Patients seen during the combined clinic had their diagnosis revised in 46% of cases and were more likely to be treated with a systemic and biologic therapy than before (25% vs 15% and 37% vs 16%, respectively) [1]

How can you quantify benefits in PsA?

Although the centre does not routinely measure clinical outcomes, these have improved (anecdotally and through observations). The key outcomes in PsA include:

- Objective measures such as:
  - Skin measures (e.g. Body Surface Area)
  - Joint measures (e.g. 66/68 joint count)
  - Functionality (e.g.Health Assessment Questionnaire)
- Patient–reported outcomes (e.g. Patient's Global Assessment)

◆

"This clinic is exceptional for diagnosis and treatment. Before it was like going to have your teeth cleaned at the dentist. Now it is like actually seeing the dentist."

Patient, SARM

Home

Key findings

Sources: KPMG interviews; secondary research: 1: Velez, N.F., Wei-Passanese, E.X., Husni, M.E., et al (2012) Management of psoriasis and psoriatic arthritis in a combined dermatology and rheumatology clinic Arch Dermatol Res. 2012 Jan; 304(1): 7–13

The clinic continues to face some challenges

Detailed site specifications

What are the key challenges at the centre?

Patient mix and volumes

Overview

The majority of patients that are referred to the centre suffer from dermatology conditions without any joint involvement; only 22% patients seen at the clinic are later diagnosed with PsA

Why is this an issue? With the high volume of dermatology patients, it is hard to keep the rheumatology specialist occupied. However, it is less of an issue here because it is an academic centre and rheumatologists can focus on their research when not seeing patients

How can it be improved? There is a need for better scheduling of appointments as well as attracting the right mix of patients

◆

Additional workload due to the increase use of biologics

Overview

The introduction of anti–TNF therapies has changed how PsA care is delivered, especially in the dermatology clinic where HCPs were not experienced with the use of biologics. For instance, anti–TNF therapies require vaccinations prior to the treatment initiation.[1] This model of care delivery requires specialised nursing support who can administer vaccinations as well as triage patients. In addition, there is a need for experienced staff to conduct administrative work

Why is this an issue? This lack of specialised nurses and admin staff leads to an even heavier burden on dermatologists and rheumatologists

How can it be improved? By providing specialised training to nurses and admin staff

◆

No co–location of an infusion clinic

Overview

Although some of the PsA therapies are administered by infusion, there is no infusion centre available at the clinic

Why is this an issue? Patients have to travel to a different centre to receive their treatment

How can it be improved? By creating an infusion clinic within or near to the centre

◆

Home

Key findings

Sources: KPMG interviews; secondary research: 1: Xie, X., et al (2014) Risk of tuberculosis infection in anti-TNF-α biological therapy: from bench to bedside. J Microbiol Immunol Infect. 47(4):268-74

Although the clinic model is difficult to replicate, the elements of care can address key challenges in PsA care (1/2)

What are the key challenges in PsA care and how can they be addressed?

🚩 1

Lack of PsA awareness among HCPs and patients

Overview

Although approximately 30% of psoriasis patients develop PsA, the majority of patients remain undiagnosed for years after the onset of symptoms.[1] In addition, patients may not be aware of the relevance of their own symptoms and therefore not report them to the HCP

Why is this an issue? Delays in diagnosis lead to accumulation of irreversible joint damage and decreased quality of life

How can it be improved? The awareness of PsA among community practitioners and dermatologists should be addressed as they are in regular contact with psoriasis patients. For instance, the team at Brigham and Women's Hospital has recently published a paper to increase HCP awareness of PsA ('As easy as PSA'). In addition, patients with psoriasis should be educated about the potential of developing PsA later in their lives

◆

🚩 2

Lack of PSA screening and referrals

Overview

Multiple studies have shown that PsA patients remain undiagnosed in the dermatology and primary care setting despite the availability of multiple validated screening tools [2]

Why is this an issue? As the majority of patients are not diagnosed until seen by a rheumatologist, the delay in referral prevents them from receiving the appropriate therapy

How can it be improved? The team at Brigham and Women's Hospital tried to address this issue by building a simple screening tool for PsA called PASE. In addition, when patients are referred to their centre, they refer them back after the appointment to avoid stepping on the toes of referring doctors and to ensure they continue to get revenue. Other centres should educate HCPs on the need for regular PsA screening among psoriasis patients

◆

🚩 = must be addressed as early as possible

🟧 = should be addressed but are not a priority

Home

Key findings

Sources: KPMG interviews; secondary research: 1: Cohen, J.M et al (2014) Psoriatis arthritis: It's as easy as 'PSA' J Am Acad Dermatol. 72: 905–906; 2: Reich et al (2009) Epidemiology and clinical pattern of psoriatic arthritis in Germany: a prospective interdisciplinary epidemiological study of 1511 patients with plaque–type psoriasis. Br J Dermatol.160(5):1040–7:12

Although the clinic model is difficult to replicate, the elements of care can address key challenges in PsA care (2/2)

What are the key challenges in PsA care and how can they be addressed? (cont)

3 Siloed approach to PsA care

Overview

PsA patients present with both joint and skin symptoms therefore requiring the input of rheumatology and dermatology specialist teams. However, these teams often work in silos, even within the same hospital

Why is this an issue? The siloed approach leads to inconsistent patient care and low patient satisfaction

How can it be improved? By fostering collaboration between dermatologists and rheumatologists. Although a combined clinic might not be feasible in some care settings, this can be achieved by creating an online connectivity platform, use of telemedicine, or conferences where dermatologist and rheumatologists can meet

◆

4 Billing

Overview

Billing might be challenging as both dermatologists and rheumatologists specialists would need to be reimbursed for patient care

Why is this an issue? Given the skin and joint symptoms associated with PsA, patients are often managed by both a rheumatologist and a dermatologist, impacting budgets of both departments they belong to

How can it be improved? By sharing of the received funding between both departments

◆

🟥 = must be addressed as early as possible

🟧 = should be addressed but are not a priority

Home

Key findings

Source: KPMG interviews

Click on each circle to go to the sub–section

Toronto Western Hospital

Canada

1 **Overview of the visit**

2 **Findings from interviews conducted at Toronto Western Hospital**

Strengths

Challenges and improvements

3 **Findings from interviews conducted in community–based clinics**

Challenges and improvements

Home

Key findings

Overview of the Toronto Western Hospital

Toronto Western Hospital

- The Psoriatic Arthritis Clinic at Toronto Western Hospital (TWH) is one of the largest centres in the world for specialised care and research in PsA. The team is led by Dr Dafna Gladman with the support of Dr Vinod Chandran
- During our time in Toronto, we also spoke to a rheumatologist from Women's College Hospital in Toronto and visited three community clinics located in the vicinity: Southlake Regional Health Centre, St Joseph's Healthcare in Hamilton and Credit Valley Medical Center in Mississauga

Core PsA team

2 **rheumatologists**

1 **Study nurse**

1 **dermatologist**

2 **researchers**

Toronto Western Hospital

PsA patient pool

1,400 PsA patients in the cohort

PsA CLINIC

led by a rheumatologist

Two and a half days (45 patients) a week

PsA COMBINED CLINIC

(rheumatologist and dermatologist)

Usually two times a month

Catchment area

Toronto

- **Combined clinic**
- **Clinical/translational research**
- **Databases**
- **Network of clinics**
- **Innovative model of care**

Source: KPMG interviews

Home

Key findings

Key strengths of the centre

Detailed site specifications

What are the key strengths of the centre?

Clinical and translational research

Overview
In addition to its involvement in clinical trials, the centre performs in translational research which aims to create a link between extensive clinical information, and molecular and genetic patient data, thereby improving the understanding of the disease and leading to better patient outcomes

Why is this a strength? Detailed study of clinical disease combined with cellular or molecular information can lead to the development of specific patient–centred therapies and better measures to study disease progression

How does it work? The ongoing research is possible thanks to grants and support from the Krembil Research Institute, the Canadian Institutes of Health Research, the Arthritis Society and the National Psoriasis Foundation

◆

Combined clinic

Combined clinic
The centre runs a combined clinic twice a month for half a day where PsA patients are seen by both rheumatology and dermatology specialists

Why is this a strength? The presence of both specialties can improve the diagnosis rate and ensure timely initiation of the correct treatment, thereby improving patient outcomes. Furthermore, the combined clinic increases patient satisfaction as patients do not need to attend separate appointments

How does it work? The combined clinic was established thanks to a close collaboration between the dermatology and rheumatology departments, as well as the co–location of the two departments within the hospital

◆

PsA and psoriasis databases

Overview
The team collects and stores information on their patients using PsA and psoriasis databases

Why is this a strength? The databases allow the centre to gather information about the disease characteristics, track the progression of the disease over time, study comorbidities and risk factors associated with PsA, and better understand the value of various interventions

How does it work? The databases form effective research tools because of the number of patients enrolled (there are currently 1,400 and 650 patients in the PsA and psoriasis databases, respectively) and the long–term follow up. However, the databases require collection of detailed patient information during each visit

◆

High retention of staff

Overview
Due to the high levels of grants and funding that the team has been able to secure, a large number of the clinical and research staff have remained at the clinic. This has also been the case for the administrative and reception staff

Why is this a strength? Low turnover of staff increases patient satisfaction resulting in better patient retention.

How does it work? High retention of staff is a result of the investigators seeking support from various agencies and securing significant grants and funding. This has been achieved by quantifying interventions and demonstrating ongoing research in PsA

◆

Source: KPMG interviews

Home

Key findings

Key challenges at the centre

Detailed site specifications

Toronto Western Hospital

2 Challenges at the centre

What are the key challenges at the centre and how can they be addressed?

Low retention in the psoriasis database

Overview

Dr Dafna Gladman has established two patient databases: one for PsA patients and one for psoriasis patients. However, the Programme has faced challenges associated with low patient retention for the psoriasis database which is due to psoriasis patients not considering their disease a problem, in the same way that PsA patients do

Why is this an issue? The low number of psoriasis patients on the database results in a decreased amount of long–term data being collected about psoriasis and its subsequent progression to PsA

How can it be improved? The number of patients on the psoriasis database could be increased by incentivising patients to join the database, educating them on the benefits of this initiative, and encouraging them to pay more attention to their disease with focus groups and educational materials

◆

Repetitive forms for patients to fill in for research purposes

Overview

Patients who are part of the cohort are asked to provide a lot of information which is then used for research purposes. However, patients complain about filling in long forms and undergoing tests at every check up at the clinic

Why is this an issue? Patients are less likely to attend visits if they view them as time–consuming and repetitive

How can it be improved? Clinicians are trying to improve it by sharing the anonymised results and outcomes with the patients via the newsletter and an annual symposium, in order to demonstrate the impact of providing information. In addition, there are plans to introduce a phone–based application, allowing patients to fill in questionnaires at their own convenience

◆

Challenges with scheduling the combined clinic

Overview

Dermatology and rheumatology departments located within the hospital have their own appointment systems, and it is difficult to obtain permission to view another department's schedule. In addition, it takes much longer to perform a rheumatology examination than a dermatology one (60 minutes versus 30 minutes) which leads to challenges with scheduling a combined clinic

Why is this an issue? Finding a time that satisfies both the rheumatology and dermatology departments remains a challenge

How can it be improved? The issue could be addressed by developing a joint scheduling system for the combined clinic, with access provided to both departments

◆

Home

Key findings

Source: KPMG interviews

KPMG

Challenges at community-based clinics in Ontario

What are the key challenges in PsA care and how can they be addressed?

Lack of awareness among community HCPs

Overview

PsA places a substantially higher burden on patients and society than is appreciated by many community HCPs. Many GPs and dermatologists do not screen for PsA or ask psoriasis patients about the symptoms associated with the disease

Why is this an issue? Because of the lack of PsA awareness, many patients go undiagnosed and undertreated for years while their disease might continue to progress

How can this be improved? Community doctors should be educated on PsA, including knowledge on early symptom detection, diagnosis and treatment options. GPs and dermatologists should also be made aware of the percentage of psoriasis patients who develop PsA so they can see if their cohorts are underdiagnosed. Examples of how knowledge can be shared between rheumatologists and GPs/dermatologists include:

Training sessions for GPs

Sessions with GPs where specialists can present on recent advances in rheumatology

Small group sessions

Interactive group sessions with GPs where patients' issues can be discussed. These could be sponsored by pharma companies

Online education

Educational platform for GPs and dermatologists to maintain competence and learn about new developments in PsA. Doctors could be incentivised to complete modules which would give them Continued Medical Education (CME) credits

Home

Key findings

Source: KPMG interviews

Challenges at community-based clinics in Ontario

What are the key challenges in PsA care and how can they be addressed? (cont)

Siloed approach

Overview

The diagnosis and treatment of PsA is often managed by either a dermatologist or a rheumatologist, depending on the severity of symptoms affecting the respective organs. Rheumatologists experience challenges accessing various specialties:

Dermatologists

It is often difficult to find dermatologists interested in PsA as they often prefer to deal with other skin conditions (i.e. cosmetics)

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Physiotherapists

It can also be challenging to find community–based physiotherapists with an interest in arthritis and PsA to help patients cope with their symptoms

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Why is this an issue? This siloed approach results in delays to diagnosis and an inconsistent approach to treatment. Increasing collaboration between dermatologists and rheumatologists would have the dual effect of diagnosing more psoriasis patients with PsA and increasing the availability of treatments to PsA patients

How can this be improved? Management of PsA patients should be done using a multidisciplinary approach where rheumatologists work closely with dermatologists and, depending on the patient's needs, have access to other specialties. Although creating a combined clinic is not always possible due to logistical difficulties, formal and informal channels of communication should be established in all directions. This could be achieved by networking during medical and scientific events, by leveraging co–location of offices within health centres and the use of technology (teleconferences, phones, etc.)

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Home

Key findings

Source: KPMG interviews

Challenges at community-based clinics in Ontario

What are the key challenges in PsA care and how can they be addressed? (cont)

Limited access to diagnostic equipment and biologic therapies

Overview
Community clinics often have limited access to diagnostic equipment, including SI (sacroiliac) joint x–rays and musculoskeletal ultrasounds. In addition, although biologic therapies are effective in most PsA patients, they are associated with substantial costs and not always covered by payers

Why is this an issue? Limited access to diagnostic equipment can delay accurate diagnosis. The lack of coverage of biologic treatment means that patients are treated with cheaper, but often less effective, alternatives

How can this be improved? The limited access to diagnostic equipment could be bypassed by developing relationships and networks with better–equipped centres

◆

Barriers in communication with ethnic minorities

Overview
Within the region there are many patients for whom English is not their native language. This can lead to barriers in communication with HCPs

Why is this an issue? The language barrier means that patients from various backgrounds cannot effectively communicate their symptoms and experiences, and doctors face challenges educating them on their disease and treatments, as well as the risks and side–effects of therapies

How can this be improved? By providing written information in a number of different languages, tailored to the region and the ethic minorities present

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Lack of tuberculosis testing

Overview
Although biologics are effective in the treatment of PsA, their use is associated with an increased risk of tuberculosis (TB) infection and reinfection.[1] However, despite the link between immunosuppressants and infections being well established, many clinicians do not screen patients for TB before the biologic treatments are initiated

Why is this an issue? Patients who are on immunosuppressant treatment, including anti–TNF–alpha therapies, have an increased risk of TB

How can this be improved? By educating healthcare professionals on the need to conduct TB testing and check for vaccinations before the initiation of biologic treatment

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Home

Key findings

Source: KPMG interviews; secondary research: 1: Xie, X., et al (2014) Risk of tuberculosis infection in anti-TNF-α biological therapy: from bench to bedside. J Microbiol Immunol Infect. 47(4):268-74

Click on each circle to go to the sub–section

Comprehensive Centre for Inflammation Medicine (CCIM) at University Medical Centre Schleswig-Holstein, Lübeck, Germany

University of Lübeck

UKSH UNIVERSITÄTSKLINIKUM Schleswig-Holstein

1 **Overview of the centre**

2 **Elements of care**

3 **Proven outcomes**

4 **Challenges at the centre**

5 **Challenges in PsA care**

Home

Key findings

An overview of the Comprehensive Centre for Inflammation Medicine

- The Comprehensive Centre for Inflammation Medicine (CCIM) is a clinic for inflammatory diseases at the University Medical Centre Schleswig–Holstein in Lübeck, Germany. The team is led by Professor Diamant Thaci
- The centre was established in 2013 through the German Research Foundation's 'Excellence Initiative' which aims to promote the highest quality research at German universities

Core PsA team

4 dermatologists

1 Study nurse

4 rheumatologists

Several researchers

3 Nurses (who provide general support)

Several medical assistants

PsA patient pool

150–200 per month

New PsA cases: 40 PsA patients per month

PsA combined clinic:

✶ 10 PsA patients per month

Catchment area

Most of Germany

✶ **Multi–disciplinary approach**

✶ **Comprehensive care**

✶ **Combined clinics**

✶ **Individualised treatment**

✶ **Translational and basic research**

✶ **Networks**

Sources of referrals:

- Dermatologists: 70%
- GPs: 20%
- Self–referrals and referrals from other specialties (including orthopedists): 10%

Source: KPMG interviews

Within the centre, there are numerous elements that improve PsA care (1/3)

What are the key strengths of the centre?

