KPMG
cutting through complexity

Optimising the Patient Pathway:

Perspectives on the Principles of High-Quality Care in Inflammatory Bowel Disease

Findings from Australia, Japan and South Korea

GBL/HUG/1015/0697

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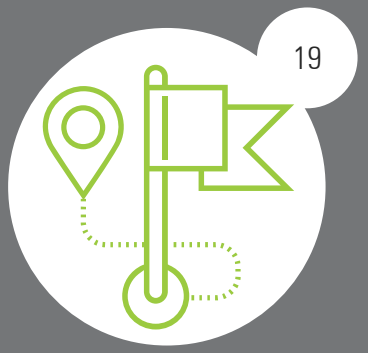
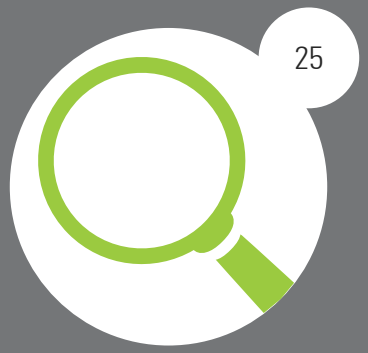




Glossary

ASC	Acute severe colitis
CT	Computed tomography
ED	Emergency department
EMR	Electronic medical record
Europe & Can	Europe and Canada
FTE	Full-time employee
GI	Gastrointestinal
GP	General practitioner/primary care physician
HCP	Healthcare professional
IBD	Inflammatory bowel disease
IBS	Irritable bowel syndrome
IT	Information technology
IV	Intravenous
MDT	Multi-disciplinary team
ME	Middle East countries: Dubai, Kuwait, Qatar and Saudi Arabia
MRI	Magnetic resonance imaging
RAH	Royal Adelaide Hospital
SC	Subcutaneous
SMS	Short message service (text message)
TUSMC	Toho University Sakura Medical Centre
TB	Tuberculosis
UC	Ulcerative colitis
YSUH	Yonsei Severance University Hospital

EXECUTIVE SUMMARY

EXECUTIVE SUMMARY

Several sources were used to meet the objectives of this project

BUILD ON THEMES IDENTIFIED IN PREVIOUS REPORT FROM EIGHT CENTRES ACROSS EUROPE & CANADA

Build on themes developed during Vita 1

- INTEGRATION OF CARE
- PATIENT CENTRICITY
- AGE APPROPRIATE CARE
- PSYCHOLOGICAL SUPPORT
- MULTIDISCIPLINARY APPROACH
- REGIONAL NETWORKS
- EDUCATIONAL FOCUS
- TEAM MORALE AND CULTURE
- RESEARCH AND CLINICAL COLLABORATION
- INNOVATIVE MODELS
- TECHNOLOGY

VISIT TWO SITES EACH IN AUSTRALIA, JAPAN & SOUTH KOREA

Visit sites in Australia, Japan and South Korea

Royal Adelaide Hospital

MAP THE PATIENT PATHWAY & RELEVANT INTERVENTIONS

Inflexion points along the patient pathway

PROJECT OBJECTIVES

- Building on our previous work, develop a **thorough understanding of the IBD patient pathway** in different areas of the world
- Reflect **specific findings** of the IBD patient pathway from sites in Australia, Japan and South Korea
- Identify examples of **successful interventions** along the IBD patient pathway

During our first project in Western Europe and Canada we developed three main themes of great care, which contained several sub-themes

PATIENT-CENTRED CARE

- INTEGRATION OF CARE
- PATIENT CENTRICITY
- AGE APPROPRIATE CARE
- PSYCHOLOGICAL SUPPORT

COLLABORATIVE APPROACH

- MULTI-DISCIPLINARY APPROACH
- REGIONAL NETWORKS
- EDUCATIONAL FOCUS
- TEAM MORALE AND CULTURE

FORWARD-THINKING MINDSET

- RESEARCH AND CLINICAL COLLABORATION
- INNOVATIVE MODELS
- TECHNOLOGY

We have now added to these themes based on our wider experiences from additional centres in Australia, Japan and South Korea

Sub-themes refined based on centre visits in 2015

PATIENT-CENTRED CARE

- INTEGRATION OF CARE
- AGE-APPROPRIATE CARE
- PSYCHOLOGICAL SUPPORT
- PATIENT CENTRICITY
- CULTURALLY APPROPRIATE CARE

COLLABORATIVE APPROACH

- MULTI-DISCIPLINARY APPROACH
- REGIONAL NETWORKS
- EDUCATIONAL FOCUS
- TEAM MORALE AND CULTURE
- PEER -TO-PEER CHALLENGE

FORWARD-THINKING MINDSET

- RESEARCH AND CLINICAL COLLABORATION
- INNOVATIVE MODELS
- TECHNOLOGY FOR PATIENTS
- TECHNOLOGY FOR CENTRES

We have refined our insights on patient-centred care, in particular in terms of the role of culture and how it can influence patient centricity and psychological support

PATIENT-CENTRED CARE

PATIENT CENTRICITY

- Great care has to go beyond being patient-centred, and **truly empower** patients to be active partners in their disease management
- However, the **degree to which patients want to influence decisions** about their care does vary depending on culture
- For example, Australian patients tend to want to be involved in treatment decisions whereas Japanese patients may want their doctor to **make decisions on their behalf**
  - Patient centricity in Japan is, however, demonstrated by their use of **publications that rank the quality of the care** delivered by specialists to enable patients to select the best doctors

CULTURALLY APPROPRIATE CARE

- Perhaps most notably in Japan, we recognised that great care is not only age appropriate but also **culturally appropriate**
- Culture can have a **strong influence** on the expected roles of the doctors, nurses and other IBD team members
- Patient behaviours are equally influenced by **cultural backgrounds**, in particular the **willingness to share symptoms openly** with a treating doctor and the acceptance towards psychological care
- This has implications for both **patient empowerment and psychological support**

PSYCHOLOGICAL SUPPORT

- Addressing the psychological aspects of IBD care remains a key theme of good care
- Culturally, **psychological support can be very hard to accept**
- In South Korea, the **stigma of accepting psychological support** prevents many patients from formally engaging with this aspect of care
- This means that it becomes even more important that the IBD team address **any psychological issues** as part of their somatic treatment interactions with patients

We collected additional insights on the theme of collaborative approach including MDT interactions and the culture of peer-to-peer challenge within the IBD team

COLLABORATIVE APPROACH

TEAM MORALE AND CULTURE

- Team morale stems from a **culture of mutual respect and collaboration** between colleagues
- Different strategies have been observed when it comes to **facilitating collaboration between different specialists**
- Of key relevance is to create an ambience of trust that enables specialists to have **regular *ad-hoc* consultations** with each other
- However, the degree of **formality when interacting with colleagues varies** between countries, *e.g.:*
  - Japanese and South Korean specialists prefer to be formally consulted and invited for multi-disciplinary team meetings, whereas Australian doctors adopt a more informal approach

PEER-TO-PEER CHALLENGE

- A strong team morale and collaborative culture enables doctors and nurses to provide **respectful peer-to-peer challenge** to their colleagues
- Furthermore **it guarantees a high standard of care** and enables a team to go through a **continuous learning** and quality review process
- Peer-to-peer challenge is considered a **key element in delivering patient-centric care** across different countries, but differences between countries can be observed
- For example, in South Korea many hospitals have a **formalised peer-review process** that doctors consider a key reason for their success in becoming a leading IBD centre
- However in Japan and Australia peer-to-peer review is **less formalised** and often takes place spontaneously

We added further reflections on the theme of forward-thinking mindset and focused on how technology can be used by patients and doctors to improve the care experience

FORWARD THINKING MINDSET

TECHNOLOGY FOR PATIENTS

- Technology can play an **important role in improving patient experience**. For example many centres report improved patient satisfaction when technology enables the patient to have **greater autonomy** in scheduling their appointments via an app, website or dedicated telephone line
- Patients also report **less anxiety** when they can refer to '**frequently asked questions**' webpages, or an app that answers their most urgent questions and discusses common symptoms
- Patients' attitudes towards the use of technology **vary greatly by country**
  - In South Korea patients show a high technology literacy and **actively demand** technological applications
  - Japanese patients tend to **prefer direct interaction** with doctors and as a result technology for patients has not been rolled out widely

TECHNOLOGY FOR CENTRES

- For centres and the IBD team members, the use of technology can offer a great opportunity to improve both the **quality and efficiency of care**
- By using technology to observe the **symptoms and biomarkers of stable patients**, the IBD team can pick up changes that may indicate a flare and hence adjust treatment plans rapidly
- By using technology to **answer frequently asked questions from patients**, the need for face-to-face appointments for stable patients can be reduced
- Doctors in all countries are **very receptive to the use of technology** but some have concerns that patient comfort with using technology varies greatly
- We note that **not all centres have IT systems** that can support more advanced technological solutions; more investment may be required

We focused on the patient pathway to identify the most important determinants of high-quality care

FIRST SYMPTOMS

FIRST SYMPTOMS

- **Patients are aware of IBD symptoms** and seek medical advice
- Community clinicians recognise **'red flag' symptoms** and refer promptly for specialist advice

INITIATION OF TREATMENT

- Initial treatment should be **goal and time-bound**, with clear criteria for moving to another therapy option
- **Early recognition of when therapy is not working** and moving swiftly to the next most appropriate treatment
- **Early access to biologics** for appropriate patients
- Early identification of **psychosocial issues** that may impede compliance with medical therapy
- Significant investment in **patient education** in the early phases of treatment