Multidisciplinary approach

Overview

PsA is a heterogeneous disease that affects both skin and joints and is associated with a number of comorbidities. At CCIM, patients have access to interdisciplinary care and the more complicated PsA cases are discussed during case conferences. During these one–hour board meetings, physicians meet and discuss patients' cases from a multidisciplinary perspective to make timely and correct diagnosis and treatment decisions

- **Weekly meetings:** These once–weekly case conferences are attended by rheumatologists, dermatologists and gastroenterologists to discuss patients with inflammatory disorders, including PsA. Depending on the case discussed, other specialties, including paediatricians, nephrologists and urologists, might also be present
- **Monthly meetings:** These are conferences which are attended by the broader team, including pathologists and microbiologists, and they are meant for discussion of any issues relating to patients and the clinic, e.g. the occurrence of opportunistic infections or how to improve the processes and procedures

Why is this a strength? The multidisciplinary approach allows HCPs to optimise the diagnosis and treatment of PsA and provide the best possible care for patients. The meetings provide a formal channel of communication where doctors can freely discuss any challenges they might have faced

How does it work? MDT meetings are facilitated by the close proximity of the individual disciplines within the hospital, the personal interest of the HCPs involved, and the availability of teleconferencing equipment

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Combined clinics

Overview

The team at the CCIM runs combined outpatient clinics once a month which are attended by dermatologists and rheumatologists, as well as junior doctors and residents, to discuss the most complex cases which require an input from both specialties. These clinics are run exclusively for the PsA patients

- **The purpose of the clinic:** During the clinic, a younger doctor introduces the patient to other doctors. These are usually the more complicated cases that require input from multiple specialties. The clinicians then make a joint decision regarding the diagnosis or readjustment of the current treatment
- **Number of patients:** During each combined clinic, the clinicians see approximately 10 patients. However, due to the high number of complex cases present at CCIM, there are plans to increase the frequency of the combined clinic

Why is this a strength? The combined clinics have been put in place to provide better care for complicated cases, since the presence of multiple specialties means that clinical decisions can be made taking into account the full scale of patient's needs. In addition, these clinics provide a good training opportunity for younger doctors, and are enjoyed by patients who do not need to attend separate dermatology and rheumatology appointments. However, the economic value of this model has not yet been studied

How does it work? The combined clinic is possible thanks to the strong relationship between the rheumatologists and dermatologists working at the centre who understand and trust each other, as well as the co–location of the two departments within the hospital and the support from the university

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Home

Key findings

Source: KPMG interviews

Within the centre, there are numerous elements that improve PsA care (2/3)

University of Lübeck

What are the key strengths of the centre?

Translational and basic research

Overview

CCIM performs a variety of large clinical studies on inflammatory diseases, including PsA. The centre is also in close and regular contact with the basic scientists of the Excellence Cluster, a joint venture of research institutes across Germany which aims to encode the origins of inflammation on genetic, genomic and functional levels.[1] Scientists from the Excellence Cluster at the University of Lübeck carry out genetic studies on the most complicated PsA cases seen in the CCIM clinic with the aim of developing personalised and more effective treatment options. In addition, patients can participate in biobank projects and thus contribute to a better understanding of inflammatory diseases

Why is this a strength? The research initiatives carried at the centre have a number of benefits to patients. They can help to:

- Develop new treatments in PsA
- Provide access to clinical trials for patients
- Provide more personalised treatment through the genetic studies of the most complex cases
- Contribute to a better understanding of PsA

How does it work? The research initiatives are possible thanks to the ongoing support of the university, various research grants and the physical proximity to the research laboratories. They are also enabled by close collaboration and regular meetings between the clinical staff and scientists

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Comprehensive care

Overview

The centre offers comprehensive care for PsA patients giving them access not only to outpatient care, but also to an infusion centre and an in–patient clinic

Why is this a strength? The comprehensive care provided at CCIM:

- Improves the efficiency of healthcare delivery
- Improves patient experience and satisfaction
- Enables continuity of care as treatment approaches change

How does it work? By providing access to:

- **An infusion centre:** The clinic has an infusion centre that allows the administration of the IV biologics, thereby decreasing the inconvenience associated with travelling to a different centre
- **An in–patient clinic:** There is a newly created ward for in–patient care at the rheumatology department. This in–patient facility is expected to expand from 10 to 25 beds by the end of 2017 due to the current capacity constraints

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Home

Key findings

Sources: KPMG interviews; secondary research: 1: Inflammation at Interfaced (2016) http://inflammation-at-interfaces.de/en; accessed 6 April 2016
Note: The Excellence Cluster is a joint venture of Kiel University and the University of Lübeck, together with the Schleswig-Holstein University Medical Centre, the Leibniz Research Centre Borstel, the Max Planck Institute for Evolutionary Biology, Plön, and the Muthesius Academy of Fine Arts and Design in Kiel

Within the centre, there are numerous elements that improve PsA care (3/3)

What are the key strengths of the centre?

Individualised treatment

Overview

At the clinic, PsA treatments are selected based on the patient’s disease characteristics including the severity of the disease, organs affected and comorbidities. Doctors also consider the patient's preferences in terms of the route of administration (IV vs sub–cut infusions) and lifestyle choices (e.g. whether the female patient is planning pregnancy)

Why is this a strength? Patients with PsA are at increased risk of a number of comorbidities including diabetes, depression, hypertension, inflammatory bowel disease, lymphoma and CV disease.[1] In addition, the presentation of the disease and its natural progression varies considerably among patients, thereby requiring a tailored approach to treatment

How does it work? Through the clinical and scientific expertise of the interdisciplinary team and the availability of a number of treatment options

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Networks and outreach programmes

Overview

The hospital has established networks and collaborations both within the organisation (e.g. between the rheumatology and dermatology departments) as well as outside the hospital, through conferences, consultations and teaching programmes

Why is this a strength? Networks and collaborations enable the centre to:

- Share knowledge, experiences and best practice
- Make other hospitals and community clinics aware of the CCIM centre and increase the number of referrals
- Increase awareness, referrals and diagnosis rate of PsA patients in the region
- Educate students on how to recognise the early symptoms of PsA

How does it work?

- **Teleconferences/video conferences:** These meetings allow the clinic to collaborate with specialists from other centres, as well as internationally. In the future, these will be used as case conferences, thereby reducing the need for patients to be referred to CCIM from a hospital elsewhere in the country
- **Seminars and consultations:** Specialists from CCIM present during conferences and organise consultations on various topics (e.g. how PsA care could be improved within the region, or how to treat the paediatric patient population). They also organise meetings with dermatologists from within the region which take place two or three times a year and aim to increase the awareness of PsA

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Home

Key findings

Sources: KPMG interviews; secondary research: 1: Ogdie A, Schwartzman S, Husni ME. (2015) Recognizing and managing comorbidities in psoriatic arthritis Curr Opin Rheumatol. 27(2): 118–126

The centre captures patient outcomes

How have these elements improved patient outcomes?

At CCIM, the treatment and management of PsA have been optimised through regular interactions between various disciplines, joint conferences and affiliated clinical research projects involving experienced scientists. There are a number of ways in which the centre has measured outcomes:

- **Checklist:** At each visit, the doctor fills in a four–page form that documents the patient's treatments, comorbidities, PsA symptoms (including swollen/painful joints, morning stiffness, dactylitis, nail psoriasis, enthesitis) and whether their severity has changed since the last visit. Doctors also measure the skin symptoms using the Psoriasis Area and Severity Index (PASI) as well as the Dermatology Life Quality Index (DLQI) at their first visit. For joint symptoms, clinicians perform the joint count of tender or swollen joints. This form will soon be available in an electronic version and form part of the patient's electronic medical record
- **Patient experience surveys:** The Centre also measures patient experience using annual patient satisfaction surveys
- **Registry:** CCIM participates in the PsoBest registry, a nationwide registry which documents the long–term efficacy, safety, patient–reported outcomes and treatment regimens of psoriasis and psoriatic arthritis patients

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Home
Key findings

Source: KPMG interviews

There are areas where PsA care could be further improved at the centre

What are the areas of improvement at the centre?

Increased patient–centricity

Overview

Although patients at CCIM are provided with excellent medical care for PsA, there is an opportunity for the centre to become more patient–centric. Lessons could be learnt from the clinical trials conducted by the centre where patients are provided with more time and support from the physicians and nurses

Why does it need improvement? Improved patient–centricity and patient engagement can help deliver optimal care

How can it be improved?

- **By providing educational materials:** Written materials on the disease and treatment which are tailored to the specific needs of patients (e.g. language skills)
- **By creating formal channels of communication:** This could be achieved using a patient newsletter which the centre could use to inform patients about current and future initiatives, ongoing research and contact details for patient support groups
- **By incorporating patient feedback:** Asking patients about their satisfaction and introducing improvements based on their feedback. For instance, the results of a recent patient satisfaction survey at CCIM revealed that patients would like to be able to book their appointments out of normal work hours

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More frequent combined clinics

Overview

During the combined clinics, rheumatologists, dermatologists and junior doctors discuss the most complicated PsA cases. This allows for a two–way approach to the care of skin and joint diseases, and enhances diagnostic accuracy and appropriate treatment choices. However, these clinics are currently only run once a month

Why does it need improvement? As the centre deals with the most complex PsA cases, the input from a rheumatologist and a dermatologist is often required to make the correct clinical decision. In addition, the number of cases treated at the centre has increased in the last year

How can it be improved? By increasing the frequency of combined clinics

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Home

Key findings

Source: KPMG interviews

There are a number of challenges that remain in PsA care (1/2)

University of Lübeck

What are the key challenges in PsA care and how can they be addressed?

1 Lack of awareness and underdiagnoses

Overview

Patients with PsA are often diagnosed with the disease several years after the onset of their symptoms. In addition, about 30 % of patients are not diagnosed until they're seen by a rheumatologist.[1] This lack of PsA diagnosis delays the initiation of the correct treatment and can lead to further progression of the disease as well as reduced patient experience

Why is this an issue?

- **Lack of training:** GPs and dermatologists often do not receive the training that would help them recognise the early symptoms of PsA and link the joint and skin manifestations
- **Short appointment times:** Dermatologists have only five to ten minutes per patient which means they are not able to ask all the questions and correctly monitor the progression of psoriasis

How can it be improved? PsA awareness among GPs and dermatologists could be improved by:

- Educating doctors on the link between the skin and joint manifestation
- Organising meetings with community doctors and dermatologists to talk about the issues they are facing

◆

2 Undertreatment

Overview

Many doctors do not prescribe any systemic therapies for PsA patients even though NSAIDs and DMARDs do not always sufficiently control the disease. In many cases, patients come to CCIM because they are not satisfied with their current treatment. In addition, GPs and internal medicine specialists do not normally optimise the biologic treatment but continue with the recommendations from the tertiary clinic, even if the disease progresses

Why is this an issue?

- **Lack of awareness:** Many doctors are not familiar with the clinical benefits associated with the use of systemic therapies or are not comfortable with their use
- **Limited reimbursement:** Systemic therapies are associated with substantially higher costs to healthcare providers, and hospitals are only reimbursed for biologics if at least two prior DMARD therapies have failed

How can it be improved? Doctors should be educated on the need to provide timely and correct treatment. This could be achieved by organising meetings and seminars to:

- Discuss the benefits of the latest therapies
- Train doctors on the use and optimisation of biologic therapies

🟥 = must be addressed as early as possible

🟧 = should be addressed but are not a priority

Home

Key findings

Sources: KPMG interviews; 1: Mease, P.J., et al., (2013) Prevalence of rheumatologist-diagnosed psoriatic arthritis in patients with psoriasis in European/North American dermatology clinics Journal of the American Academy of Dermatology, 69(5), 729–735

There are a number of challenges that remain in PsA care (2/2)

University of Lübeck

What are the key challenges in PsA care and how can they be addressed? (cont)

3 Siloed approach to PsA care

Overview

Before PsA patients are referred to CCIM, they are often treated for either their skin or joint manifestations only. This leads to sub–optimal treatment outcomes and further progression of some aspects of their disease

Why is this an issue? This siloed approach to the PsA treatment is caused by a lack of communication and interaction between different departments as well as low awareness of PsA among GPs dermatologists

How can it be improved? By increasing awareness of PsA among GPs, fostering collaboration between dermatologists and rheumatologists, and organising MDT meetings

◆

4 Reimbursement

Overview

As the reimbursement environment is getting increasingly more strict, hospitals are facing challenges with funding and reimbursement. For instance, biologic therapies are reimbursed by the Medical Service of Health Insurance (Medizinischer Dienst der Krankenkassen (MDK)) only when doctors adhere to the European Congress of Rheumatology (EULAR) guidelines, i.e. use biologics if two prior DMARD therapies have failed [1]

Why is this an issue? Due to the limited resources and the high costs associated with the PsA treatments

How can it be improved? If a patient suffers from an aggressive form of the disease, they can be enrolled into clinical trials which bypass the need to administer two DMARD treatments prior to the biologic therapy. This can also be addressed by securing additional funding. At CCIM, the public insurance covers only approximately 25% of the costs incurred per patient. However, the clinic receives funding from other sources including scientific grants and privately funded research programmes

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🟥 = must be addressed as early as possible

🟧 = should be addressed but are not a priority

Home

Key findings

Sources: KPMG interviews; 1: Gossec, L. et al (2015) European League Against Rheumatism (EULAR) recommendations for the management of psoriatic arthritis with pharmacological therapies: 2015 update. Ann Rheum Dis. 0:1–12

Hospital Italiano de Buenos Aires

Argentina

Click on each circle to go to the sub–section

Home

Key findings

An overview of the rheumatology unit

HOSPITAL ITALIANO
de Buenos Aires

- The rheumatology unit at the Hospital Italiano leads the care of PsA patients. Since 2011 the team has been led by Dr Enrique Soriano
- Although the team consists primarily of rheumatologists, they work closely with their colleagues in dermatology and orthopaedic surgery

Core PsA team

6
consultant rheumatologists

1
dermatologist
(participates in combined clinic)

4
rheumatologists sonographers
(included in the six mentioned above)

9
rheumatology fellows
(fellowships last three years)

6
registrar rheumatologists

Several
researchers

Patient pool

380
active patients

- **Weekly combined clinic**
- **8–10 PsA patients per clinic**
- **Approx. 45 PsA patients per month**[1]

Catchment area

Buenos Aires

- **Combined clinic**
- **Peer education and training**
- **Healthcare network**
- **Electronic medical records**
- **Expertise in sonography**

Sources of referrals

- 90% of patients are referred by GPs
- 10% of patients are self-referred which involves paying an extra fee

Home

Key findings

Source: KPMG interviews

Within the clinic, there are numerous elements that improve PsA care (1/2)

Detailed site specifications

HOSPITAL ITALIANO
de Buenos Aires

2 Elements of care

What are the key strengths of the centre?

Multidisciplinary approach/ combined clinic

Overview

The centre offers a unique model of PsA care where patients are seen by both a rheumatologist and a dermatologist at the same time at a combined clinic

Why is this a strength? This model enables improved collaboration to:

- Improve treatment of more difficult cases of PsA
- Share expertise by analysing patients together in greater depth and making a joint decision
- Improve patient experience by giving patients access to multiple medical specialists
- Provide opportunities for rheumatologists and dermatologists to share clinical experience
- Provide a means of self–audit by enabling physicians to cross–check their findings with each other

How does it work? The rheumatologists and dermatologist hold a weekly combined clinic where new patients have a consultation of up to 30 minutes with both a rheumatologist and a dermatologist (existing patients are likely to have a shorter consultation of 15 minutes). This provides a forum where both specialists can immediately share their opinions on a patient's condition

What are the limitations?

- The demand from patients for combined clinics is growing but increasing the capacity of the combined clinics requires extra clinicians.
- The hospital does not receive extra funding to carry out the combined clinics so its success relies a great deal on the effort and initiative of the doctors involved

◆

Peer education

Overview

There is a strong focus on building education programmes with two–and–a–half days a year dedicated to inviting rheumatologists from both within the country and abroad to come to Hospital Italiano for preceptorships on different rheumatology conditions, including PsA. The centre also trains medical students as the hospital is a teaching hospital

Why is this a strength? Training programmes and education of HCPs:

- Enables doctors from other hospitals and different specialties to recognise symptoms of PsA and to be able to relate musculoskeletal symptoms to skin problems
- Improves awareness of a disease that is highly undiagnosed

How does it work? Preceptorships enable doctors to share the latest learnings in disease areas with other doctors both within the country and abroad. For example, the preceptorship in 2014 included a presentation on the latest therapies for psoriasis as well as discussion of specific patient case studies

◆

Home

Key findings

Source: KPMG interviews

Within the clinic, there are numerous elements that improve PsA care (2/2)

HOSPITAL ITALIANO
de Buenos Aires

What are the key strengths of the centre?

Collaboration with a network

Overview

Hospital Italiano (tertiary hospital), San Justo (secondary hospital) and 20 additional peripheral community health centres belong to the same health maintenance organisation (HMO) or network

Why is this a strength? The system helps to speed up referrals because there is much more close interaction between specialist rheumatologists and GPs in the peripheral centres. The network between Hospital Italiano, San Justo and primary care centres enables:

- Rheumatologists from Hospital Italiano to build strong relationships with GPs and train them on musculoskeletal complaints
- Patients to go to primary care centres close to where they live whilst still getting access to specialist care through the specialist clinics

How does it work? Rheumatologists from Hospital Italiano hold clinics in San Justo and eight of these community health centres. The peripheral centres include both specialists and GPs; however, all of the centres within the network refer patients to Hospital Italiano if there is suspicion of PsA as the PsA expertise is concentrated at Hospital Italiano

What are the limitations?

As with the combined clinic there are a limited number of clinics per week held at the peripheral centres so it does remain easier to access specialist care at Hospital Italiano

◆

Electronic medical records

Overview

The team at Hospital Italiano has designed an electronic medical records (EMR) system that is now used throughout the hospital and at the other peripheral centres within the wider network

Why is this a strength? It ensures that all medical staff, administrative staff and patients have easy and accurate access to patient information

How does it work? By designing the EMR system in house, the centre has been able to customise it to meet the needs of the team

◆

Rheumatologist sonographers

Overview

Four rheumatologists are specially trained in ultrasound which is used to confirm any suspicions about inflammatory joints, lower back pain and ultimately the diagnosis of PsA

Why is this a strength? Ultrasound helps in clinical evaluation as it is a tool that allows the rheumatologist to assess skin, nails and joints. This is particularly useful for patients who are overweight or obese, as ultrasound is a more targeted way of checking fingers or joints than a clinical examination and therefore makes the diagnosis more accurate

How does it work? The rheumatologist sonographers hold clinics specifically for ultrasound assessments

◆

Source: KPMG interviews

Home

Key findings

However, the centre continues to face some challenges

HOSPITAL ITALIANO
de Buenos Aires

What are the key challenges at the centre?

Lack of nurses

Overview

The centre has very few nurses with most of them being deployed on the intensive care units

Why is this an issue? This challenge is not specific to the Hospital Italiano as nurses are in short supply countrywide due to a lack of people training to become nurses. The nurses that do work do not have the capacity to take on more responsibility as in the specialist nurse role that exists in other countries

How can it be improved? The centre manages without a team of specialist nurses by having rheumatologists be responsible for all patient tests and checks. The rheumatologists share work between themselves by relying on each other to assess patients and take measurements. The team also relies heavily on fellows to support the more senior consultants

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Managing patient comorbidities

Overview

It is challenging to take care of and manage all the comorbidities that PsA patients may have

Why is this an issue? PsA patients are likely to have a whole host of comorbidities such as cardiovascular disease, inflammatory bowel disorders, obesity and depression, but the team is not currently able to focus enough time and attention to these comorbidities

How can it be improved? The centre already has the tools to capture and track comorbidities with the EMR system. However, with the limited time that the team has with patients the tendency is to focus on PsA itself rather than also addressing comorbidities. In the future, the team is seeking to incorporate more questions on comorbidities – particularly anything related to cardiovascular disease. The centre is also hoping to train one of its rheumatologist sonographers on ultrasounds of the heart in order to boost the team's capacity to monitor cardiovascular comorbidities. There are also additional diagnostic tools such as the Framingham Risk Score that can be used to evaluate comorbidities – in this case the 10–year cardiovascular risk of the patient

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Patient education/ support

Overview

There appears to be low awareness of PsA and the possibility of having a combined skin and joint condition. Hospital Italiano does not have a great deal of formalised patient support in terms of either support groups or targeted initiatives

Why is this an issue? Dr Soriano is hoping to build on the area of patient education in the future

How can it be improved? The centre already has high–quality educational material produced in house. However, the centre could push forward more group therapy which is currently not that popular among patients. It could also develop other ways of disseminating information to patients

◆

Home

Key findings

Source: KPMG interviews

Country-wide key challenges in PsA care include the delay in diagnosis and the siloed approach to care delivery

What are the key challenges in PsA care and how can they be addressed?

1 Siloed approach to PsA care

Overview

PsA patients present with both joint and skin symptoms therefore requiring the input of rheumatology and dermatology specialist teams. However, these teams often work in silos even within the same hospital due to competition between medical specialties and lack of communication

Why is this an issue? The siloed approach leads to inconsistent patient care and makes it more challenging to share expertise from different specialists

How can it be improved? Hospital Italiano has a combined clinic to ensure that expertise is shared between rheumatologists and dermatologists, and that patients get access to both specialists. Although the centre does not have patient satisfaction surveys, anecdotally patient response to the combined clinics is positive

A combined clinic could be much more complicated to set up in other centres in Argentina because if different doctors have contracts with different medical plans it can be difficult to refer a patient between specialists. That is because this may mean the patient has to pay extra if one of the specialists does not sit within their insurance plan

An EMR system also facilitates easy communication between specialists as both groups can access patient histories and see detailed notes from other specialists

◆

2 Lack of data on delay in diagnosis

Overview

Argentina currently lacks data on the delay between first symptoms and treatment of patients with PsA. The centre plans to lead a study to capture this delay in diagnosis

Why is this an issue? Understanding the delay in diagnosis is important because studies have shown that delaying diagnosis and ultimately the treatment of PsA are associated with increased disability and damage for the patient in the long term [1]

How can it be improved? The team is planning on implementing a patient journey study to capture the duration between the appearance of first symptoms to the diagnosis and the initiation of treatment. The EMR system will be a key tool for capturing the relevant data

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🚩 = must be addressed as early as possible

🚩 = should be addressed but are not a priority

Home

Key findings

Sources: KPMG interviews; secondary research: 1: Gladman D.D. et al. (2011) Do patients with psoriatic arthritis who present early fare better than those presenting later in the disease? Ann Rheum Dis. 70(12):2152-4

Groote Schuur Hospital, Cape Town, South Africa

Click on each circle to go to the sub–section

1 **Overview of the centre**

2 **Elements of care**

3 **Challenges at the centre**

4 **Challenges in PsA care**

Home

Key findings

An overview of the rheumatology department at Groote Schuur Hospital, Cape Town

- The rheumatology department at Groote Schuur Hospital is led by Professor Asgar Kalla
- The department collaborates closely with the specialist dermatology department at the hospital where the majority of PsA patients are referred from

Core PsA team

2 full–time rheumatologists

6 nurses (who provide general support)

2 part–time consultant physicians

1 medical officer (medical support personnel)

Several medical registrars and fellows

Several private dermatologists (who come in for certain clinics)

GROOTE SCHUUR HOSPITAL

PsA patient pool

220 PsA patients monthly

5 New PsA cases monthly

Arthritis clinic

- 100–120 per clinic,
- 20–30 PsA patients
- Twice a week

Catchment area

Cape Town
(Groote Shuur area)

Collaborative approach

Treatment of comorbidities

Patient and peer education

Outreach activities

Sources of referrals

- 90% specialist dermatology service
- 5% GPs (independent private practice)
- 5% other services (including community health centres)

Home

Key findings

Source: KPMG interviews

Within the clinic, there are numerous elements that improve PsA care (1/2)

What are the key strengths of the centre?

Patient and peer education

Overview

Rheumatologists from the team focus on providing timely and adequate patient and peer education

Why is this a strength? Training programmes and education of HCPs and patients:

- Enable doctors to recognise symptoms of PsA to be able to relate musculoskeletal symptoms to skin problems
- Improve awareness of a disease that is highly undiagnosed
- Improve referrals to specialists who can initiate the correct treatment
- Help patients cope with the disease

How does it work? The team organises educational sessions for primary care which focus on signs of arthritis and help doctors identify which patients to refer to the specialists. In addition, rheumatologists run sessions for patients during which they increase patients' understanding on the disease and help them cope with any challenges they may encounter. These sessions are organised every couple of months and the meetings are broadcast at community health centres to ensure that patients who are unable to reach the hospital can benefit from them as well

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Collaborative approach

Overview

The centre is characterised by a collaborative approach where rheumatologists and other team members can discuss any issues and get support from each other whilst offering the best care for their patients. The rheumatology department has also established a close relationship with other hospital departments, including the specialist dermatology department where the majority of PsA patients are referred from

Why is this a strength? The team–based model ensures that senior doctors can provide guidance to less experienced team members. In addition, clinical decisions are reached in a collaborative way ensuring better care. Thanks to good relationships with other departments, the centre can offer a more holistic approach to care and provide consistent treatment

How does it work? Rheumatologists organise regular meetings with other departments. For instance, they meet with the radiology team each month to review X–ray scans and help clinicians differentiate between patients with different forms of arthritis (i.e. rheumatoid arthritis vs psoriatic arthritis)

◆

Home

Key findings

Source: KPMG interviews

Within the clinic, there are numerous elements that improve PsA care (2/2)

Detailed site specifications

What are the key strengths of the centre?

Treatment of comorbidities

Overview

The team at the rheumatology department applies a holistic approach to the management of PsA, including treatment of associated comorbidities

Why is this a strength? Patients with PsA are at an increased risk of a number of comorbidities, including hypertension, cardiovascular diseases and diabetes.[1] To ensure that optimal care is provided, patients' comorbidities should be closely monitored and their treatment initiated in a timely manner

How does it work? Clinicians make sure that patients are educated on the risk of developing various comorbidities and emphasise the need for regular monitoring. In some cases, rheumatologists from the team can initiate treatment of related comorbidities (e.g. blood pressure treatment if patients suffer from hypertension). In more complex cases, patients are referred to other hospital departments

◆

Outreach

Overview

Professor Kalla is involved in outreach activities at primary care clinics in lower income areas, including Khayelitsha, Gugulethu and Eastern Cape

Why is this a strength? The aim of the outreach clinics is to improve access to care in hard–to–reach communities. Some of the population across the area is socio–economically disadvantaged with many being unemployed and unable to reach the centre and obtain appropriate care. The outreach activities bring significant benefits to the patients, including:

- Improved diagnosis of PsA
- Better access to care
- Better monitoring of patients
- Improved patient experience

How does it work? The outreach clinics were established thanks to the personal interest and dedication of the involved rheumatologists. Furthermore, it was possible to set up outreach clinics under hospital coverage in the community

◆

Home

Key findings

Sources: KPMG interviews; secondary research: 1. Ogdie A, Schwartzman S, Husni ME. (2015) Recognizing and managing comorbidities in psoriatic arthritis Curr Opin Rheumatol. 27(2): 118–126

However, the centre continues to face some challenges

What are the key challenges at the centre?

Limited access to biologics

Overview

The centre has very limited access to biologics. Since 2012, the state has reimbursed the biologic treatment for only 10 rheumatology patients per year for the entire centre

Why is this an issue? The high cost associated with biological therapies coupled with the lack of biosimilars on the market prevents the state from funding biologics for many patients who could potentially benefit from their use. With limited resources, priority is given to reimbursement of drugs for infectious diseases such as AIDS, which places a significant clinical, social and economic burden in South Africa

How can it be improved? The centre addresses the issue by having a process for allocation of biologics, with disease severity being the key factor in the decision–making process

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Lack of resources

Overview

The centre is facing challenges related to the high demand for their services and a limited workforce. This becomes especially difficult around vacation times when some of the doctors are on annual leave

Why is this an issue? Due to the lack of resources, there is a long waiting list for PsA patients who often have to wait three to four months from their initial diagnosis to be seen by a rheumatologist

How can it be improved? The team is dedicated to their patients and work extra hours – they put the wellbeing of their patients first

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Lack of database

Overview

Clinicians at the rheumatology department do not have access to an electronic platform to capture patient data

Why is this an issue? The use of electronic patient databases enables clinicians to capture detailed patient information to help them make better informed decisions, which is especially important for chronic diseases such as PsA. Clinicians at Groote Schuur Hospital have to rely on a paper–based system which can lead to inconsistency and missing data

How can it be improved? Due to limited funds from the hospital, the database could be put in place if external support was provided

◆

Home

Key findings

Source: KPMG interviews

There are a number of country-wide challenges (1/2)

What are the key challenges in PsA care and how can they be addressed?

1 Low diagnosis rate

Overview

In South Africa, the diagnosis rate of PsA is very low because of the limited number of rheumatologists and low awareness of PsA among general practitioners. Most GPs are not skilled in the diagnosis and management of PsA and they often misdiagnose patients as they attribute the joint pain to non–inflammatory causes

Why is this an issue? The lack of correct diagnosis means that patients who present to the centre have already had the disease for a long time and have accumulated irreversible damage in their joints. These patients are more difficult to treat and their outcomes tend to be worse than in early diagnosed PsA patients

How can it be improved? By sharing information on the key steps in diagnosing PsA, including education on how to differentiate between inflammatory and non–inflammatory pain, as well as on how to take a full medical history to reach a positive or negative conclusion

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2 Fragmented system

Overview

The healthcare system in South Africa is highly fragmented with each individual province having their own healthcare system

Why is this an issue? Due to the fragmented system, treatment decisions in PsA are often inconsistent, leading to wide variations in treatment quality and success. It can also result in increased inequalities in access to healthcare across the country

How can it be improved? Specialists from different provinces should come together to draw up guidelines across the PsA care pathway. These should then be followed in all centres across South Africa to ensure consistency and standardisation of care

◆

Home

Key findings

🟥 = must be addressed as early as possible

🟧 = should be addressed but are not a priority

Source: KPMG interviews

There are a number of country-wide challenges (2/2)

What are the key challenges in PsA care and how could they be addressed?

3 High incidence of TB

Overview

TNF inhibitors are associated with an increased risk of developing an active disease in patients with a latent TB infection.[1] As South Africa is one the countries with the largest number of new cases of tuberculosis annually [2], clinicians at Groote Schuur Hospital typically prescribe treatments which are associated with lower risk of developing TB

Why is this an issue? TNF inhibitors have demonstrated good efficacy in patients suffering from many inflammatory diseases, including PsA. However, high incidence and prevalence rates of TB in South Africa prevent doctors from prescribing these treatments, even to patients with the most severe disease, which means that many patients do not receive the most effective therapies

How can it be improved? National guidelines should be developed to help clinicians exclude TB prior to commencing biologic treatments. These should also outline best practice recommendations for PsA patients with previous TB infection

◆

4 Limited epidemiological data

Overview

Currently, there is very limited epidemiological data on the prevalence and incidence rates of PsA in South Africa

Why is this an issue? The lack of contemporary epidemiological data of PsA means that it is not possible to benchmark the severity of PsA, monitor its evolution over time or measure how populations benefit from new interventions

How can it be improved? Studies on the prevalence and incidence of PsA should be conducted as they can provide answers to the optimal management of PsA in this setting

◆

▶ = must be addressed as early as possible

▶ = should be addressed but are not a priority

Home

Key findings

Source: KPMG interviews; secondary research:1:Xie, X., et al (2014) Risk of tuberculosis infection in anti–TNF-α biological therapy: from bench to bedside. J Microbiol Immunol Infect. 47(4):268-74

KPMG

Guy's and St Thomas' Hospital

London, UK

Guy's and St Thomas' NHS Foundation Trust NHS

Click on each circle to go to the sub–section

Home

Key findings

Overview of the Service at Guy's and St Thomas' Hospital, London, UK

Guy's and St Thomas' NHS Foundation Trust NHS

- The Rheumatoid Arthritis (RA) Centre at Guy's and St Thomas' Hospital is a specialised clinic that was set up in 2004 to improve outcomes of patients with inflammatory diseases including RA and PsA. The centre is led by Dr Bruce Kirkham
- The group has established a close collaboration with the Special Psoriasis Clinic at St John's Institute of Dermatology to provide comprehensive care for PsA patients

Core PsA team

- **12** rheumatologists
- **2** nurse specialists
- **5** dermatologists[1]
- **1** advanced nurse practitioner
- **Several** trainees and research fellows
- **1** technical assistant

Guy's and St Thomas' NHS Foundation Trust NHS

PsA patient pool

- **700** active patients
- **537** patients in the database

PsA COMBINED CLINIC

(rheumatologist and dermatologist)

Once a week

Catchment area

London Boroughs of Southwark and Lambeth, South East England

- **Combined clinic**
- **Electronic database**
- **Clinical and translational research**
- **MDTs**
- **Advanced nurse practitioner**
- **Relationship with stakeholders**
- **Rheumatologist–sonographers**

Sources of referrals

- Patients are referred from primary care and dermatology
- Patients often request to be referred to the RA centre due to its reputation

Home

Key findings

Notes: 1: Dermatologists from the Special Psoriasis Clinic at St John's Institute of Dermatology
Sources: KPMG interviews

Within the clinic, there are numerous elements that improve PsA care (1/3)

Guy's and St Thomas' NHS Foundation Trust NHS

What are the key strengths of the centre?