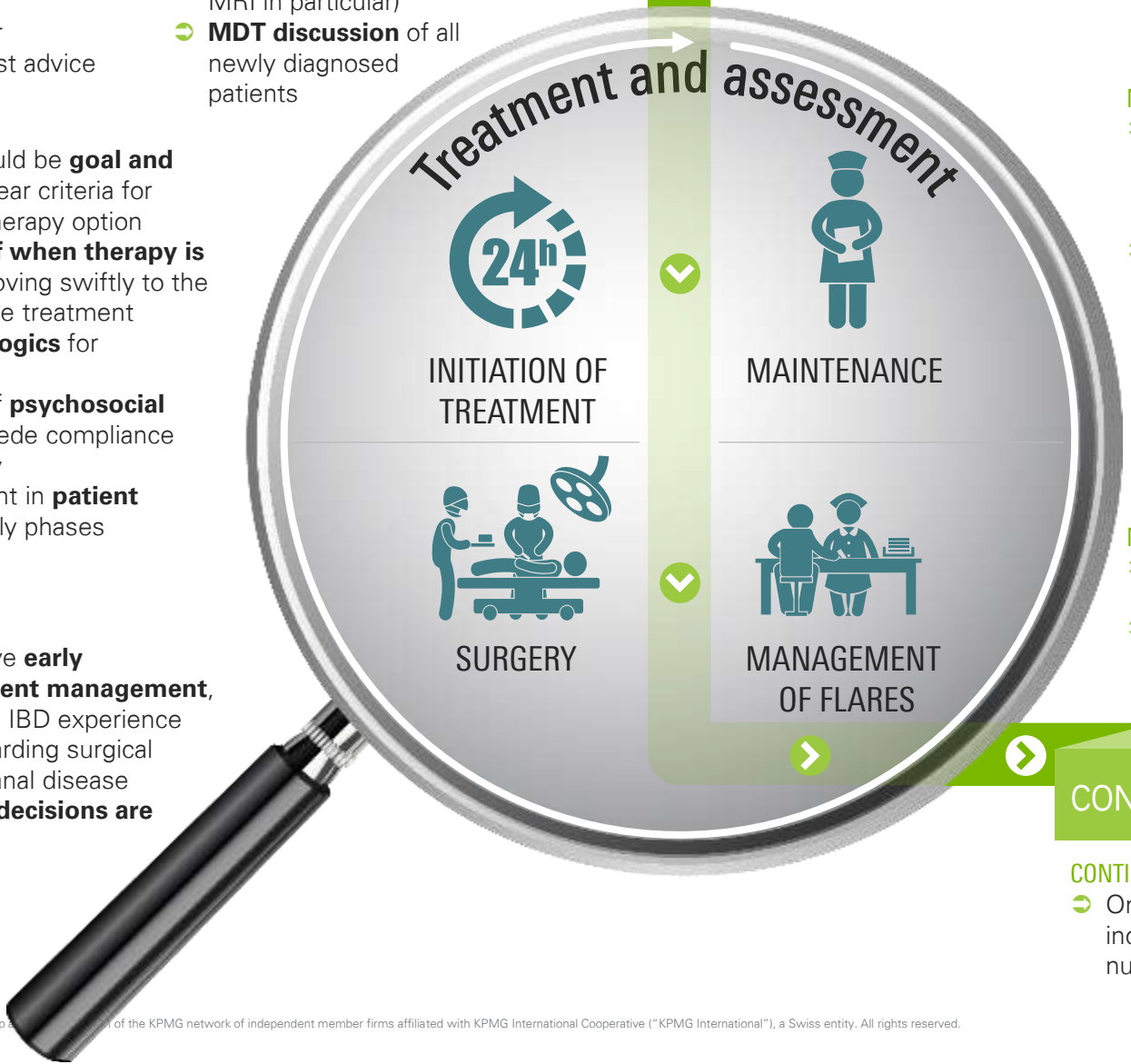
SURGERY

- Surgeons should have **early involvement in patient management**, and ideally extensive IBD experience
- **Early decisions** regarding surgical interventions in perianal disease
- **Ideally, all surgical decisions are discussed in an MDT setting**

DIAGNOSIS

DIAGNOSIS

- Diagnosis of IBD is made **rapidly and accurately**
- Fast access to **required diagnostics** (endoscopy and small bowel MRI in particular)
- **MDT discussion** of all newly diagnosed patients



MAINTENANCE

- **Easy and rapid access to IBD centre**, often through **IBD nurses** as a single point of contact supported by IBD specialists
- **Regular follow-up** for stable patients using disease activity indices to confirm disease status

MANAGEMENT OF FLARES

- Rapid **recognition of deterioration of patient's condition**
- **Rapid access** for **flare patients to IBD expertise**, often through **IBD nurses** including remote support

CONTINUOUS PATIENT CARE

CONTINUOUS PATIENT CARE

- Ongoing **multi-disciplinary support** including psychology, dietetics and stoma nursing as required

Our interviews highlighted some of the key steps for a centre that undertakes the journey towards high-quality IBD care and beyond

USE STEP-WISE INTERVENTIONS

START

ESTABLISH A STRONG IBD TEAM

- Ensure that core team members across several specialities (gastroenterology and surgery, with the support of imaging and pathology) have specialist IBD experience and training

Yonsei Severance Hospital built its reputation by training a team of specialists to offer dedicated IBD care, to a standard that exceeded what was then considered to be the norm

ENSURE PATIENT FLOW FROM COMMUNITY REFERRALS

- Work with the community to ensure a steady flow of correct IBD referrals

Professor Suzuki of Toho University Hospital built the reputation of his centre from scratch, through regular interaction with local doctors, educating them about IBD symptoms and referral criteria

IMPROVE DELIVERY OF CARE THROUGH REGULAR AND OBJECTIVE PEER REVIEW

- Introduce systems to ensure regular, objective peer review, to continuously improve the delivery of IBD care to patients

St Vincent's Hospital fosters a culture of peer challenge and review, with a range of opinions shared and debated at the MDT meetings

HIRE AND TRAIN SPECIALISED IBD NURSING PERSONNEL

- Either hire or train dedicated nurses who are responsible for IBD patient education, care coordination and *ad-hoc* patient support

By employing a dedicated IBD nurse, Royal Adelaide Hospital improved both patient satisfaction and service efficacy

INTEGRATE RESEARCH INTO CENTRE ACTIVITIES AND COOPERATE WITH OTHER IBD CENTRES ON RESEARCH

- Build a patient and imaging database that allows the centre to conduct research and work with other international centres on improvement of care research projects

Fukuoka University Hospital conducts research in all clinical IBD fields and in collaboration with study groups across Japan. It also cooperates with other hospitals on research, and on care improvement projects

AND BEYOND!

- Foster a culture of continuous improvement

Asan Medical Centre built an extensive patient and imaging database which allowed them to conduct extensive research, and furthermore to train junior doctors by using past examples of challenging cases

For each stage of the IBD pathway we observed unique features for all the countries we visited (1/2)

FIRST SYMPTOMS

BOWEL DISEASE AWARENESS CAMPAIGNS

- Patients are well aware of bowel diseases and symptoms

DIRECT ACCESS TO SPECIALISTS

- Patients can self-refer directly to specialists and often choose doctors by reputation
- Patients usually see a primary care physician before a referral to secondary care

RED FLAG EDUCATION FOR GPs[a]

- Leading IBD centres have recently introduced a list of 'red flags' that should prompt GPs to suspect IBD and refer the patient to an IBD specialist

LIMITED PATIENT AND GP EDUCATION

- Patients have very little symptom and general health awareness, GPs also lack awareness; a combination of both factors often leads to delayed referrals

DIAGNOSIS

INTESTINAL TUBERCULOSIS SCREENING

- Due to the high prevalence of intestinal TB, patients are routinely screened for TB to inform treatment choice
- In the majority of Gulf countries intestinal TB screening is part of the IBD treatment routine
- Not part of routine care unless TB is suspected

INITIATION OF TREATMENT

TREATMENT WITH LEUKOCYTAPHERESIS

- Many patients treated with leukocytapherisis
- This treatment is not widely available

Australia · Japan · South Korea · Europe & Canada · Dubai, Kuwait, Qatar & Saudi Arabia

(a) For a study that identified early 'red flags' for Crohn's disease, see: Danese S, Fiorino G, et al. Development of Red Flags Index for Early Referral of Adults with Symptoms and Signs Suggestive of Crohn's Disease: An IOIBD Initiative, JCC, 2015

For each stage of the IBD pathway we observed unique features for all the countries we visited (2/2)

TREATMENT AND ASSESSMENT

MAINTENANCE

ACCESS TO BIOLOGICS

- Most patients can only receive treatment with biologics once they have received 3 months of conventional therapy and failed on this treatment
- Patients can only receive a biologic once they have reached the required Mayo CDAI score threshold of 2 or higher
- Few restrictions on biologic use

DOCTOR/PATIENT COMMUNICATION CHANNELS

- Doctors, nurses and patients routinely interact using digital communications and applications, and technological media are strongly integrated in patient education
- Telemedicine is growing fast but still accounts for a relatively small proportion of patient interaction
- Patients tend to prefer face-to-face interaction and rarely use digital communication channels

CONTINUOUS PATIENT CARE

CONTINUOUS PATIENT CARE

CULTURAL ACCEPTANCE OF PSYCHOLOGICAL THERAPIES

- Patients often refuse to accept psychological care due to the associated perceived stigma
- Psychological care is more widely accepted by patients
- Traditional family structures play an important role in providing psychological support systems

OTHER UNIQUE FEATURES FROM ACROSS THE PATIENT PATHWAY

TECHNOLOGY

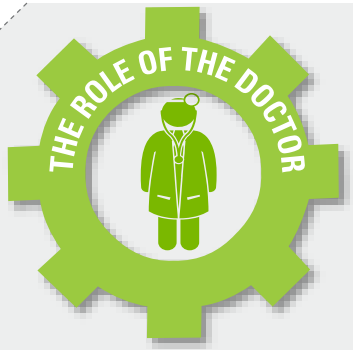
EXTENT OF DIGITAL RECORD KEEPING

- Centres have advanced EMR systems
- Centres rely on hand-written patient notes supported by hospital clinical information systems
  - Varying degrees of digital record keeping
- Often a combination of EMR (*e.g.* laboratory test results) and paper files

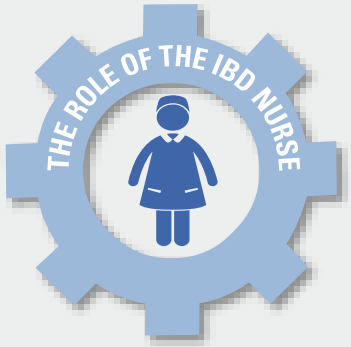
Australia | Japan | South Korea | Europe & Canada | Dubai, Kuwait, Qatar & Saudi Arabia

We have also observed geographical differences in the roles of doctors and nurses, and the behaviour of patients in their care

Where we observed differences



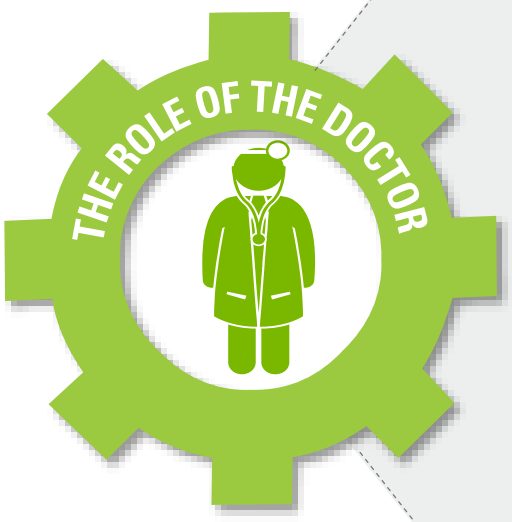
- Degree of hierarchy and formality of doctors
- Degree of specialisation of doctors leading IBD care



- Degree of autonomy in delivery of IBD treatment
- Degree of specialisation in IBD care

- Level of technology literacy and attitudes to remote care
- Attitudes towards psychological interventions

Local cultural differences may play a part in the observed variations in the role of the doctor



- IBD may be managed by generalist gastroenterologists, especially in rural areas
- Doctors are relatively informal in their interactions with patients
- Almost all doctors work in both the private and public sector, and tend to maintain their generalist gastroenterology practice in addition to providing IBD care in a public hospital

- Doctors lead all IBD care and tend to make all clinical decisions
- The hospital team is strongly hierarchical
- Very few senior female doctors

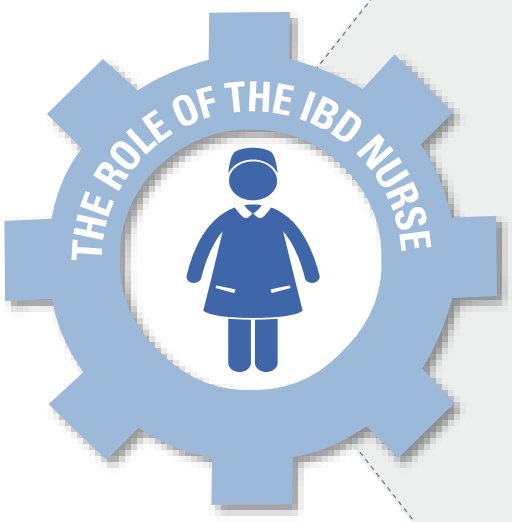
- Doctors have a strong desire to be viewed as high-quality care providers
- This is in part driven by 'doctor shopping' activities, whereby patients approach several different doctors before deciding which one they would like to have as their practitioner

- Doctors tend to have a friendly and informal relationship with patients
- Publically funded systems often do not have enough senior doctor resource to see all patients, which is one contributing factor in the development of extended nursing roles

- Doctors are well respected and tend to have a relatively formal relationship with patients, especially where a female patient is receiving treatment from a male doctor
- Whilst patients respect doctors, they often seek alternative treatment options and either 'doctor shop' or seek treatment abroad if they can afford to do so

Australia | Japan | South Korea | Europe & Canada | Dubai, Kuwait, Qatar & Saudi Arabia

IBD nurse roles vary across the world in terms of their autonomy and degree of IBD specialisation



- Have both IBD specialist nurses and IBD nurse practitioners:
  - Both play an active role in patient treatment, care coordination and education
  - Medicare billing restrictions have limited the expansion of their role (only formally designated nurse practitioners can bill to Medicare)

- General gastroenterology nurses (not IBD specialised) support the clinics with:
  - Informal roles (*e.g.* patient counselling)
  - Some care coordination activities
- Play a limited or no role in patient treatment (*e.g.* prescribe drugs)

- Dedicated IBD nurses in place:
  - Play an active educational and pastoral role
  - Capture patient data and coordinate treatment appointments

- Varies by country, but on the whole IBD nurses have a high degree of specialisation and autonomy

- Varies by country. In some countries (*e.g.* Kuwait), general gastroenterology nurses offer support to patients and to the IBD specialist, whereas in other countries (*e.g.* Dubai), specialist IBD nurses are in place and have a high degree of specialisation and autonomy

Australia | Japan | South Korea | Europe & Canada | Dubai, Kuwait, Qatar & Saudi Arabia

As with the role of the doctors, local culture may play a part in observed variations in patient behaviour

- Patients in rural areas:
  - May not seek advice regularly, if at all
  - May present with advanced disease
  - May prefer more radical interventions to maintain their independence; *e.g.* earlier ileostomy or colostomy as a more definitive treatment

- Patients often use ranking guides to seek out top physicians
- Prefer face-to-face appointments, often more frequently than observed in other countries
- Female patients are often hesitant to share their symptoms with male doctors

- Highly comfortable with using technology independently to engage remotely with clinics
- Often reluctant to accept psychological interventions due to perceptions of stigma
- Patients may 'doctor shop' which can lead to conflicting advice

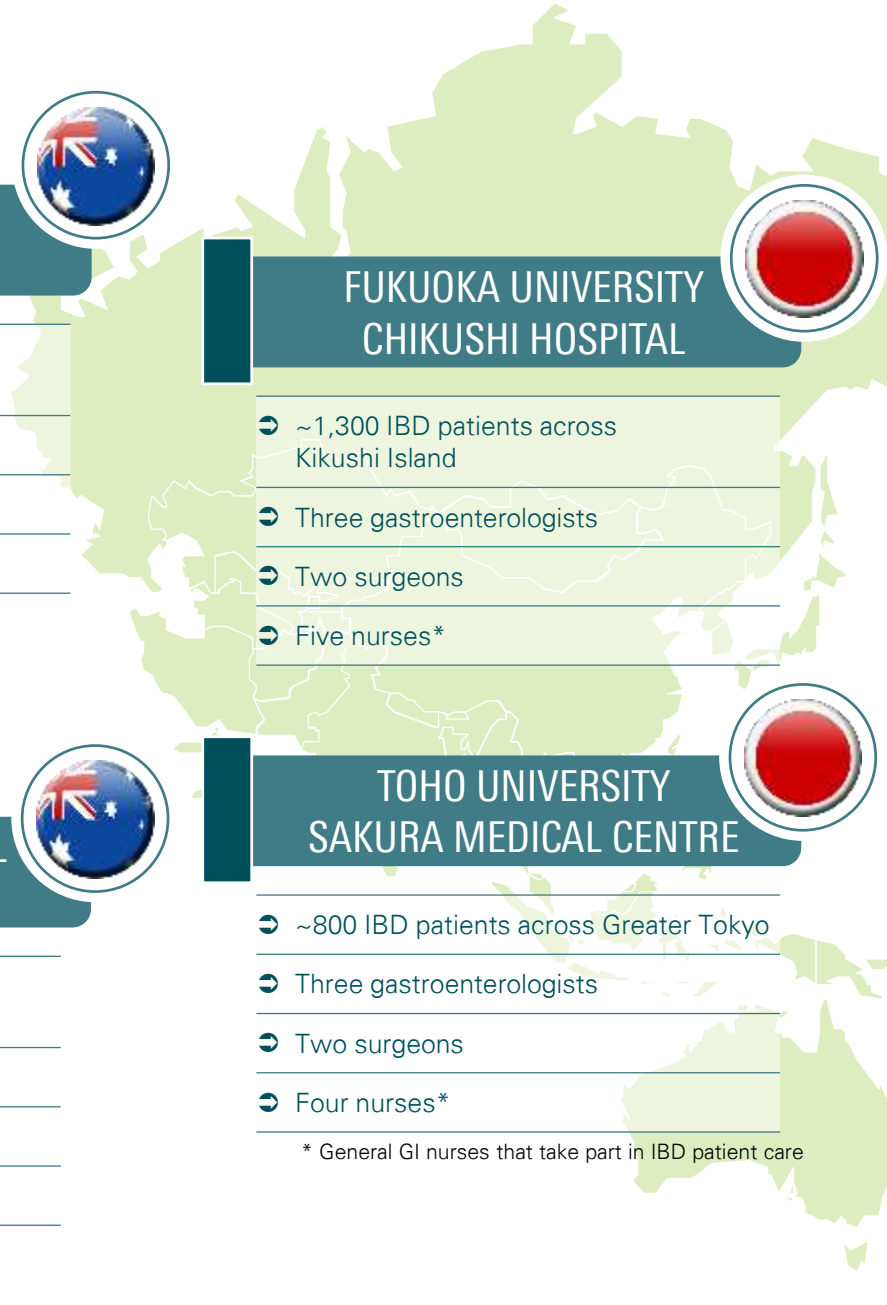
- Patients have relatively low technical literacy, but are very ready to educate themselves and then take full ownership of their treatment regime
- Patients are often less informed about what bowel habits constitute 'normal'. As a result, they often seek treatment late