Combined clinic

Overview

Rheumatologists and St John's dermatology department run a combined PsA clinic once a week. Unlike the combined clinics we observed at other centres, the goal of the combined clinic at Guy's and St Thomas' is to reassess and manage the difficult–to–treat and complex cases of PsA rather than to provide the initial diagnosis

Why is this a strength? The combined clinic has a number of benefits for patients and healthcare professionals:

- **Treatment change:** An internal audit of all combined clinics run between September 2013 and August 2015 showed that the majority of PsA patients had active joint or skin disease which required an escalation or adjustment of their current treatment in order to treat symptoms or complications. In 80% of cases their treatment was changed or readjusted when they were seen in the combined clinic, thanks to the collaborative input of rheumatologists and dermatologists identifying treatments that could better address their symptoms. These were complex patients having already had a mean of 5 medications Most patients attended the clinic only once, suggesting that the treatment change was successful in addressing their issues
- **Better access to drugs:** Some treatments are only available for either psoriasis or arthritis so patients can access treatments they would not get if they were treated by just one specialist
- **Improved collaboration:** As the combined clinic takes place every week, the dermatologists and rheumatologists are constantly in touch and can discuss other patients in an ad hoc manner
- **Increased patient satisfaction:** Doctors reported that some patients request to be referred to them because they have heard of the combined clinic
- **Learning opportunities:** The combined clinic makes dermatologists more aware of the joint symptoms and rheumatologists more aware of the skin manifestations of PsA

How does it work? The clinic is held once–weekly for patients with the most complex disease. During each clinic 2–3 patients are seen by the team; they are usually seen by a dermatologist first who assesses their skin symptoms before the combined clinic starts. The special psoriasis clinic and rheumatology clinic then run over the rest of the morning making it very convenient for patients who need to visit both clinics, but are not seen in the combined clinic

◆

MDT meetings

Overview

After every Thursday clinic at the centre, MDT meetings are organised for the rheumatology staff. The meetings allow clinicians to discuss patient cases in an open and collaborative environment, leading to better decisions regarding the management of patients. These meetings focus on complex cases of inflammatory diseases, including PsA

Why is this a strength?

- **Improved management:** Discussing complex cases with the more experienced doctors can lead to better treatment decisions
- **Learning opportunities:** MDT is also a powerful learning tool for the junior doctors and trainees. They can observe how the senior doctors make their clinical decisions but they are also asked to present their own patients as a learning exercise

How does it work?

- **Attending HCPs:** During each MDT meeting rheumatologists, nurses and trainees are present
- **Frequency:** MDTs take place every week after the rheumatology clinic so that patients seen during the same day can be discussed

◆

Source: KPMG interviews

Home

Key findings

Within the clinic, there are numerous elements that improve PsA care (2/3)

Guy's and St Thomas' NHS Foundation Trust NHS

What are the key strengths of the centre?

Specialist nurse

Overview

The centre has an advanced nurse practitioner and recently two nurse specialists working with the rheumatologists providing support for patients and in coordinating patient care. In particular, the nurse team is responsible for:

- Day–to–day patient management
- Patient education and support
- Monitoring of safety and effectiveness of treatments
- Altering dose and changing some of the drug treatment via agreed guidelines
- Prescription of medications, including biologics, by the advanced nurse practitioner

Why is this a strength? Improved patient education allows patients to be in control of the disease and can lead to improved adherence to treatment. Compliance with treatment is better if the nurse team is involved in the therapy pathway. In addition, presence of a nurse who can prescribe treatments, improves efficiency of healthcare delivery as patients need less frequent appointments with rheumatologists

How does it work? The nurse team carries on these activities during a clinic for newly diagnosed patients which takes place four times a week and is supported by a 24/7 voicemail support service. The nurse practitioner also organises pregnancy clinics which provide pregnancy advice to PsA patients and their families

◆

Electronic database

Overview

The centre places an emphasis on routine data monitoring for continuous quality improvement. This has led to the development of an electronic database where data on treatments and outcomes are collected. The centre also employs a database manager who maintains the database and analyses the obtained data

Why is this a strength? The database enables doctors to collect extensive data on their patients, including treatments, clinical outcomes and patient quality of life. The database allows them to better understand the disease progression of the individual patients, leading to better–informed decisions. In addition, a thorough analysis of the datasets could improve the understanding of the disease and value of the various treatment options

How does it work? The database is updated by clinicians during each patient's visits which can be challenging due to the short appointment times. Clinicians collect data on patient's treatments as well as outcomes, including joint symptoms (68 joint count), skin symptoms, physician and patient global scores, Psoriasis Area Severity Index (PASI) which collected in a subset of patients, as well as the functional scale (Health Assessment Questionnaire, HAQ). At Guy's & St Thomas', clinicians are very interested in quality of life measures and they are one of the few centres to collect data on health related quality of life using the EQ–5D (EuroQuol 5 dimensions questionnaire)

◆

Home

Key findings

Source: KPMG interviews

KPMG

Within the clinic, there are numerous elements that improve PsA care (3/3)

Guy's and St Thomas' NHS Foundation Trust NHS

What are the key strengths of the centre?

Relationship with stakeholders

Overview

The rheumatologists have a close relationship with local commissioners and work closely with primary care to ensure rapid and accurate referrals

Why is this a strength?

- **Links with primary care:** The strong relationship with primary care ensures rapid and accurate referrals for patients with inflammatory disorders, including rheumatoid arthritis and PsA. Thanks to the development of the early arthritis pathway at the RA Centre, GPs are more aware of the signs of inflammation and refer patients to the centre promptly
- **Links with local commissioners:** The relationship with local commissioners enables the centre to provide better access to treatments. For instance, clinicians from the RA Centre have made an agreement with local commissioners so that patients can receive biological therapy without the requirement of having failed two DMARD treatments before (as outlined in the NICE guidelines[1])

How does it work? When the centre was first established, its lead clinicians came together with the Primary Care Trust (PCT), King's College Hospital, orthopaedists and occupational therapy leads to discuss musculoskeletal disorders. They worked together on pathways and protocols with the goal to create service that puts the patient in the centre of care. Whenever the centre wants to introduce a new element of care, they discuss it with the stakeholders during meetings that take place every three months

◆

Rheumatologists sonographers

Overview

Rheumatologists at Guy's and Thomas' are trained to perform ultrasonography which is used for diagnosing and monitoring of PsA patients

Why is this a strength? Clinical evaluation of PsA may be challenging and can lead to an underestimation of the extent of inflammation and joint damage. Ultrasonography can be especially important when blood tests fail to provide a clear answer as it is a highly sensitive method for early detection of inflammatory joint changes.[2] Having these procedures performed by a rheumatologist rather than a radiologist allows for continuity of care and helps to build trust between the doctor and the patient. In addition, when patients see the inflammation on the screen in real time, they are more likely to understand the extent of their disease and become more engaged in the treatment

How does it work? Ultrasonographs are not used at every visit but are helpful when other tests do not provide a clear differential diagnosis

◆

Home

Key findings

Source: KPMG interviews; secondary research: 1: NICE (2010) Etanercept, infliximab and adalimumab for the treatment of psoriatic arthritis. TA199; 2: Solivetti, F., et al. (2007) Ultrasound and psoriatic arthritis – Review of the literature and general considerations J Ultrasound. 2007 Jun; 10(2): 63–67

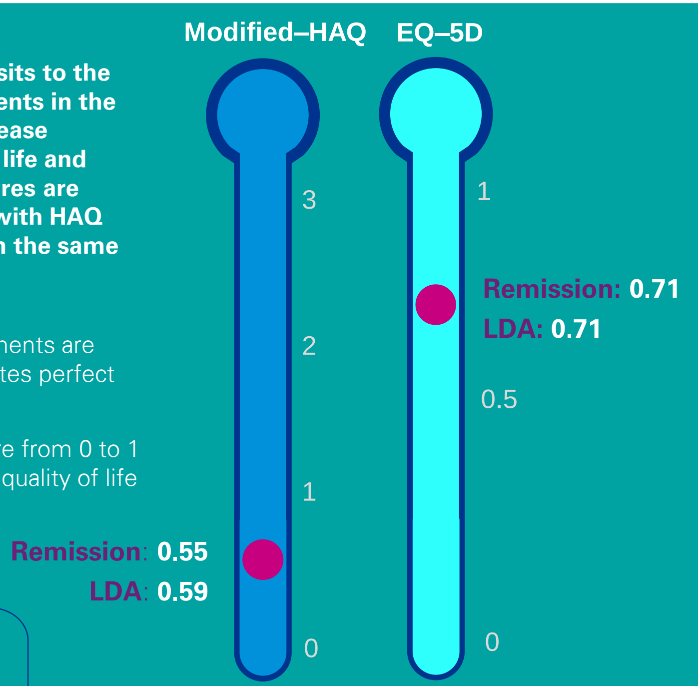
These elements have improved patient outcomes

What targets should be achieved in PsA?

- At Guy's & St Thomas', rheumatologists are interested in health–related quality of life (EQ–5D) and health function (HAQ) but consider them as outputs of controlling other variables. Since 2004, the centre uses a treat–to–target approach to PsA care where treatment target is defined as remission (DAS 28 < 2.6) or Low Disease Activity score (LDA) (DAS 28 between 3.2–2.6). Currently, the centre is exploring the Minimal Disease Activity measure
- Dr Kirkham and his team demonstrated that disease activity is highly correlated with patient's quality of life and functional scores. Patients in remission achieve good EQ5–D and HAQ scores, suggesting that remission is a valid goal in PsA [1]
- In addition, there was no marked difference in outcomes between patients in the state of remission and in low disease activity, suggesting that low disease activity might be enough to achieve the optimum quality of life and functional scores [1]

Data based on 537 patient visits to the centre suggest that PsA patients in the state of remission or low disease activity have good quality of life and functional scores. DAS28 scores are calculated on the database, with HAQ and EQ–5D scores entered on the same day

- **Modified HAQ:** Measurements are from 0 to 3 where 0 indicates perfect functional score
- **EQ–5D:** Measurements are from 0 to 1 where 1 indicates perfect quality of life



Patients in the state of remission (DAS 28 < 2.6): 46% and with low disease activity (DAS 28 between 3.2–2.6): 14%

Home

Key findings

Source: KPMG interviews; 1: unpublished data

The centre is facing some challenges

Guy's and St Thomas' NHS Foundation Trust NHS

What are the key challenges faced by the centre?

1

Limited number of nurses

Overview

Guy's and St Thomas' has a large specialised centre for inflammatory diseases, including RA and PsA, with many active patients who require regular support. However, the centre is under–resourced and until recently employed only one advanced nurse specialist

Why is this an issue? To provide optimal care for PsA patients, it is important to have the right amount of healthcare professionals who can dedicate their time to individual patients. However, with limited resources, this is not always possible

How can it be improved? By hiring more nurses and providing them with specialist training. However, it can take up to two years to train a specialist rheumatology nurse

◆

2

Treatment of comorbidities

Overview

Although the centre is excellent at treating joint and skin symptoms associated with PsA, the treatment of comorbidities could be further improved. Due to the lack of resources, not enough time is spent to address patients' comorbidities

Why is this an issue? Patients with PsA have a high risk of comorbidities, including hypertension, cardiovascular diseases and diabetes [1]. Lack or regular monitoring for patients' comorbidities and delayed treatment initiation can lead to suboptimal patient outcomes

How can it be improved? The centre is addressing this issue by educating patients on the risks of developing complications associated with PsA, especially the risk of cardiovascular diseases

◆

⚑ = must be addressed as early as possible

⚑ = should be addressed but are not a priority

Source: KPMG interviews; 1: Ogdie, A., Schwartzman, S., Husni, M.E. (2015) Recognizing and managing comorbidities in psoriatic arthritis Curr Opin Rheumatol. 27(2):118–26

Home

Key findings

There are a number of challenges that persist in PsA care

What are the key challenges in PsA care and how can they be addressed?

1 Underdiagnosis of PsA

Overview

Up to 30% of people with psoriasis also develop PsA, but many can go undiagnosed due to their additional symptoms not being picked up in the dermatology clinic [1]

Why is this an issue? Underdiagnosis of PsA patients is caused by a number of reasons:

- **Short consultation times:** Dermatology consultations are often very short, lasting only three to five minutes. This limited time often prevents doctors from a thorough clinical examination of their patients
- **Lack of interest:** Many dermatologists are not interested in PsA and do not actively look for the symptoms
- **Lack of patient awareness:** Some patients do not connect their joint pain with their skin condition so they do not inform their doctor about them when attending an appointment for their skin
- **Lack of effective screening tools:** Current screening tools are not specific enough to distinguish between different types of arthritis. Even with a good understanding of rheumatology it can still be hard to differentiate between different disease types

How can it be improved? This could be addressed by reaching out to GPs and dermatologists and educating them on the prevalence and the severity of PsA. It is key to teach them how to recognise early symptoms of inflammation so that the referral is made to the specialist in a timely manner. There are important advantages to both dermatologists and rheumatologists to work more closely as they do at Guy's & St Thomas', extending beyond psoriatic disease, but breaking down institutional and geographic barriers can be difficult

◆

2 Comorbidities including depression and anxiety

Overview

Psoriasis patients often report mental health concerns such as anxiety and depression, and a wide range of emotional reactions including shame, embarrassment, anger and helplessness.[2] Developing a painful, disabling joint disease can worsen their mental health. A study conducted at rheumatology clinics showed that 17.6% of patients with PsA also suffer from depression [3]

Why is this an issue? Patients with psoriasis and PsA can have major psychological issues because a lot of them never had to deal with a chronic disease prior to the diagnosis. Helping patients to adequately handle their psychological problems and communicate properly about the disease is vital to providing optimal care

How can it be improved? Upon diagnosis, PsA patients should be provided with timely psychosocial support. At Guy's & St Thomas', most of the support is provided by the advanced nurse practitioner who can identify symptoms of distress and depression, can help patients cope with the disease and, if needed, suggests seeing a specialist. There is a psychologist in the specialist psoriasis centre at the hospital and the rheumatologists are considering employing one as well. The dermatology department uses a system called IMPARTS that collects data on anxiety and depression filled in using a tablet. It has proven to be a very good tool to identify new cases of psychological distress, with approximately 70% of cases previously not recognised

◆

🟥 = must be addressed as early as possible

🟧 = should be addressed but are not a priority

Source: KPMG interviews; secondary research: 1: https://www.psoriasis.org/psoriatic-arthritis (accessed 6 April 2016); 2: de Korte J., et al. (2004) Quality of life in patients with psoriasis: a systematic literature review J Investig Dermatol Symp Proc. 9(2):140-147; 3: Freire, M., et al. (2011) Prevalence of symptoms of anxiety and depression in patients with psoriatic arthritis attending rheumatology clinics. Reumatol Clin. 7(1):20–26

The Prince of Wales Hospital Hong Kong

Click on each circle to go to the sub–section

1 **Overview of the centre**

2 **Elements of care**

3 **Challenges at the centre**

4 **Challenges in PsA care**

Home

Key findings

Overview of the rheumatology division at the Prince of Wales Hospital

The Prince of Wales Hospital, Hong Kong

- The Rheumatology Division at the Prince of Wales Hospital (PWH) is led by Professor Lai–Shan Tam
- The team consists primarily of rheumatologists and nurses; however, they work closely with colleagues in other divisions to offer comprehensive care for PsA patients

Core PsA team

4 **rheumatologists**

2 **dermatologists**

1 **rheumatology nurse**

6 **nurses** (including a department operation manager, ward Managers, and nurses–in–charge)

1 **research nurse**

Several **researchers**

Patient pool

485

Patients in the database

- 20–40 new PsA patients per year
- PsA research clinic (109 PsA patients)

Catchment area

New Territories East Cluster [1]

- **Multidisciplinary approach**
- **Comprehensive care**
- **Research clinic**
- **Database**
- **Nurse–led clinic**

Sources of referrals

- More than 70% of the referrals come from dermatologists
- The remaining referrals come from GPs as rheumatologists (as the team can manage more complicated PsA cases)

Home

Key findings

Notes: [1] The catchment area of the New Territories East Cluster includes Shatin, Tai Po and North District, although the cluster also provides tertiary and quaternary services to the entire population of Hong Kong Sources: KPMG interviews

Within the clinic, there are numerous elements that improve PsA care (1/2)

Detailed site specifications

The Prince of Wales Hospital, Hong Kong

2 Elements of care

What are the key strengths of the centre?