- Patients tend to have lower levels of general education and healthcare awareness. This is especially true of those over 40. As a consequence, they seek treatment late and take limited ownership of their treatment regime
- Due to the traditionally high level of gender segregation in public life, many female patients find it challenging to report their symptoms to a male doctor

Australia | Japan | South Korea | Europe & Canada | Dubai, Kuwait, Qatar & Saudi Arabia

OUR APPROACH

In this report we capture findings from six IBD centres across Australia, Japan and South Korea



ROYAL ADELAIDE HOSPITAL

- ~800 IBD patients in Adelaide and throughout South Australia
- Five gastroenterologists
- Two surgeons
- Three IBD nurses

FUKUOKA UNIVERSITY CHIKUSHI HOSPITAL

- ~1,300 IBD patients across Kikushi Island
- Three gastroenterologists
- Two surgeons
- Five nurses*

ASAN MEDICAL CENTRE

- ~5,700 IBD patients in Seoul and throughout South Korea
- Five gastroenterologists
- Three surgeons
- Two IBD nurses

ST VINCENT'S HOSPITAL MELBOURNE

- ~2,000 IBD patients in Melbourne and suburbs
- Five gastroenterologists
- Five surgeons
- Three IBD nurses

TOHO UNIVERSITY SAKURA MEDICAL CENTRE

- ~800 IBD patients across Greater Tokyo
- Three gastroenterologists
- Two surgeons
- Four nurses*

* General GI nurses that take part in IBD patient care

YONSEI SEVERANCE UNIVERSITY HOSPITAL

- ~1,300 IBD patients in the Greater Seoul area
- Three gastroenterologists
- Two surgeons
- One IBD nurse

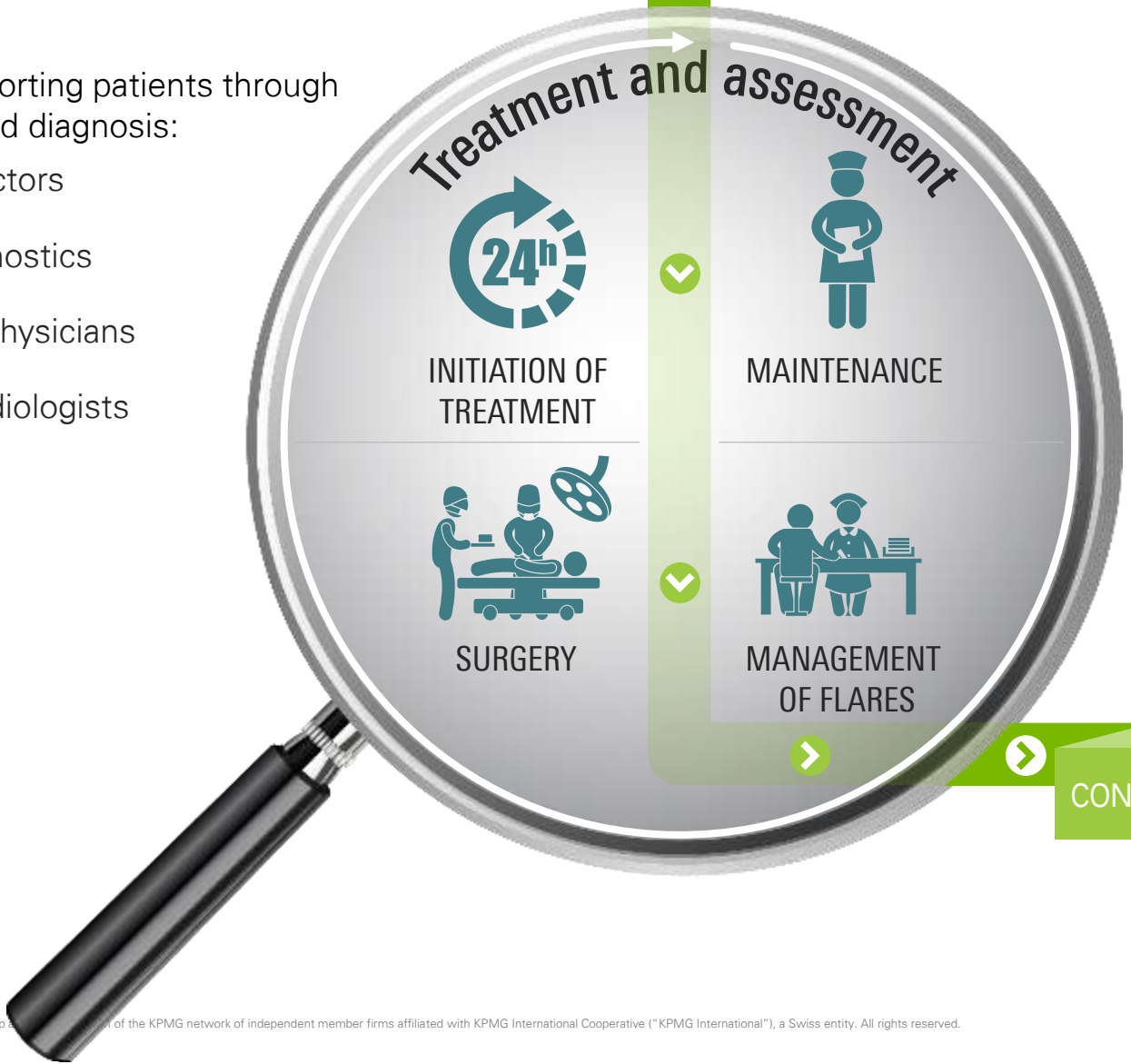
FIRST SYMPTOMS

DIAGNOSIS

We spoke with staff members who are involved in all steps of the IBD patient pathway…

Practitioners supporting patients through first symptoms and diagnosis:

- Community doctors
- Pathology/diagnostics
- IBD-specialist physicians
- GI-specialist radiologists
- Surgeons



Practitioners supporting continuous patient care:

- Specialist nurses
- Pathology/diagnostics
- IBD-specialist physicians
- GI-specialist radiologists
- Researchers

CONTINUOUS PATIENT CARE

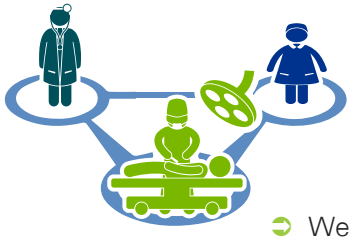
…and observed their interactions, collecting centre data where possible

What did we observe?

PROCESSES

- We wanted to observe the day-to-day activities of the members of the IBD teams we visited

TEAM INTERACTION



- We aimed to assess the level of interaction between the members of the IBD team

PREMISES

- We wanted to understand the patient experience and asked our hosts to walk us around the IBD services on a typical patient journey
- One of our goals was to understand whether co-locations of services benefited from a multi-disciplinary approach, and if so, then in what way

What data did we collect?

PROCESSES

- When centres described innovative pathways and medical procedures, we asked to be given hard copies to fully understand them, and how they educated staff and patients

EDUCATIONAL MATERIAL

- To understand the patient experience, we asked the centres to share any educational material that they give their patients, and their families and carers

FORMS FROM IBD DATABASES

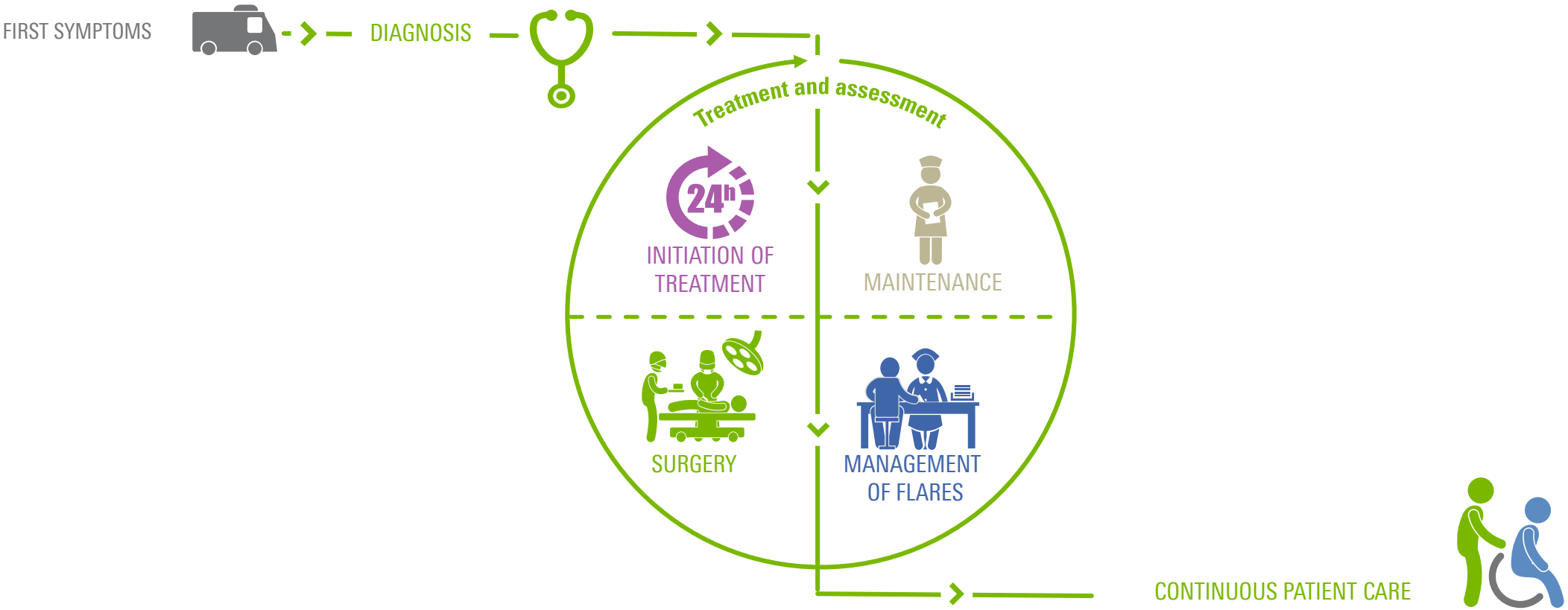
- Some centres are currently setting up IBD databases to record data on their patient cohort. Where available, we requested details of the type of information recorded, and how it was used

DETAILS OF PATIENT NUMBERS

- We could only estimate patient volumes as many centres did not collect operational data which distinguished an IBD diagnosis from GI pathologies

We then consolidated our findings from the six centres for each stage of the patient pathway (1/2)

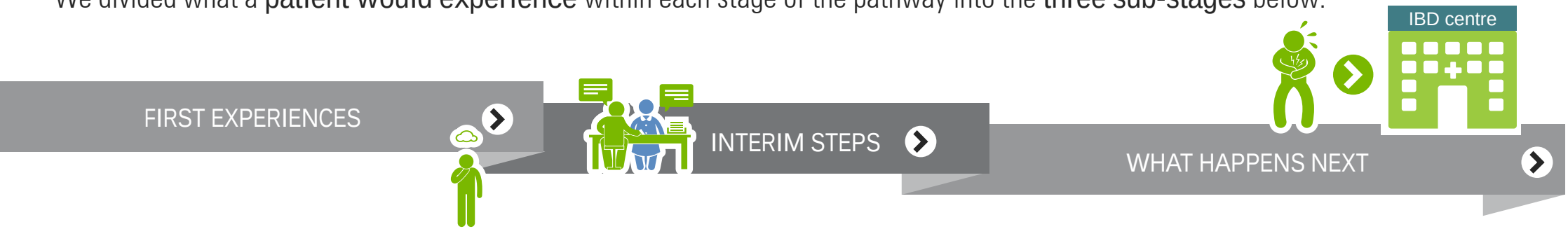
Phase of patient pathway: We divided our findings by each individual step on the patient pathway



We then consolidated our findings from the six centres for each stage of the patient pathway (2/2)

Patient journey during each pathway phase:

We divided what a **patient would experience** within each stage of the pathway into the **three sub-stages** below:



We also collected **key insights** on each pathway stage in **three categories**:

1. **Good care:** We collected evidence of what centres believe constitutes 'good practice' in this phase of the pathway

2. **Barriers to good care:** We collected evidence on the common barriers that need to be overcome to provide good care

3. **Successful interventions:** In order to reflect what the centres changed to improve their approach to IBD care, we included further detail on successful interventions

KEY FINDINGS:
The Patient Pathway

The patient pathway for Inflammatory Bowel Disease: a clinical perspective

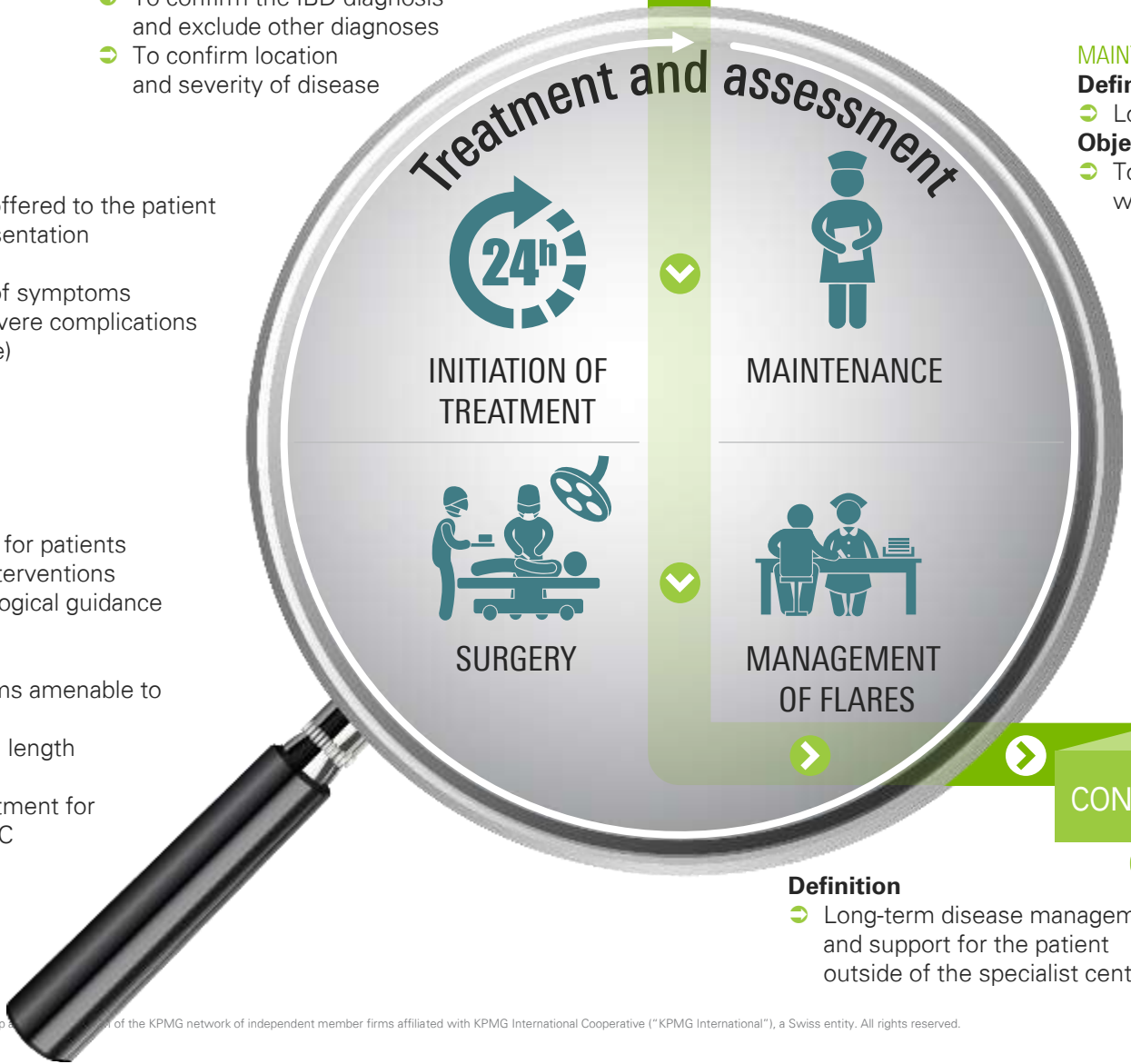
FIRST SYMPTOMS

FIRST SYMPTOMS
Definition
- The period of time between a patient first becoming unwell and being referred for diagnostic tests to confirm a diagnosis

DIAGNOSIS

DIAGNOSIS
Definition
- The process and activities required to make a diagnosis

Objective
- To confirm the IBD diagnosis and exclude other diagnoses
- To confirm location and severity of disease



INITIATION OF TREATMENT
Definition
- The initial treatment offered to the patient to treat their first presentation

Objective
- To induce remission of symptoms
- To treat any active severe complications (*e.g.* abscess drainage)

SURGERY
Definition
- Surgical interventions for patients with IBD (including interventions performed with radiological guidance or during endoscopy)

Objective
- To treat acute problems amenable to surgical intervention
- Preservation of bowel length and function
- Can be definitive treatment for some patients with UC

MAINTENANCE
Definition
- Long-term therapy for IBD

Objective
- To maintain the patient in remission and with as high a quality of life as possible

MANAGEMENT OF FLARES
Definition
- Treatment for a flare of IBD in a patient who has been diagnosed and is aware that they are suffering from a re-occurrence of severe symptoms

Objective
- To return the patient to remission as soon as possible

CONTINUOUS PATIENT CARE

CONTINUOUS PATIENT CARE
Definition
- Long-term disease management and support for the patient outside of the specialist centre

Objective
- To support patients to adhere to their treatment plan
- To ensure the patient is aware of when to seek medical advice

The patient pathway for Inflammatory Bowel Disease: **a patient's perspective**

FIRST SYMPTOMS

FIRST SYMPTOMS

I begin to feel sick, I am becoming tired, losing my appetite and weight, and I have prolonged, bloody diarrhoea. After some time, I go and see my GP who runs initial tests. I am becoming more and more worried about my symptoms and their impact upon my life.

I have also heard of patients who did not see a doctor and then their symptoms got so bad that they needed to go to the Emergency Department suffering from high fever, vomiting and extreme pain.

Eventually I am sent to see a specialist. I give a blood and stool sample for a range of tests…

DIAGNOSIS

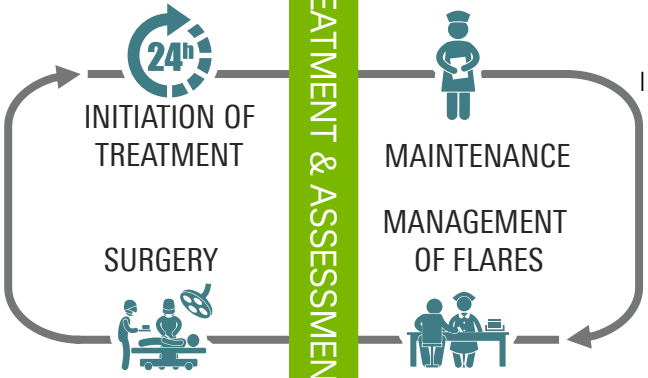
DIAGNOSIS

…I undergo imaging tests and have a colonoscopy. The colonoscopy worries me, but I am told it is necessary to get an accurate diagnosis.