Research clinic

Overview

The rheumatology team at PWH is highly interested in comorbidities linked with PsA. The researchers are currently investigating the association of inflammation with premature atherosclerosis and bone loss in patients with rheumatic diseases including PsA [1,2]. These research activities have been incorporated into the clinical setting so that patients who fulfil the enrolment criteria can attend the research clinic rather than the routine clinic and, thereby, receive higher quality care. Out of 485 PsA patients, approximately 22% are seen in this clinic

Why is this a strength? In addition to providing new insights into the comorbidities associated with PsA, the research clinic offers benefits to participating patients, including:

- **Shorter waiting times:** Due to the limited number of rheumatologists, it can take up to two years for a PsA patient to be seen for the initial assessment. However, patients in the research clinic can be seen as quickly as within two weeks
- **Earlier access to biologics:** In Hong Kong, patients need to have failed at least three DMARD therapies and have at least four tender or swollen joints before they are eligible for treatment biologics. Enrolment in these studies provides early access to treatments that would otherwise be unavailable for many patients
- **Improved care:** In the research clinic, the rheumatology team can provide a more holistic approach to patient care. With longer and more frequent appointments, they can measure disease activity and optimise treatment, monitor the patient's quality of life and screen for comorbidities

How does it work? Creation of the research clinic was possible due to the team's interest in PsA and external funding obtained from the Health and Medical Research Fund

◆

Comprehensive care

Overview

The routine clinic offers comprehensive care for PsA which encompasses an out–patient clinic, day clinic, as well as an in–patient service

Why is this a strength? PsA patients at PWH benefit from all necessary services located within the hospital. That way they do not need to be referred to other clinics which ensures continuity of care and improves patient experience

How does it work? The rheumatology division has been set–up to provide the following services:

- **Rheumatology Specialty Out–patient Clinic (SOPC)**: For initial treatment and follow–up of PsA patients, subcutaneous injections of biologics and musculoskeletal ultrasounds
- **Day clinic:** For infusion of biologic treatments
- **In–patient service**: For patients requiring tertiary care, e.g. during disease flare up, for overnight procedures, for treatment on infection, etc.

◆

Home

Key findings

Sources: KPMG interviews; secondary research: 1: Zhu, T., et al (2015) Density, structure, and strength of the distal radius in patients with psoriatic arthritis: the role of inflammation and cardiovascular risk factors. Osteoporos Int. 26(1):261-72; 2: Tam, L.-S., et al (2008) Cardiovascular risk profile of patients with psoriatic arthritis compared to controls—the role of inflammation. Rheumatology. 47 (5): 718-723

Within the clinic, there are numerous elements that improve PsA care (2/2)

What are the key strengths of the centre?

Collaborative approach

Overview

The centre offers multidisciplinary care involving rheumatologists, nurses and other specialists to provide comprehensive and patient–centred care

Why is this a strength? Due to the department policy and limited funding, it is currently not possible to set up a combined clinic during which PsA patients can be seen simultaneously by multiple specialists. However, the high level of informal collaboration and meetings across the MDT allows for knowledge sharing and management of PsA patients, taking into account both joint and skin symptoms, as well as associated comorbidities

How does it work? The MDT at PWH consists of:

- **Rheumatologists:** Rheumatologists are at the core of the MDT. The leader of the team maintains the standard of care and conveys the vision and leadership to the team. Junior doctors can learn from their more experienced colleagues
- **Nurses:** Nurses assist doctors in disease and drug monitoring as well as patient education and counselling. A rheumatology nurse has set up a nurse–led clinic for PsA and rheumatoid arthritis patients which helps ensure continuity of care
- **Dermatologists:** There is a good level of collaboration between the dermatology and rheumatology departments, through formal channels (e.g. referral pathways) and informal networks (ad hoc communication)
- **Other specialists:** The team collaborates closely with other specialists that may be required to provide patient care, including radiologists and cardiologists

◆

Rheumatology nurse

Overview

At PWH, the rheumatology nurse assists doctors in the screening of early arthritis patients, monitoring disease activity, adverse reactions and long–term comorbidities

Why is this a strength? Due to the limited number of rheumatologists, the waiting time for a follow–up appointment with a rheumatologist is approximately six months. With the average waiting time of three months, nurse–led clinics enable patients to talk to healthcare professionals and obtain advice in between appointments with rheumatologists

How does it work? The rheumatology nurse provides a number of advantages to the department and patients:

- **In–patient service:** Education and support for patients requiring tertiary care
- **Day–patient service:** Patient assessment, biologics infusion
- **Out–patient service (rheumatology nurse–led clinic):** Disease and drug monitoring, education and counselling, musculoskeletal ultrasound clinic
- **Rheumatology helpline:** Telephone service where patients can receive advice on the disease and treatments
- **Coordination with other team members:** Including coordinating with the research and the clinical team

◆

Source: KPMG interviews

Home

Key findings

However, the centre continues to face challenges

What are the key challenges at your centre?

1 Limited access to biologics

Overview

Although biologics have proven to be effective in the treatment of PsA, their access is currently very limited In Hong Kong. To be eligible for the biologic treatment, patients need to have failed three DMARD therapies and have minimum of four tender or swollen joints

Why is this an issue? Many patients with severe PsA are not provided with treatment that can sufficiently control their disease, leading to worse clinical outcomes and reduced quality of life

How can this be improved? Although the reimbursement of biologics is very limited in Hong Kong, the centre has been successful in securing funding from other sources. Patients can receive their treatments through the Samaritan Fund, a government fund which provides financial help to low–income patients, subsidising the cost of expensive treatments and medical devices.[1] Currently, approximately a third of all patients on biologics have their treatment covered through this fund. In addition, patients at PWH can receive early access to treatments through the research clinic, if they meet defined eligibility criteria

◆

2 Lack of resources

Overview

With Hong Kong's expanding population and escalating demand for rheumatology services, the hospital is facing significant challenges associated with the lack of manpower and resources

Why is this an issue? Lack of capacity results in long waiting times for patients' appointments. It can take up to two years to be seen by the rheumatologist for an initial visit and six months to get a follow–up appointment. Therefore, specialists are unable to provide timely diagnosis and initiate early treatment

How can this be improved? The centre has addressed this issue by incorporating research into the clinical setting. If patients meet the eligibility criteria for the studies, they can attend the research clinics through which they obtain quicker access to specialists. In addition, since 2013, the centre has utilised nurse–led clinics where patients can be assessed by a specialised rheumatology nurse in between the follow–up appointments with rheumatologists

◆

🟥 = must be addressed as early as possible

🟧 = should be addressed but are not a priority

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Key findings

Sources: KPMG interviews; secondary research: 1: Hospital Authority (2016) http://www.ha.org.hk/visitor/ha_visitor_text_index.asp?Content_ID=10048 (accessed 6 April 2016)

Country-wide key challenges in PsA care: lack of collaboration and limited PsA awareness among dermatologists

Detailed site specifications

The Prince of Wales Hospital, Hong Kong

What are the key challenges at your centre?

1

Siloed approach to PsA care

Overview

PsA patients present with both joint and skin symptoms therefore requiring the input of rheumatology and dermatology specialist teams. However, these teams often work in silos leading to suboptimal patient outcomes. Collaboration between dermatology and rheumatology teams is hindered in Hong Kong due to the lack of dermatologists in most hospitals as they normally work in the Social Hygiene Clinics which are responsible for the management, prevention and control of sexually transmitted diseases (STD) and skin diseases

Why is this an issue? The siloed approach leads to inconsistent patient care and makes it more challenging to share expertise from different specialists

How can this be improved? Developing formal and informal channels of communication between the dermatologists in the hygiene clinics and rheumatologists is key to providing comprehensive care for PsA patients. This could be further improved by making dermatologists more aware of the joint symptoms and rheumatologists more aware of the skin manifestations

◆

2

Low awareness among dermatologists and GPs

Overview

GPs and dermatologists are in the prime position to identify early symptoms of PsA; however, their knowledge of PsA tends to be very low. For many dermatologists their knowledge of PsA is limited to their early medical training in rheumatology. Therefore, it may be challenging for them to link the joint and skin symptoms and differentiate between inflammatory and non–inflammatory pain, as well as between PsA and rheumatoid arthritis

Why is this an issue? Due to the limited knowledge, GPs and dermatologists frequently attribute joint pain to non–inflammatory causes and either provide inadequate treatment or refer patient to another specialist, e.g. an orthopaedic surgeon. Therefore, it can be difficult to identify patients before their disease has progressed and they have accumulated an irreversible joint damage

How can this be improved? Self–learning can be slow and is not always effective for clinicians. Rheumatologists should organise educational seminars for dermatologists as well as other stakeholders who might encounter PsA patients

◆

🚩 = must be addressed as early as possible

🟧 = should be addressed but are not a priority

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Key findings

Source: KPMG interviews

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Annual Patient Newsletter at the Toronto Western Hospital (1/7)

PsA psoriatic arthritis research program

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THE UNIVERSITY OF TORONTO PSORIATIC ARTHRITIS PROGRAM

JULY 2015

The Psoriatic Arthritis Clinic now 37 years old treats over 1300 patients who are being closely followed and thus constitutes the largest and the most comprehensively studied group of psoriatic arthritis patients in the world. Both the clinic and the doctors associated with it are recognized internationally for the expertise which has evolved from this unique facility.

The purpose of this Newsletter is to update our patients on advances in both scientific and clinical research and treatment. We also provide some basic information about psoriatic arthritis for new patients entering the clinic.

The Psoriatic Arthritis Research Program Team

WHAT IS PSORIATIC ARTHRITIS?

Relatively common, psoriasis (Ps) is a skin disease affecting 3% of the population. One - third of these patients may then develop psoriatic arthritis (PsA) which is a systemic inflammatory arthritis associated with psoriasis. Psoriatic arthritis may lead to osteoarthritis if not treated promptly but is quite different from osteoarthritis.

Patients with PsA first arrive at the clinic with a lot of pain, swelling and

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PsA psoriatic arthritis research program

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stiffness of the affected wrists, hands and/or knees and feet joints. They may also suffer neck or other back pain. Frequently patients have swelling of whole digits (fingers or toes), so called "sausage digits" or dactylitis, and/or inflammation at the sites where tendons insert into bones called enthesitis (plantar fasciitis being an example). PsA was poorly understood and was not treated very aggressively by physicians prior to 1978. Fortunately, this clinic has played a large role in understanding the disease and its severity and how it affects the lives of patients. Treatment options have greatly improved for patients through the research carried out by this clinic. However, the actual cause of the disease and the reason for its persistence still remain somewhat of a mystery but it is actively being investigated.

What Causes Psoriatic Arthritis?

Evidence shows us that whether someone develops psoriatic arthritis depends both on their own body's genetic make-up, i.e. their immune system's ability to handle things, and the environmental stresses placed on their body. Sometimes injury (an insult to skin or joints or the immune system) may trigger psoriasis or arthritis. Dr. Lihi Eder, our post-doctoral fellow has demonstrated that infection and heavy lifting predispose patients with psoriasis to develop PsA. She also found that smoking predisposes people to develop psoriasis, but oddly, once patients with psoriasis smoke, they are less likely to have PsA. Current investigations continue to focus on the relationship between genetic and environmental factors.

Are hereditary factors important in Psoriatic Arthritis?

About 40% of patients with PsA have relatives with either psoriasis or PsA, suggesting a rather significant hereditary contribution. Close blood relatives of patients with psoriatic arthritis have about 30 times the risk of developing psoriatic arthritis compared to the general population. If you already have psoriasis, our studies and those of other investigators show that

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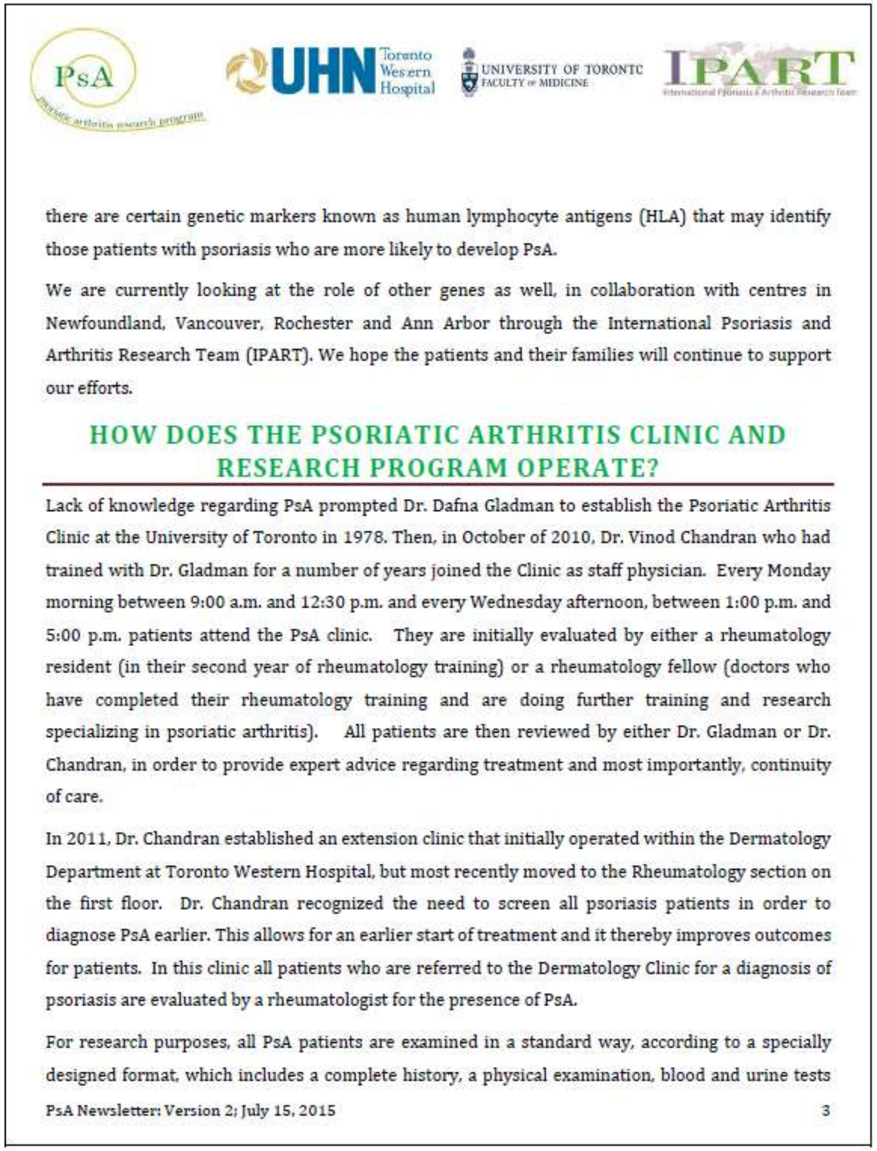
Annual Patient Newsletter at the Toronto Western Hospital (2/7)



there are certain genetic markers known as human lymphocyte antigens (HLA) that may identify those patients with psoriasis who are more likely to develop PsA.