Eventually, they tell me I have Inflammatory Bowel Disease. I am told that this condition can take the form of either Crohn's disease or ulcerative colitis.

I am given more information about the disease, how it can progress and be treated; this is a relief as I finally know what I am dealing with.

TREATMENT & ASSESSMENT



INITIATION OF TREATMENT

I am prescribed a short course of steroids and some longer term anti-inflammatory drugs. The nurse tells me that depending on the severity of my condition, I may require a range of other treatments.

I have heard of patients who had to be fed through a tube or had to have an operation. Initially I worry about side effects and whether the medication will help me, but the nurse reassures me and offers me some helpful information on my treatment.

SURGERY

I am really anxious about surgery, especially the idea of needing a stoma. I am told it is usually the last resort, but unfortunately I am likely to require an operation at some point in my disease's course. I hope I won't need it at a busy or important time of my life.

MAINTENANCE

I feel better, my symptoms have improved and I am told I am in remission. My doctor tells me during my follow-up appointments that I need to take my medication regularly, while a nurse gives me more information on how to take my medication and regularly checks how I am getting on in general. Now, I only need to see the doctor every 2-3 months.

MANAGEMENT OF FLARES

I experience severe symptoms again, but I know that I can get in touch with a nurse at my IBD centre immediately. I am told to come to the hospital for some tests and am informed that I am likely to require a similar regime to what first put me into remission.

I am also told that my doctors may want to increase my treatment with a drug I have not yet tried, such as a 'biologic'.

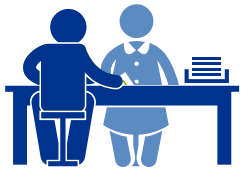
CONTINUOUS PATIENT CARE

CONTINUOUS PATIENT CARE

I have regular meetings with nurses and my doctor. During the meetings I am taught that IBD is a chronic condition that I will have for the rest of my life. This makes me very sad and worried but I am told that I can live a relatively normal life if I adhere strictly to my treatment plan. I am relieved to hear that the specialist nurses and doctors will support me in this through regular communication and monitoring, and by putting me in touch with therapy and group support services.

FIRST SYMPTOMS

PATIENT JOURNEY – DETAILED DESCRIPTION



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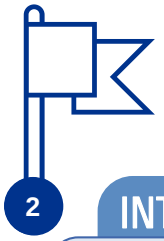
WHAT HAPPENS NEXT

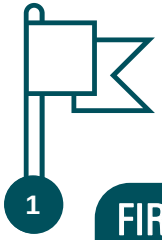
- Patient gets increasingly worried and cannot cope with symptoms anymore, or symptoms worsen
- Patient is referred/self-refers to a gastroenterology specialist
- Some patients may present to the emergency department due to severity of symptoms



2

INTERIM STEPS

- Patient sees GP and reports symptoms
- GP may try initial treatment for alternative conditions such as IBS
- Patient's symptoms persist or worsen



1

FIRST EXPERIENCES

Patient first notices symptoms *e.g.:*

- Night-time diarrhoea
- Increased frequency of bowel movements
- Blood in bowel movements
- Weight loss
- Low energy levels

PATIENT JOURNEY – FIRST SYMPTOMS

ATTRIBUTES OF GOOD CARE

1 WHAT DOES GOOD CARE LOOK LIKE?

- A standardised referral pathway exists in the local health system that is integrated in the training of local doctors
- As a result community doctors have a good awareness of 'red flags'[(a)] that warrant a prompt referral to an IBD specialist and are aware that they have to monitor these symptoms for 2-3 weeks before they should refer a patient to a specialist
- This practice of conscious monitoring enables GPs to avoid mis-referrals of cases that could have continued to be treated in the community
- Symptoms that doctors in the community are trained to monitor closely before considering a referral to an IBD centre include *e.g.*:
  - Night-time diarrhoea
  - Weight loss >5%
  - Frequent and frequently bloody bowel movements
  - Strong bowel movement urgency
- GPs are also aware of faecal calprotectin and where possible conduct the test before referring the patient to a specialist
- If symptoms persist, the GP refers the patient promptly and the patient gets an appointment with a specialist within 2-3 weeks

(a) For a study that identified early 'red flags' for Crohn's disease, see: Danese S, Fiorino G, *et al*. Development of Red Flags Index for Early Referral of Adults with Symptoms and Signs Suggestive of Crohn's Disease: An IOIBD Initiative, JCC, 2015

PATIENT JOURNEY – FIRST SYMPTOMS

COMMON BARRIERS AND SUCCESSFUL INTERVENTIONS

2 WHAT ARE THE COMMON BARRIERS TO GOOD CARE?

- IBD is a rare condition; referring doctors may have limited experience with the condition
- IBD-specific 'red flag'[(a)] protocols that referring doctors can use to assist a referral decision are not in widespread use
  - Due to referring doctors not recognising the potential symptoms of IBD, the time taken to reach a correct diagnosis can be 2 years or more
- Availability of ad-hoc appointments for new patients is often limited in specialist centres
- There is a lack of awareness of specialist IBD services, resulting in patients being seen by a generalist gastroenterologist or (in the case of children) a paediatrician first

3 WHAT ARE SOME OF THE SUCCESSFUL INTERVENTIONS?

- Awareness campaigns to increase patient awareness of symptoms that warrant immediate medical attention
- Community doctor education programmes
- Creating standard referral protocols that are built upon the 'red flag indicators'[(a)] that triage patients to IBD specialist care when required

(a) For a study that identified early 'red flags' for Crohn's disease, see: Danese S, Fiorino G, *et al*. Development of Red Flags Index for Early Referral of Adults with Symptoms and Signs Suggestive of Crohn's Disease: An IOIBD Initiative, JCC, 2015

FIRST SYMPTOMS – SUCCESSFUL INTERVENTIONS

Introducing an education programme for community doctors

What was the objective?

- To increase cooperation with community doctors and improve their rates of referral of suspected IBD cases

What was achieved?

- The centres initiated regular educational sessions about IBD with community doctors and medical personnel from secondary care centres

How was it achieved?

- IBD centres hosted educational sessions to which GPs, and doctors from smaller primary and more rural secondary centres, were invited
- Doctors from the IBD centres delivered educational presentations about IBD symptoms, as well as highlighting 'red flags' that might indicate IBD
- Doctors from the IBD centre answered questions and distributed educational material (*e.g.* flyers); online material was not yet used at this point in time

How did the centre measure success?

- IBD specialists report an anecdotally higher referral rate and improvements in correct referrals

세브란스 SEVERANCE

東邦大学

ASAN MEDICAL CENTER 서울아산병원

Key factors to consider when replicating this intervention

- Existing IBD knowledge levels of referring doctors
- Statistics on symptoms that referring doctors are most likely to see
- List of community doctors who refer to IBD centres

FIRST SYMPTOMS – SUCCESSFUL INTERVENTIONS

Creating an outreach clinic to improve rural referral rates and standards of care

What was the objective?

- The centres wanted to improve referral rates and standards of care for IBD patients living in rural areas

What was achieved?

- The centre set up satellite clinics outside their normal catchment area

How was it achieved?

- Senior IBD physicians and an IBD specialist nurse started to run clinics in a health centre outside of the city centre
- In this more rural centre the specialists support local, non-IBD specialist gastroenterologists to provide care to IBD patients

How did the centre measure success?

- Up-skilling of the local clinicians led to improved care for local patients
- The centre is now about to extend this successful model to another peripheral centre

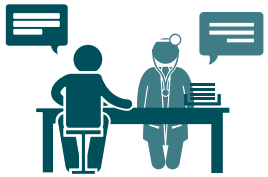
ST VINCENT'S HOSPITAL MELBOURNE

Key factors to consider when replicating this intervention

- Identify key rural centres that would benefit the most from cooperation (*e.g.* target centres with higher numbers of patients with IBD)
- Willingness and technical capability of rural centre to participate
- Financial implications of running an outreach programme

DIAGNOSIS

PATIENT JOURNEY – DETAILED DESCRIPTION



1

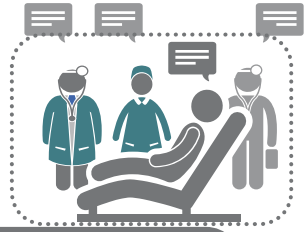
FIRST EXPERIENCES

- Patient is referred by a GP to a specialist gastroenterologist, sees a specialist directly, or is seen in the emergency department with acute symptoms
- Initial diagnostic tests may be conducted, *e.g.*:
  - Blood tests including inflammatory markers
  - Faecal calprotectin
  - Intestinal TB screening

2

INTERIM STEPS

- Patients who are clinically suspected of having IBD undergo endoscopy
- Further imaging tests such as small bowel MRI, ultrasound or CT are conducted
- The diagnosis is confirmed in an MDT meeting if necessary



3

WHAT HAPPENS NEXT

- The diagnosis is communicated to the patient by the doctor
- The patient has the opportunity to discuss their diagnosis with their doctor or IBD nurse
- Information is made available to the patient to take away with them or access online

PATIENT JOURNEY – DIAGNOSIS

ATTRIBUTES OF GOOD CARE

1 WHAT DOES GOOD CARE LOOK LIKE?

- Within a hospital or specialist centre the treating doctors have rapid (<2 weeks waiting time) access to required investigations (*e.g.* endoscopy) and imaging procedures (*e.g.* MRI)
- The diagnosing doctor is part of an experienced MDT who work collaboratively to diagnose patients with challenging cases
- The doctors within the MDT have access to reference cases and images, and can use them to improve their diagnosis accuracy
- Prompt access to all required investigations and in-depth cross-medical sector expertise allows the ultimate diagnosis to be made accurately, and within a relatively short time frame after the patient first presents to the centre
- Patients are then given full and realistic information about their disease. They are informed about how their disease is likely to progress and that it may require surgery at some point in the future. They are also made aware of the various treatment options that exist
- After this first educational session, early consultations with surgeons (often in joint clinics) should be considered. This is done to ensure that potential surgical treatment options are understood and that the patient's anxiety about surgery is managed from the beginning of their treatment and onwards

PATIENT JOURNEY – DIAGNOSIS

COMMON BARRIERS AND SUCCESSFUL INTERVENTIONS

2 WHAT ARE THE COMMON BARRIERS TO GOOD CARE?

- Limited or slow access to investigations; rate-limiting steps tend to be endoscopy and MRI
- Limited or no access to local gastroenterology specialists for patients in remote areas
- Lack of a strong collaborative and regularly scheduled MDT meeting (including gastroenterology, radiology, pathology and surgery) to support diagnosis
- Poor coordination of investigations (*e.g.* results not available at clinic appointment, which creates delays and inconvenience for patients)
  - The time frame from community doctors mis-diagnosing patients (*e.g.* IBS is wrongly diagnosed) to a correct diagnosis often lasts 2 years or longer
- Delayed access to specialist IBD advice in acute presentations to the ED

3 WHAT ARE SOME OF THE SUCCESSFUL INTERVENTIONS?

- MDT meetings that take place at least every month, and ideally every week, to discuss challenging patients and to peer-review diagnoses
- Creating networks between specialist centres and rural/less specialised medical service providers
- Use of medical history and imaging databases to provide reference cases to assist in accurate diagnosis
- Building in-centre expertise in order to be able to diagnose speedily
- Joint clinics for both IBD physicians and surgeons to see patients in parallel and in some cases simultaneously

DIAGNOSIS – SUCCESSFUL INTERVENTIONS

Creating a comprehensive patient history and imaging database to improve standards of care and diagnosis accuracy

What was the objective?

- To improve diagnosis accuracy rates and standards of care through improved training tools

What was achieved?

- Patient data and images were collected in a dedicated database, giving doctors reference cases to use in diagnosis

How was it achieved?

- Since the centre's inception, patient history and images have been collected and stored in an accessible IT database
- This IT database is supported by the centre's dedicated Systems Management Division
- Doctors are trained to use cases from this database and are able to reference these when diagnosing a new patient

How did the centre measure success?

- Access to the database allowed junior doctors a higher level of knowledge of IBD and allowed them to improve their differential IBD diagnosis skills. Staff believe this database is a key contributor to Asan's success in achieving a high (>90%) accurate diagnosis level

ASAN MEDICAL CENTER
서울아산병원

Key factors to consider when replicating this intervention

- Data retention laws
- Data security risks and patient concerns
- IT hardware and data management system availability
- Financial and logistical effort to establish a patient history and imaging database

DIAGNOSIS – SUCCESSFUL INTERVENTIONS

Creating a collaborative multi-disciplinary team to support diagnosis

What was the objective?

- To improve the accuracy and speed of diagnosis

What was achieved?

- The centre ensured that diagnoses were made quickly and accurately through the MDT approach and by involving other medical departments

How was it achieved?

- Weekly face-to-face meetings with staff from GI surgery, radiology, GI medicine and pathology were formalised and attendance was made mandatory
- Key cases were (and are) discussed during these meetings and new, challenging cases are prioritised

How did the centre measure success?

- Involvement of the MDT allowed for more prompt and accurate differential diagnoses to be made
- This improved not only patients' disease progression, but also their attitude towards the treating team – as a result patient satisfaction and rapport with clinical staff improved

Key factors to consider when replicating this intervention

- Time required to prepare for and run
- Access to non-gastroenterology staff (*e.g.* radiologists, pathologists) with sufficient experience in treating IBD patients
- Willingness of team members that are not aligned to gastroenterology (*e.g.* radiologists, pathologists) to participate in the meetings

TREATMENT INITIATION – CONVENTIONAL THERAPIES[a]

PATIENT JOURNEY – DETAILED DESCRIPTION

1

FIRST EXPERIENCES

- Physician discusses IBD severity and lifestyle requirements with the patient
- Physician suggests a treatment option in line with severity of condition

2

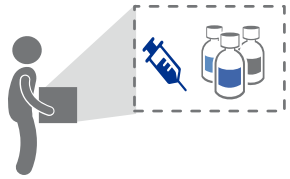
INTERIM STEPS

- Patient is instructed on how to take the prescribed medication by physician and/or IBD nurse
- Patient is monitored and has regular follow-up appointments with physician and/or IBD nurse

3

WHAT HAPPENS NEXT

- Patient reports treatment success – *i.e.* reduction of bowel movements and pain, improved appetite and weight gain – during follow-up consultation
- Patient is moved onto a less frequent (*e.g.* every 2-3 months) follow-up routine



(a) Conventional therapies include but are not limited to anti-inflammatories and steroids, immunosuppressants, elemental feeding and other non-biologic medical therapies

PATIENT JOURNEY – TREATMENT INITIATION – CONVENTIONAL THERAPIES[a]

ATTRIBUTES OF GOOD CARE

1 WHAT DOES GOOD CARE LOOK LIKE?

- The IBD physicians and/or IBD nurses take time to have a detailed conversation with the patient to explore their symptoms and to understand the lifestyle requirements
- As a result of this conversation a treatment plan is developed. This plan is ideally both goal-based (*e.g.* go to work every day, be able to do sports every week) and time-bound (*e.g.* control symptoms within 6 weeks) – the patient plays an active role in shaping the goals of the treatment plan
- Using the treatment plan as the key point of reference, a treatment option is chosen
- Patients then receive information/training about the drug treatment option they have been prescribed (*e.g.* mode of action, dosing frequency and side effects)
- After a short period of time, the patient is potentially asked to come back to the clinic to discuss whether the treatment is delivering the desired effects and whether they feel closer to reaching the goals of the treatment plan
- Treating physicians and/or IBD nurses have had training on psychosocial issues to be able to recognise them during the follow-up appointment. Consequently they can refer the patient to psychological therapies if required

(a) Conventional therapies include but are not limited to anti-inflammatories and steroids, immunosuppressants, elemental feeding and other non-biologic medical therapies

PATIENT JOURNEY – TREATMENT INITIATION – CONVENTIONAL THERAPIES[a]

COMMON BARRIERS AND SUCCESSFUL INTERVENTIONS

2 WHAT ARE THE COMMON BARRIERS TO GOOD CARE?

- Treating IBD physicians and/or IBD nurses have insufficient time to discuss treatment options and requirements with the patient
- IBD physicians and/or IBD nurses have insufficient time to instruct the patient on how to take their medication
- Psychosocial issues that may affect compliance are not fully recognised and addressed; limited or no access to psychological support services
- Treating IBD physicians and/or IBD nurses are not aware of lifestyle implications of different treatment options
- Lack of consideration of indirect health impact of IBD on the patient such as iron deficiency, bone health, and the impact on school or work routines

3 WHAT ARE SOME OF THE SUCCESSFUL INTERVENTIONS?

- Train a dedicated nurse who can educate patients on their treatment and/or create enough time for physicians to explain the treatment to patients
- Implement treatment plans that are goal-based and time-bound
- Ensure opportunities for treatment plans to be peer-reviewed, through MDT discussions or ad-hoc meetings
- Create patient associations to support patients when IBD treatment is first initiated

(a) Conventional therapies include but are not limited to anti-inflammatories and steroids, immunosuppressants, elemental feeding and other non-biologic medical therapies

TREATMENT INITIATION – BIOLOGICS[a]

PATIENT JOURNEY – DETAILED DESCRIPTION

1

FIRST EXPERIENCES

- The patient does not respond well to conventional treatment
- Patient meets local severity thresholds for immediate initiation of biologics
- Patient requests a more advanced treatment due to worsening symptoms

2

INTERIM STEPS

- Patient undergoes suitability assessment
- Patient and doctor discuss biologic options (SC *vs* IV), considering patient's lifestyle factors
- When patient receives treatment with SC biologic, they are trained on injecting themselves by physicians and/or IBD nurse
- Patient is monitored and has regular follow-up

3

WHAT HAPPENS NEXT

- Patient reports treatment success – *e.g.* reduction of bowel movements and pain, improved appetite and weight gain
- Patient is moved onto a less frequent (*e.g.* every 2-3 months) follow-up routine. In some cases this routine is managed remotely, using telephone clinics and remote faecal calprotectin testing

(a) Biologic therapies include treatments such as adalimumab, certolizumab pegol, golimumab, infliximab, natalizumab and vedolizumab

PATIENT JOURNEY – TREATMENT INITIATION – BIOLOGICS[a]

ATTRIBUTES OF GOOD CARE

1 WHAT DOES GOOD CARE LOOK LIKE?

- Physicians ensure that all other appropriate treatment options have been exhausted and that biologics are the most beneficial treatment option for the patient
- The patient is fully informed of the potential risks and benefits of biologic therapy
- The patient and the physician revisit the goals of the patient's treatment plan together. The patient is then able to choose, in conjunction with their physician, the biologic that best suits their lifestyle and treatment requirements
- The patient is asked to attend a clinic appointment soon after the first biologic dose has been administered in order to review and assess treatment success and any side effects
- When the patient is prescribed SC biologics, they are trained to self-administer their treatment correctly
- The patient is monitored regularly to ensure that their treatment is working correctly and they are not suffering from side effects
- The patient is trained to identify changes in their condition which could indicate side effects or the beginning of an IBD flare