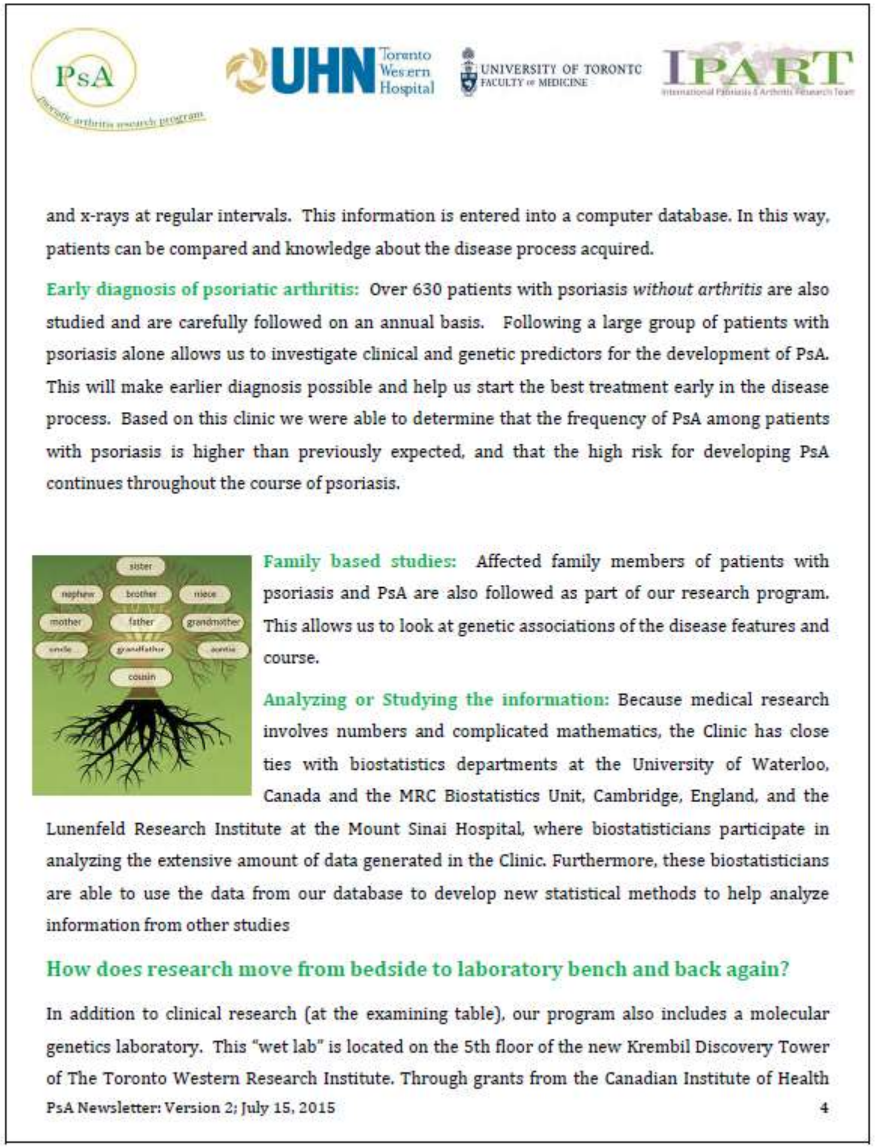
We are currently looking at the role of other genes as well, in collaboration with centres in Newfoundland, Vancouver, Rochester and Ann Arbor through the International Psoriasis and Arthritis Research Team (IPART). We hope the patients and their families will continue to support our efforts.

HOW DOES THE PSORIATIC ARTHRITIS CLINIC AND RESEARCH PROGRAM OPERATE?

Lack of knowledge regarding PsA prompted Dr. Dafna Gladman to establish the Psoriatic Arthritis Clinic at the University of Toronto in 1978. Then, in October of 2010, Dr. Vinod Chandran who had trained with Dr. Gladman for a number of years joined the Clinic as staff physician. Every Monday morning between 9:00 a.m. and 12:30 p.m. and every Wednesday afternoon, between 1:00 p.m. and 5:00 p.m. patients attend the PsA clinic. They are initially evaluated by either a rheumatology resident (in their second year of rheumatology training) or a rheumatology fellow (doctors who have completed their rheumatology training and are doing further training and research specializing in psoriatic arthritis). All patients are then reviewed by either Dr. Gladman or Dr. Chandran, in order to provide expert advice regarding treatment and most importantly, continuity of care.

In 2011, Dr. Chandran established an extension clinic that initially operated within the Dermatology Department at Toronto Western Hospital, but most recently moved to the Rheumatology section on the first floor. Dr. Chandran recognized the need to screen all psoriasis patients in order to diagnose PsA earlier. This allows for an earlier start of treatment and it thereby improves outcomes for patients. In this clinic all patients who are referred to the Dermatology Clinic for a diagnosis of psoriasis are evaluated by a rheumatologist for the presence of PsA.

For research purposes, all PsA patients are examined in a standard way, according to a specially designed format, which includes a complete history, a physical examination, blood and urine tests



and x-rays at regular intervals. This information is entered into a computer database. In this way, patients can be compared and knowledge about the disease process acquired.

Early diagnosis of psoriatic arthritis: Over 630 patients with psoriasis *without arthritis* are also studied and are carefully followed on an annual basis. Following a large group of patients with psoriasis alone allows us to investigate clinical and genetic predictors for the development of PsA. This will make earlier diagnosis possible and help us start the best treatment early in the disease process. Based on this clinic we were able to determine that the frequency of PsA among patients with psoriasis is higher than previously expected, and that the high risk for developing PsA continues throughout the course of psoriasis.

Family based studies: Affected family members of patients with psoriasis and PsA are also followed as part of our research program. This allows us to look at genetic associations of the disease features and course.

Analyzing or Studying the information: Because medical research involves numbers and complicated mathematics, the Clinic has close ties with biostatistics departments at the University of Waterloo, Canada and the MRC Biostatistics Unit, Cambridge, England, and the Lunenfeld Research Institute at the Mount Sinai Hospital, where biostatisticians participate in analyzing the extensive amount of data generated in the Clinic. Furthermore, these biostatisticians are able to use the data from our database to develop new statistical methods to help analyze information from other studies

How does research move from bedside to laboratory bench and back again?

In addition to clinical research (at the examining table), our program also includes a molecular genetics laboratory. This "wet lab" is located on the 5th floor of the new Krembil Discovery Tower of The Toronto Western Research Institute. Through grants from the Canadian Institute of Health

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Annual Patient Newsletter at the Toronto Western Hospital (3/7)

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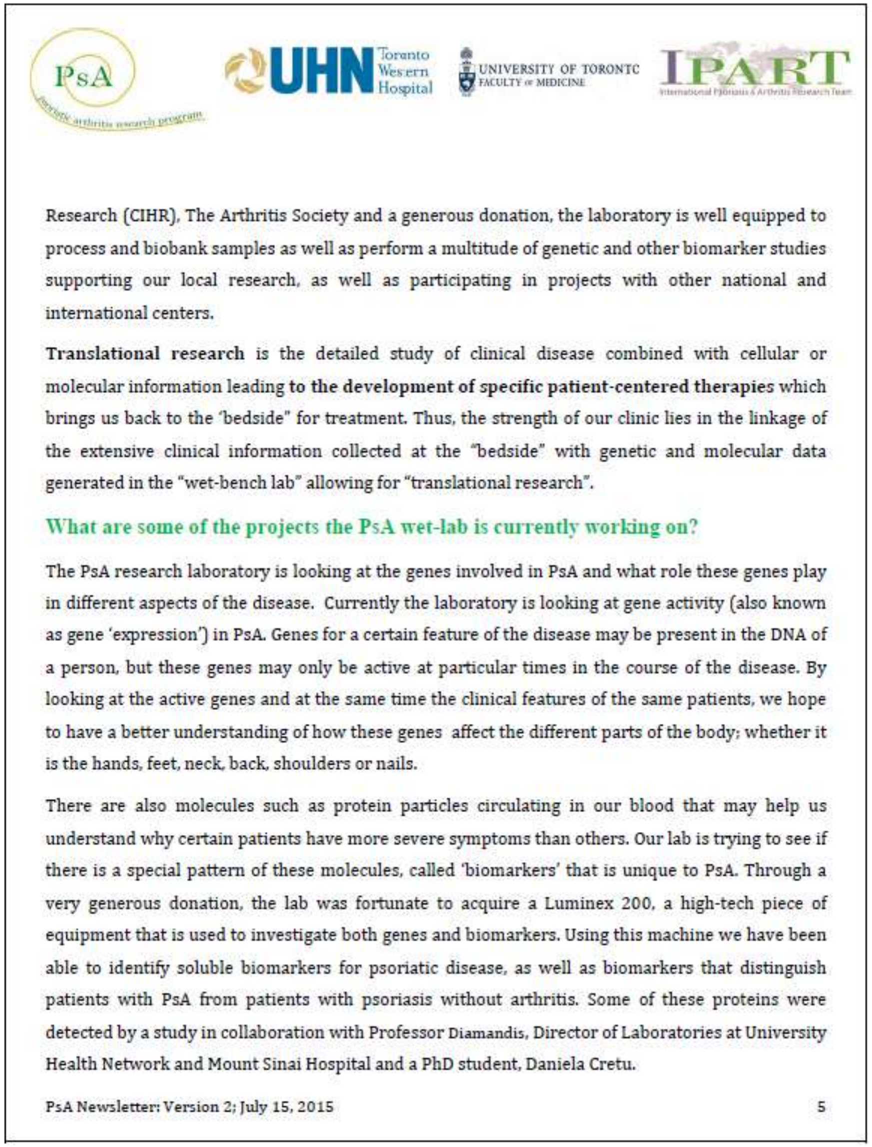

PsA psoriatic arthritis research program
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Research (CIHR), The Arthritis Society and a generous donation, the laboratory is well equipped to process and biobank samples as well as perform a multitude of genetic and other biomarker studies supporting our local research, as well as participating in projects with other national and international centers.

Translational research is the detailed study of clinical disease combined with cellular or molecular information leading **to the development of specific patient-centered therapies** which brings us back to the 'bedside" for treatment. Thus, the strength of our clinic lies in the linkage of the extensive clinical information collected at the "bedside" with genetic and molecular data generated in the "wet-bench lab" allowing for "translational research".

What are some of the projects the PsA wet-lab is currently working on?

The PsA research laboratory is looking at the genes involved in PsA and what role these genes play in different aspects of the disease. Currently the laboratory is looking at gene activity (also known as gene 'expression') in PsA. Genes for a certain feature of the disease may be present in the DNA of a person, but these genes may only be active at particular times in the course of the disease. By looking at the active genes and at the same time the clinical features of the same patients, we hope to have a better understanding of how these genes affect the different parts of the body; whether it is the hands, feet, neck, back, shoulders or nails.

There are also molecules such as protein particles circulating in our blood that may help us understand why certain patients have more severe symptoms than others. Our lab is trying to see if there is a special pattern of these molecules, called 'biomarkers' that is unique to PsA. Through a very generous donation, the lab was fortunate to acquire a Luminex 200, a high-tech piece of equipment that is used to investigate both genes and biomarkers. Using this machine we have been able to identify soluble biomarkers for psoriatic disease, as well as biomarkers that distinguish patients with PsA from patients with psoriasis without arthritis. Some of these proteins were detected by a study in collaboration with Professor Diamandis, Director of Laboratories at University Health Network and Mount Sinai Hospital and a PhD student, Daniela Cretu.

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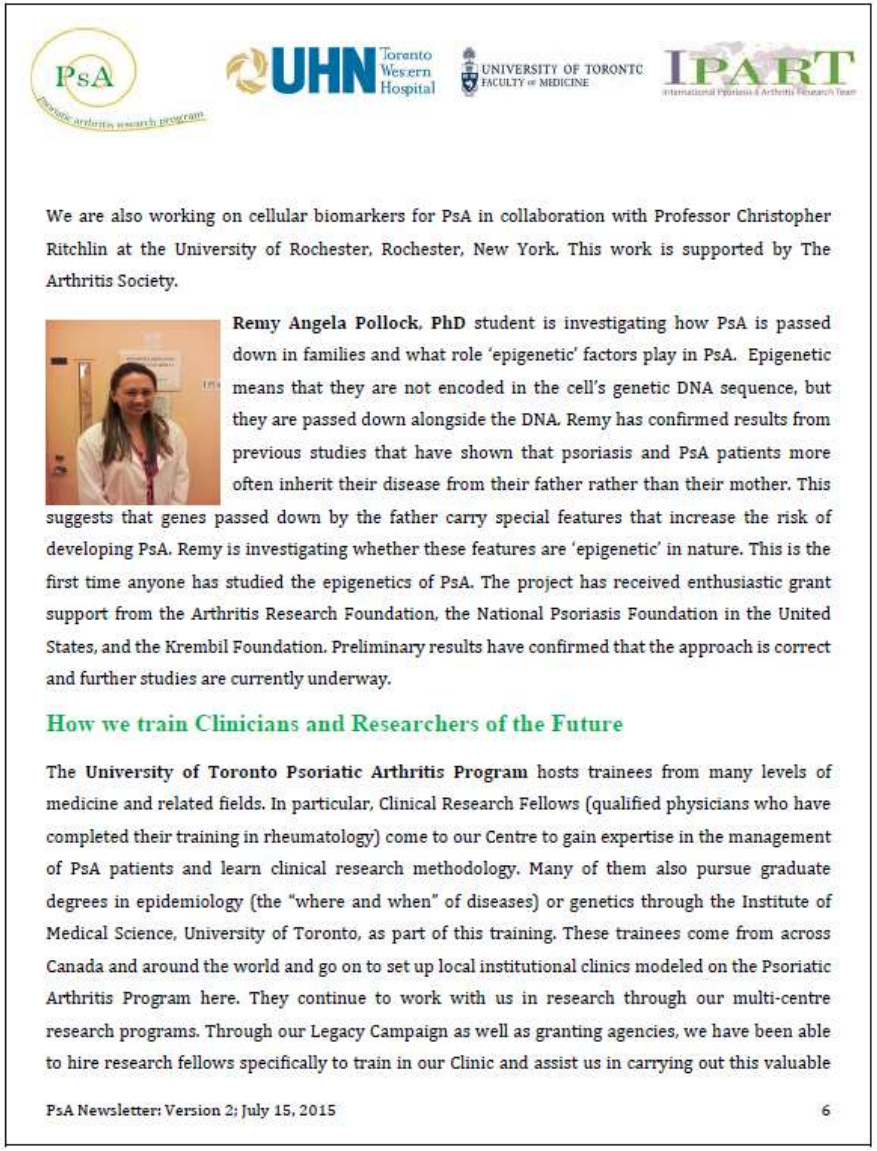

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We are also working on cellular biomarkers for PsA in collaboration with Professor Christopher Ritchlin at the University of Rochester, Rochester, New York. This work is supported by The Arthritis Society.

Remy Angela Pollock, PhD student is investigating how PsA is passed down in families and what role 'epigenetic' factors play in PsA. Epigenetic means that they are not encoded in the cell's genetic DNA sequence, but they are passed down alongside the DNA. Remy has confirmed results from previous studies that have shown that psoriasis and PsA patients more often inherit their disease from their father rather than their mother. This suggests that genes passed down by the father carry special features that increase the risk of developing PsA. Remy is investigating whether these features are 'epigenetic' in nature. This is the first time anyone has studied the epigenetics of PsA. The project has received enthusiastic grant support from the Arthritis Research Foundation, the National Psoriasis Foundation in the United States, and the Krembil Foundation. Preliminary results have confirmed that the approach is correct and further studies are currently underway.

How we train Clinicians and Researchers of the Future

The **University of Toronto Psoriatic Arthritis Program** hosts trainees from many levels of medicine and related fields. In particular, Clinical Research Fellows (qualified physicians who have completed their training in rheumatology) come to our Centre to gain expertise in the management of PsA patients and learn clinical research methodology. Many of them also pursue graduate degrees in epidemiology (the "where and when" of diseases) or genetics through the Institute of Medical Science, University of Toronto, as part of this training. These trainees come from across Canada and around the world and go on to set up local institutional clinics modeled on the Psoriatic Arthritis Program here. They continue to work with us in research through our multi-centre research programs. Through our Legacy Campaign as well as granting agencies, we have been able to hire research fellows specifically to train in our Clinic and assist us in carrying out this valuable

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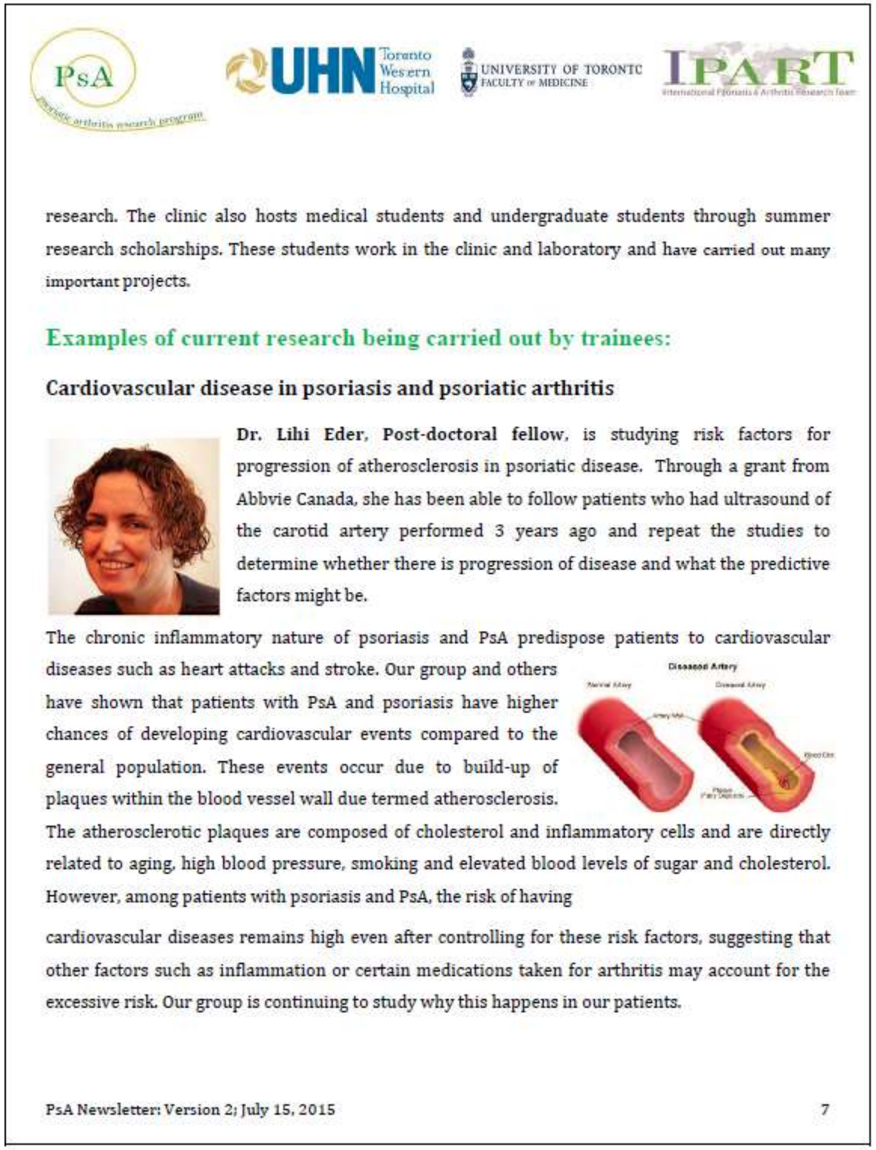
Annual Patient Newsletter at the Toronto Western Hospital (4/7)



PsA psoriatic arthritis research program — UHN Toronto Western Hospital — UNIVERSITY OF TORONTO FACULTY OF MEDICINE — IPART International Psoriasis & Arthritis Research Team

research. The clinic also hosts medical students and undergraduate students through summer research scholarships. These students work in the clinic and laboratory and have carried out many important projects.

Examples of current research being carried out by trainees:

Cardiovascular disease in psoriasis and psoriatic arthritis

Dr. Lihi Eder, Post-doctoral fellow, is studying risk factors for progression of atherosclerosis in psoriatic disease. Through a grant from Abbvie Canada, she has been able to follow patients who had ultrasound of the carotid artery performed 3 years ago and repeat the studies to determine whether there is progression of disease and what the predictive factors might be.

The chronic inflammatory nature of psoriasis and PsA predispose patients to cardiovascular diseases such as heart attacks and stroke. Our group and others have shown that patients with PsA and psoriasis have higher chances of developing cardiovascular events compared to the general population. These events occur due to build-up of plaques within the blood vessel wall due termed atherosclerosis. The atherosclerotic plaques are composed of cholesterol and inflammatory cells and are directly related to aging, high blood pressure, smoking and elevated blood levels of sugar and cholesterol. However, among patients with psoriasis and PsA, the risk of having cardiovascular diseases remains high even after controlling for these risk factors, suggesting that other factors such as inflammation or certain medications taken for arthritis may account for the excessive risk. Our group is continuing to study why this happens in our patients.

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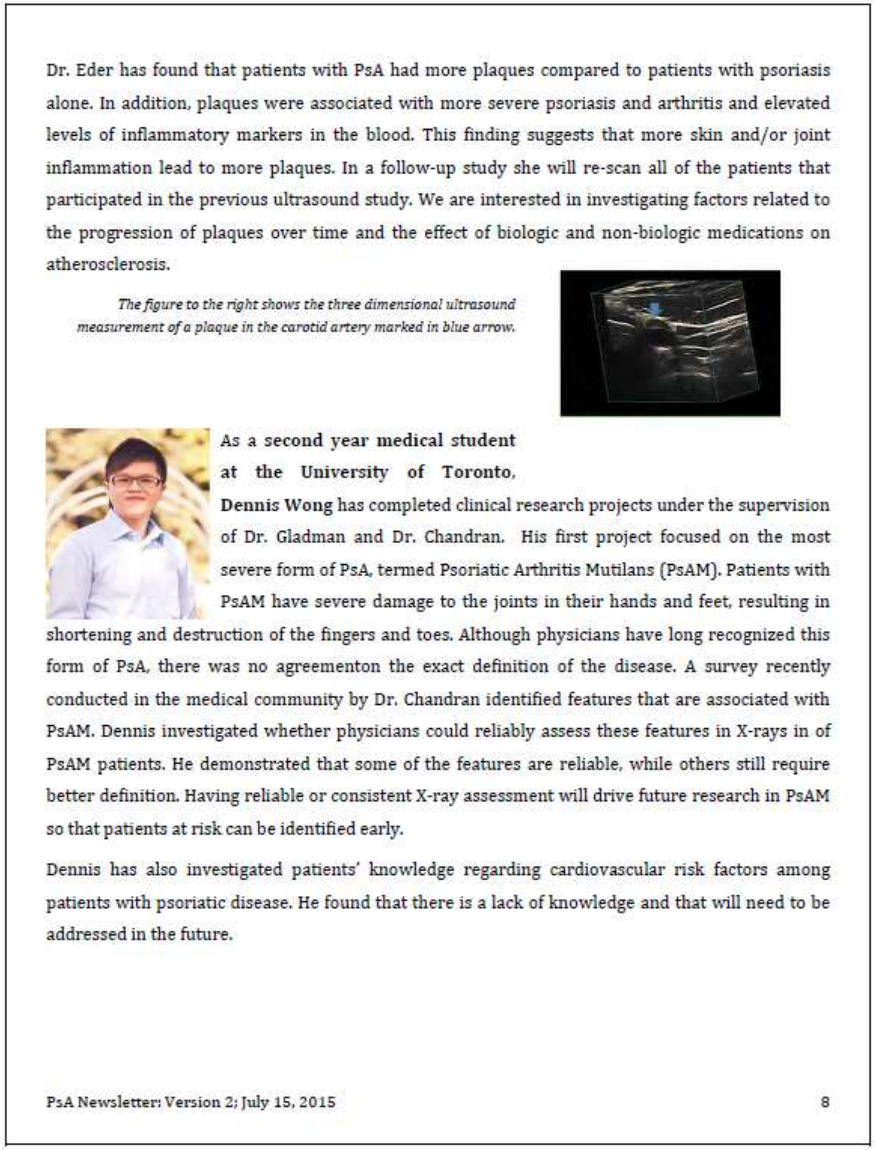

Dr. Eder has found that patients with PsA had more plaques compared to patients with psoriasis alone. In addition, plaques were associated with more severe psoriasis and arthritis and elevated levels of inflammatory markers in the blood. This finding suggests that more skin and/or joint inflammation lead to more plaques. In a follow-up study she will re-scan all of the patients that participated in the previous ultrasound study. We are interested in investigating factors related to the progression of plaques over time and the effect of biologic and non-biologic medications on atherosclerosis.

The figure to the right shows the three dimensional ultrasound measurement of a plaque in the carotid artery marked in blue arrow.

As a **second year medical student at the University of Toronto, Dennis Wong** has completed clinical research projects under the supervision of Dr. Gladman and Dr. Chandran. His first project focused on the most severe form of PsA, termed Psoriatic Arthritis Mutilans (PsAM). Patients with PsAM have severe damage to the joints in their hands and feet, resulting in shortening and destruction of the fingers and toes. Although physicians have long recognized this form of PsA, there was no agreementon the exact definition of the disease. A survey recently conducted in the medical community by Dr. Chandran identified features that are associated with PsAM. Dennis investigated whether physicians could reliably assess these features in X-rays in of PsAM patients. He demonstrated that some of the features are reliable, while others still require better definition. Having reliable or consistent X-ray assessment will drive future research in PsAM so that patients at risk can be identified early.

Dennis has also investigated patients' knowledge regarding cardiovascular risk factors among patients with psoriatic disease. He found that there is a lack of knowledge and that will need to be addressed in the future.

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Annual Patient Newsletter at the Toronto Western Hospital (5/7)

Matthew Got is a second year medical student at the University of Toronto currently working on a clinical research project under the supervision of Dr. Gladman and Dr. Chandran. He is interested in understanding how the various aspects of psoriatic arthritis (PsA) affect patients and their quality of life. His research project focuses on a newly developed composite outcome index called the Psoriatic Arthritis Disease Activity Score (PASDAS). By taking into consideration select clinical measures, patient-reported outcomes, and laboratory values, PASDAS incorporates rates the various domains of PsA to calculate a summary score that aims to reflect the patient's overall level of disease activity. Using a sample of 200 patients, Matthew is currently developing a cut-off value on the 0-10 scale of summary scores in PASDAS that would reflect minimal disease activity. This then becomes a target for treatment followed by rheumatologists.

Under the mentorship of Dr. Gladman and Dr. Chandran, **Ian Tin Yue Wong, University of British Columbia (UBC) medical student**, is currently working on a clinical research project exploring the impact of psoriasis and psoriatic arthritis on sleep quality. Patients completed a series of quality of life assessment questionnaires including a validated sleep quality assessment questionnaire either at their clinic visit or over the telephone. Patients were assessed by a rheumatologist and asked questions regarding disease-related and non-disease related factors that may impact sleep. Some disease-related factors include pain, itchiness, anxiety, depression and severity of psoriasis. Non-disease related factors included smoking and alcohol consumption. To date, we have assessed over 60 psoriasis only (PsC) and 110 psoriatic arthritis (PsA) patients from the IPART research program. Through this study, we aim to compare the prevalence and quality of sleep disturbance in patients with psoriasis without arthritis and PsA, and to identify associated disease-related and demographic factors. By learning about the impact of psoriatic disease on sleep quality, clinicians can better tailor a patient's therapeutic plan according to their respective needs and preserve their quality of life. Although at this time there is no cure for psoriasis and psoriatic arthritis, Ian believes that by better understanding the complications of psoriasis and psoriatic arthritis, we can help serve patients and the psoriatic disease community through research and community awareness of the impact of this disease.

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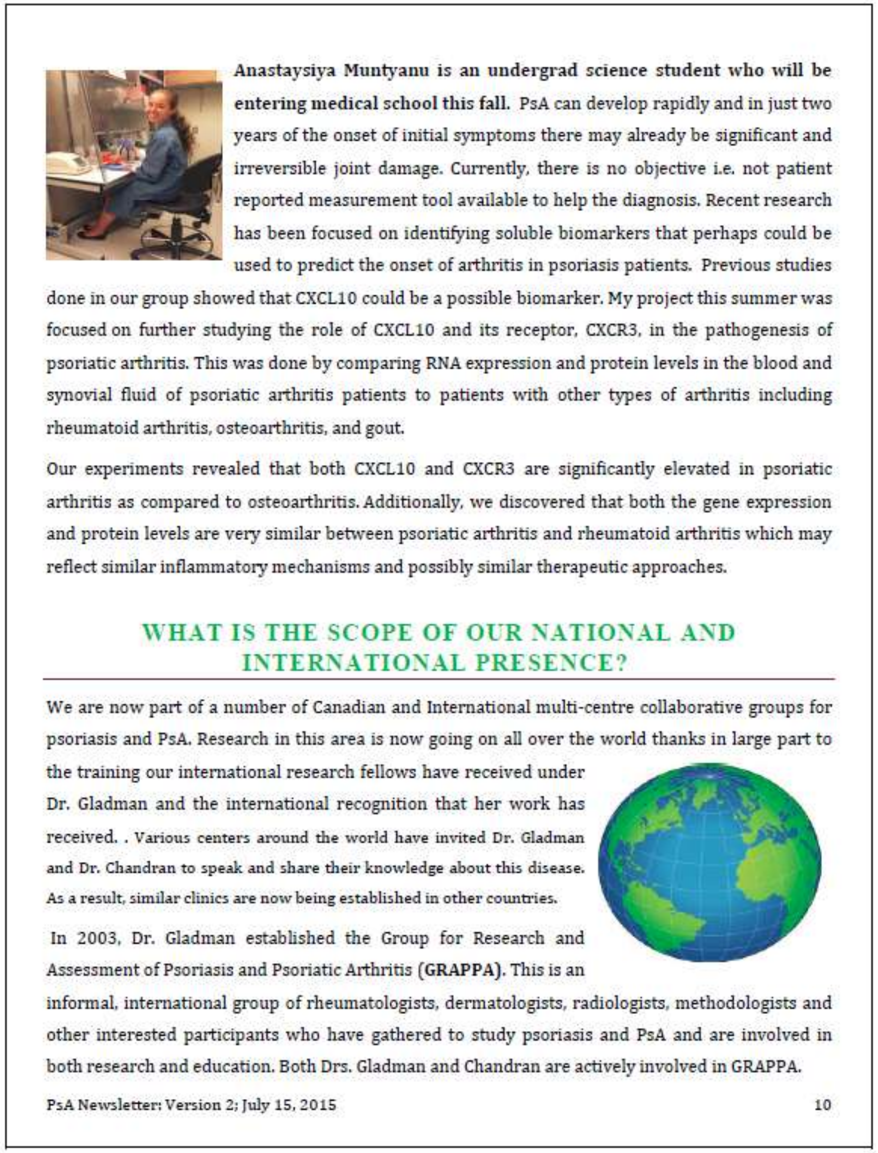

Anastaysiya Muntyanu is an undergrad science student who will be entering medical school this fall. PsA can develop rapidly and in just two years of the onset of initial symptoms there may already be significant and irreversible joint damage. Currently, there is no objective i.e. not patient reported measurement tool available to help the diagnosis. Recent research has been focused on identifying soluble biomarkers that perhaps could be used to predict the onset of arthritis in psoriasis patients. Previous studies done in our group showed that CXCL10 could be a possible biomarker. My project this summer was focused on further studying the role of CXCL10 and its receptor, CXCR3, in the pathogenesis of psoriatic arthritis. This was done by comparing RNA expression and protein levels in the blood and synovial fluid of psoriatic arthritis patients to patients with other types of arthritis including rheumatoid arthritis, osteoarthritis, and gout.

Our experiments revealed that both CXCL10 and CXCR3 are significantly elevated in psoriatic arthritis as compared to osteoarthritis. Additionally, we discovered that both the gene expression and protein levels are very similar between psoriatic arthritis and rheumatoid arthritis which may reflect similar inflammatory mechanisms and possibly similar therapeutic approaches.

WHAT IS THE SCOPE OF OUR NATIONAL AND INTERNATIONAL PRESENCE?

We are now part of a number of Canadian and International multi-centre collaborative groups for psoriasis and PsA. Research in this area is now going on all over the world thanks in large part to the training our international research fellows have received under Dr. Gladman and the international recognition that her work has received. . Various centers around the world have invited Dr. Gladman and Dr. Chandran to speak and share their knowledge about this disease. As a result, similar clinics are now being established in other countries.

In 2003, Dr. Gladman established the Group for Research and Assessment of Psoriasis and Psoriatic Arthritis (**GRAPPA**). This is an informal, international group of rheumatologists, dermatologists, radiologists, methodologists and other interested participants who have gathered to study psoriasis and PsA and are involved in both research and education. Both Drs. Gladman and Chandran are actively involved in GRAPPA.

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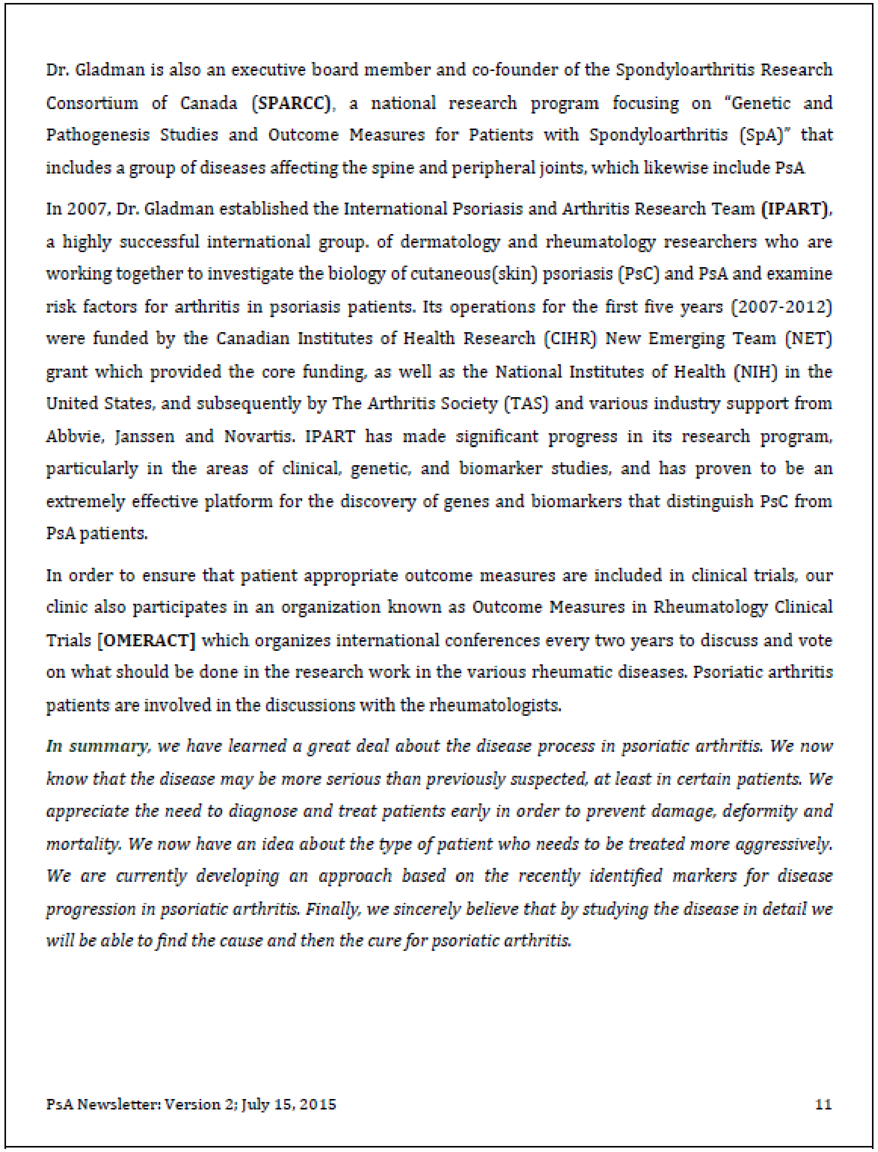
Annual Patient Newsletter at the Toronto Western Hospital (6/7)



Dr. Gladman is also an executive board member and co-founder of the Spondyloarthritis Research Consortium of Canada (**SPARCC**), a national research program focusing on “Genetic and Pathogenesis Studies and Outcome Measures for Patients with Spondyloarthritis (SpA)” that includes a group of diseases affecting the spine and peripheral joints, which likewise include PsA

In 2007, Dr. Gladman established the International Psoriasis and Arthritis Research Team (**IPART**), a highly successful international group. of dermatology and rheumatology researchers who are working together to investigate the biology of cutaneous(skin) psoriasis (PsC) and PsA and examine risk factors for arthritis in psoriasis patients. Its operations for the first five years (2007-2012) were funded by the Canadian Institutes of Health Research (CIHR) New Emerging Team (NET) grant which provided the core funding, as well as the National Institutes of Health (NIH) in the United States, and subsequently by The Arthritis Society (TAS) and various industry support from Abbvie, Janssen and Novartis. IPART has made significant progress in its research program, particularly in the areas of clinical, genetic, and biomarker studies, and has proven to be an extremely effective platform for the discovery of genes and biomarkers that distinguish PsC from PsA patients.

In order to ensure that patient appropriate outcome measures are included in clinical trials, our clinic also participates in an organization known as Outcome Measures in Rheumatology Clinical Trials [**OMERACT**] which organizes international conferences every two years to discuss and vote on what should be done in the research work in the various rheumatic diseases. Psoriatic arthritis patients are involved in the discussions with the rheumatologists.

In summary, we have learned a great deal about the disease process in psoriatic arthritis. We now know that the disease may be more serious than previously suspected, at least in certain patients. We appreciate the need to diagnose and treat patients early in order to prevent damage, deformity and mortality. We now have an idea about the type of patient who needs to be treated more aggressively. We are currently developing an approach based on the recently identified markers for disease progression in psoriatic arthritis. Finally, we sincerely believe that by studying the disease in detail we will be able to find the cause and then the cure for psoriatic arthritis.

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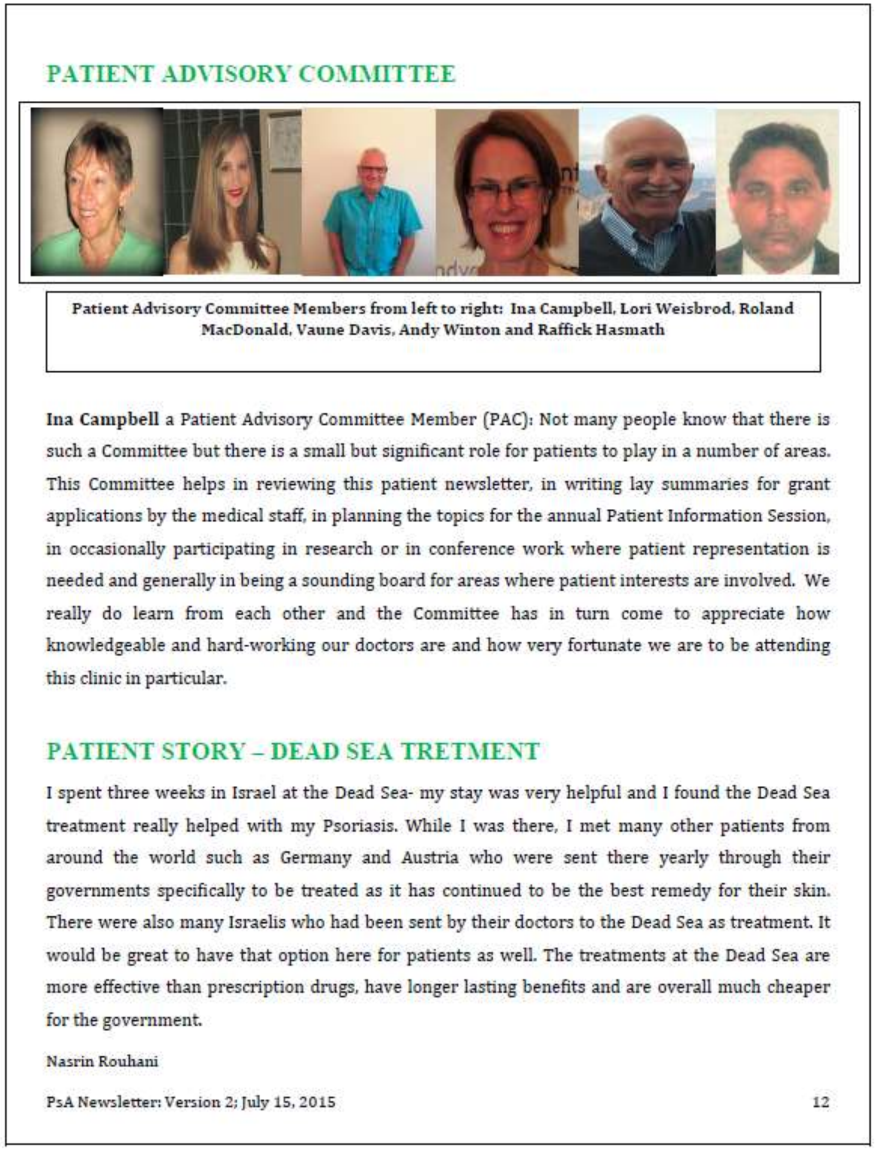

PATIENT ADVISORY COMMITTEE

Patient Advisory Committee Members from left to right: Ina Campbell, Lori Weisbrod, Roland MacDonald, Vaune Davis, Andy Winton and Raffick Hasmath

Ina Campbell a Patient Advisory Committee Member (PAC): Not many people know that there is such a Committee but there is a small but significant role for patients to play in a number of areas. This Committee helps in reviewing this patient newsletter, in writing lay summaries for grant applications by the medical staff, in planning the topics for the annual Patient Information Session, in occasionally participating in research or in conference work where patient representation is needed and generally in being a sounding board for areas where patient interests are involved. We really do learn from each other and the Committee has in turn come to appreciate how knowledgeable and hard-working our doctors are and how very fortunate we are to be attending this clinic in particular.

PATIENT STORY – DEAD SEA TRETMENT

I spent three weeks in Israel at the Dead Sea- my stay was very helpful and I found the Dead Sea treatment really helped with my Psoriasis. While I was there, I met many other patients from around the world such as Germany and Austria who were sent there yearly through their governments specifically to be treated as it has continued to be the best remedy for their skin. There were also many Israelis who had been sent by their doctors to the Dead Sea as treatment. It would be great to have that option here for patients as well. The treatments at the Dead Sea are more effective than prescription drugs, have longer lasting benefits and are overall much cheaper for the government.

Nasrin Rouhani

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Annual Patient Newsletter at the Toronto Western Hospital (7/7)

BOOKS AVAILABLE: Drs. Gladman and Chandran co-authored two books one directed to patients and one to physicians providing general information about psoriatic arthritis.

Psoriatic Arthritis (The Facts)
By Dafna D. Gladman, Vinod Chandran

Psoriatic Arthritis
By Dafna Gladman, Cheryl F. Rosen, Vinod Chandran

VIDEO: A video about the Psoriatic Arthritis Clinic can be found on the following link:

http://www.uhnres.utoronto.ca/studies/cpsrd/

WHAT ARE OUR FUTURE PLANS?

- To continue with our efforts in identifying predictive factors for disease progression, joint damage, poor quality of life, and mortality in psoriatic arthritis.
- To identify genetic factors associated with drug response and sensitivity, particularly with respect to anti-TNF agents and methotrexate.
- To identify biomarkers for disease progression and response to therapy.
- To continue our 'family study' by increasing our multi-case family collection, as well as sibling trios and sibling pairs, so that we have enough data on these families to be able to identify gene(s) responsible for susceptibility to psoriatic arthritis.

A Special Thank You to Our Supporters

Menkes Family Plaque unveiling May 28, 2014

This Clinic owes a huge debt to all who have been treated and voluntarily agreed to participate in our research studies here. Without you our discoveries about this disease and the treatments now available would not necessarily have been possible. Also we are immensely grateful to our financial donors, big or small, who support our work as well. Without you, we could not be doing this work

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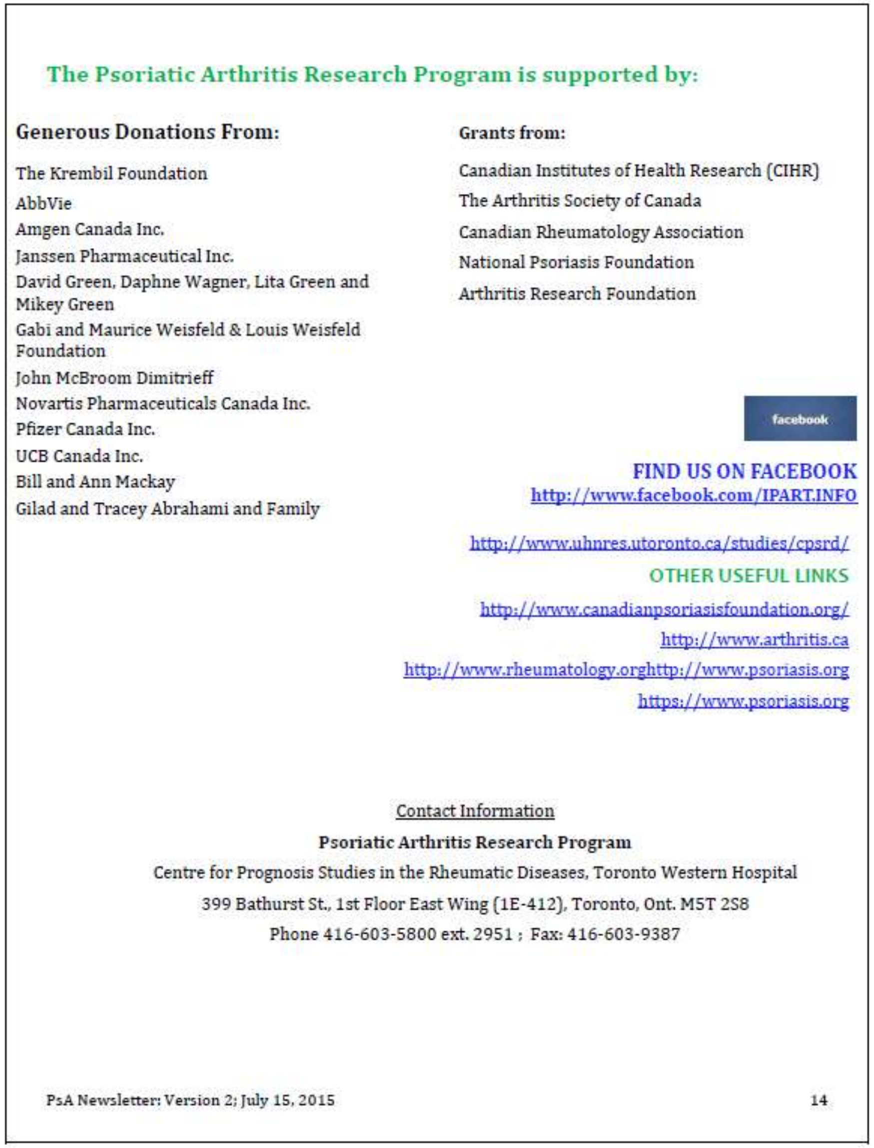

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The Krembil Foundation
AbbVie
Amgen Canada Inc.
Janssen Pharmaceutical Inc.
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Pfizer Canada Inc.
UCB Canada Inc.
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The Arthritis Society of Canada
Canadian Rheumatology Association
National Psoriasis Foundation
Arthritis Research Foundation

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http://www.rheumatology.orghttp://www.psoriasis.org
https://www.psoriasis.org

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Note: The newsletter was reprinted with permission from Dr Dafna Gladman

Table of abbreviations (1/2)

Acronym	Definition	Acronym	Definition
ACR20	American College of Rheumatology Score	**ESR**	Erythrocyte Sedimentation Rate Test
AIDS	Acquired Immune Deficiency Syndrome	**EULAR**	European League Against Rheumatism
ASQoL	Ankylosing spondylitis quality of life	**GP**	General Practitioner
BRASS	Brigham and Women's Rheumatoid Arthritis Sequential Study	**GRAPPA**	Group for Research and Assessment of Psoriasis and Psoriatic Arthritis
BSA	Body Surface Area	**HAQ**	Health Assessment Questionnaire
CASPAR	Classification Criteria for Psoriatic Arthritis	**HCP**	Healthcare Practitioner
CATCH	The Canadian Early Arthritis Cohort	**HIV**	Human Immunodeficiency Virus
CCIM	Comprehensive Centre for Inflammation Medicine	**HMO**	Health Maintenance Organisation
CME	Continual Medical Education	**IV**	Intravenous
COPPAR	Brigham Cohort for Psoriasis and Psoriatic Arthritis	**KOL**	Key Opinion Leader
CPDAI	Composite Psoriatic Disease Activity Index	**KPI**	Key Performance Indicator
CRP	C–Reactive Protein	**MDA**	Minimal Disease Activity
CV	Cardio Vascular	**MDT**	Multi–Disciplinary Team
DAPSA	Disease Activity Index for Psoriatic Arthritis	**MSK**	Musculoskeletal
DAS 28	Disease Activity Score	**NICE**	National Institute for Health and Care Excellence
DFG	German Research Foundation	**NSAIDs**	Non–Steroidal Anti–Inflammatory Drugs
DLQI	Dermatology Quality of Life	**PASDAS**	Psoriatic Arthritis Disease Activity Score
DMARDs	Disease Modifying Anti–Rheumatic Drugs	**PASE**	Psoriatic Arthritis Screening Evaluation
EARP	Early Arthritis for Psoriatic patients	**PASI**	Psoriasis Area Severity Index
EMR	Electronic Medical Record system	**PASQ**	Psoriatic Arthritis Screening Questionnaire
EQ–5D	European Quality of Life 5 Dimensions	**PEST**	Psoriatic Epidemiology Screening Tool

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Key findings

Table of abbreviations (2/2)

Acronym	Definition	Acronym	Definition
PDE4	Phosphodiesterase 4	**SPARCC**	Spondyloarthritis Research Consortium of Canada
PsA	Psoriatic Arthritis	**TAP**	The Arthritis Programme
PsARC	Psoriatic Arthritic Response Criteria	**TB**	Tuberculosis
PWH	Prince of Wales Hospital	**TNF**	Tumour Necrosis Factors
QoL	Quality of Life	**ToPAS**	Toronto Psoriatic Arthritis Patient Screen
RA	Rheumatoid Arthritis	**ToPAS 2**	Toronto Psoriatic Arthritis Patient Screen 2
SARM	Skin and Related Musculoskeletal Diseases	**TWH**	Toronto Western Hospital
SI	Sacroiliac	**VAS**	Visual Analogue Scale
SOPC	Specialty Out–Patient Clinic		

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Key findings

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