(a) Biologic therapies include treatments such as adalimumab, certolizumab pegol, golimumab, infliximab, natalizumab and vedolizumab

PATIENT JOURNEY – TREATMENT INITIATION – BIOLOGICS[a]

COMMON BARRIERS AND SUCCESSFUL INTERVENTIONS

2 WHAT ARE THE COMMON BARRIERS TO GOOD CARE?

- Treating IBD physicians and/or IBD nurses have insufficient time to discuss treatment options and treatment requirements with the patient
- IBD physicians and/or IBD nurses have insufficient time to instruct the patient on how to take their medication
- Psychosocial issues that may affect compliance are not fully considered; limited or no access to psychological support services
- Treating IBD physicians and/or IBD nurses are not aware of lifestyle implications of different treatment options
- Lack of consideration of indirect impact of IBD such as iron deficiency, bone health, and the impact on school or work routines

3 WHAT ARE SOME OF THE SUCCESSFUL INTERVENTIONS?

- Train a dedicated nurse who can educate patients on their treatment and/or create enough time for physicians to explain the treatment to patients
- Implement treatment plans that are goal-based and time-bound
- Ensure opportunities for treatment plans to be peer-reviewed, through MDT discussions or ad-hoc meetings

(a) Biologic therapies include treatments such as adalimumab, certolizumab pegol, golimumab, infliximab, natalizumab and vedolizumab

TREATMENT INITIATION – SUCCESSFUL INTERVENTIONS

Addressing patients' lifestyle needs when deciding treatment methods

What was the objective?

- To minimise the disruption IBD causes to patients' lives, and increase their overall satisfaction levels

What was achieved?

- Doctors discussed lifestyle factors with patients and according to these requirements suggested a range of biologic treatment options to the patient

How was it achieved?

- Doctors used specific factors to assess the patients' lifestyle requirements to recommend a treatment option – *e.g.:*
  - Age
  - Proximity to treatment centre
  - Likelihood to comply with treatment regime
  - Work and travel schedule
  - Patients' need for frequent interaction with HCPs

How did the centre measure success?

- Patients reported higher satisfaction levels and felt that they truly 'owned' their treatment decision. As a result higher treatment compliance was anecdotally reported

ACROSS ALL IBD CENTRES

Key factors to consider when replicating this intervention

- Effective framework to capture most relevant patient lifestyle factors
- Sufficient awareness creation to introduce IBD physicians to biologic treatment options available

TREATMENT INITIATION – SUCCESSFUL INTERVENTIONS

Introducing treatment awareness sessions between patients and IBD nurses

What was the objective?

- To improve self-management techniques of patients and treatment compliance rates

What was achieved?

- Dedicated IBD nurses now have appointments with patients during their treatment initiation phase

How was it achieved?

- During the appointments nurses discussed the features of the drug the patient had been prescribed, as well as product dosing, intake regularity and potential side effects, and how to report these
- Nurses trained patients to inject themselves with SC biologics, monitored the first self injection and made themselves available for follow-up questions

How did the centre measure success?

- Patients reported higher confidence in their treatment choice and were more compliant with their treatment
- Fewer follow-up appointments were requested by patients (on average two fewer follow-up appointments were requested per patient)

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ST VINCENT'S HOSPITAL
세브란스 SEVERANCE
Royal Adelaide Hospital

Key factors to consider when replicating this intervention

- Develop standardised protocols that nurses can use when training patients on their new treatment option
- Train nurses in different product features and on how to advise patients

MAINTENANCE AND CONTINUOUS ASSESSMENT

PATIENT JOURNEY – DETAILED DESCRIPTION

1

FIRST EXPERIENCES

- As symptoms subside and the patient feels well, they are formally or informally transitioned off the more intensive initial treatment schedule
- Follow-up appointments and investigations become less frequent
- Appointments are often coordinated by an IBD nurse

2

INTERIM STEPS

- Patients undergo regular follow-ups (every 2-3 months), where standard tests are conducted as required
- Endoscopies are usually conducted every 2-3 years for mild and moderate cases

3

WHAT HAPPENS NEXT

- Patients remain in maintenance phase as long as condition remains stable
- If condition deteriorates patients move on to the flare management phase

PATIENT JOURNEY: MAINTENANCE AND CONTINUOUS ASSESSMENT

ATTRIBUTES OF GOOD CARE

1 WHAT DOES GOOD CARE LOOK LIKE?

- Patient care is managed as efficiently as possible, with ideally one single point of contact, such as an IBD nurse. If this point of contact falls away (*e.g.* due to a change in staff) a comprehensive handover procedure takes place and where possible, all patients are discussed
- The IBD nurse acts as the main point of contact for the patient, and also acts as a point of contact for the main treating physician. The IBD nurse tries to establish a rapport with patients, and actively encourages patients to report their symptoms and lifestyle needs as soon as they occur
- Patients take ownership of their treatment plan and its goals, and are as a result well informed about, and adhere to, their treatment routine
- All members of the IBD team have a clear protocol for identifying symptom changes (*e.g.* comprehensive questions and relevant diagnostic tests) and are able to identify a flare in a timely fashion when the patient reports a change in symptoms
- Patients are given sufficient information and training to manage their condition proactively (*e.g.* which symptoms could indicate a flare and who to call if they notice any changes or are worried); they are also aware who they can contact if they experience a sudden strong flare of symptoms during non-working hours at 'their' IBD clinic

PATIENT JOURNEY – MAINTENANCE AND CONTINUOUS ASSESSMENT

COMMON BARRIERS AND SUCCESSFUL INTERVENTIONS

2 WHAT ARE THE COMMON BARRIERS TO GOOD CARE?

- Lack of dedicated staff to coordinate treatment schedules of regular IBD patients
- Unwillingness of patients to adhere to a treatment routine
- Patients often 're-frame normality', *i.e.* they accept a level of symptom control that, although better than previously experienced, could be further optimised if the treating clinicians were made aware of symptoms
- Patients have an insufficient level of trust in community care, resulting in an increased burden on specialist clinics

3 WHAT ARE SOME OF THE SUCCESSFUL INTERVENTIONS?

- Hiring and training dedicated IBD nurses who:
  - Act as the single point of contact for regular IBD patients
  - Manage patient care to minimise inefficiencies and total patient visits
- Strong patient education to enable patients to know how and when to contact the IBD centre for advice (often via the IBD nurses)
- Creating automated appointment management systems such as SMS appointment reminders
- Creating accessible sources of information on IBD to enable patients to treat their own condition, such as blogs, multimedia CDs, apps and telephone hotlines

MAINTENANCE AND CONTINUOUS ASSESSMENT – SUCCESSFUL INTERVENTIONS

Using blogs, SMS and social media to communicate information to patients and reduce the need for follow-up appointments

What was the objective?

- To improve patient engagement, improve their ability to monitor and manage their own condition, and to counter misinformation about IBD

What was achieved?

- Senior IBD specialists and the IBD nurse at Yonsei used technology to inform and communicate with patients and to improve patient self management

How was it achieved?

- Professor Cheon at Yonsei Severance University Hospital introduced a blog for patients which he regularly updated with news on IBD treatment and other seasonal updates. The sign on his consultation room contained a link to his blog, so patients could access it while they waited
- The IBD nurse now uses Twitter to communicate with patients and update them with nutritional advice and changes to the clinic schedule. She also now uses text messages to remind patients about their appointments and check on their general well-being

How did the centre measure success?

- Requests for ad-hoc follow-up appointments decreased by ~20%

세브란스 SEVERANCE

Key factors to consider when replicating this intervention

- Develop standardised protocols that nurses can use when training patients on their new treatment options
- Train nurses in different product features and on how to advise patients

MAINTENANCE AND CONTINUOUS ASSESSMENT – SUCCESSFUL INTERVENTIONS

Creating specialised IBD nurse positions who act as a single point of contact for patients to improve adherence

What was the objective?

- To improve treatment adherence, and overall satisfaction and efficiency for patients

What was achieved?

- The centres created specialised IBD nurse positions, whose roles were to coordinate and support IBD patients

How was it achieved?

- Nurses were given specialised IBD training, which included training in special needs of IBD patients, as well as training in efficient care coordination
- Their role included overall case management to smooth the patient journey, by scheduling appointments and booking tests
- They also met patients when they arrived for their 2-3 monthly routine follow-up appointment
- IBD nurses educated patients on IBD and its treatment
- A significant part of their role was (and is) providing ad-hoc support to patients, often through a dedicated phone hotline or email address

How did the centre measure success?

- Patient journeys and satisfaction levels were improved
- Patient maintenance and adherence to treatment was improved (reduction of missed appointments by 40%)
- Inefficiencies were reduced *e.g.* through IBD nurses ensuring that investigation results were available for the patient appointments

ASAN MEDICAL CENTER 서울아산병원

ST VINCENT'S HOSPITAL MELBOURNE

세브란스 SEVERANCE

Key factors to consider when replicating this intervention

- Availability of funding *e.g.* some healthcare systems only allow a centre to have an IBD nurse once a specific patient pool size has been reached. The size of this pool depends heavily on the local IBD prevalence but is generally assumed to be >40 IBD patients
- Health system restrictions on the role of nurses in patient care

FLARE MANAGEMENT

PATIENT JOURNEY – DETAILED DESCRIPTION

1

FIRST EXPERIENCES

- IBD physicians, through their monitoring of patients' symptoms during follow-up appointments (with associated tests), identify signs suggesting a flare
- Patient reports flare up of symptoms such as pain or more frequent bowel movements
- IBD nurses or other team member become concerned following interactions with patient

2

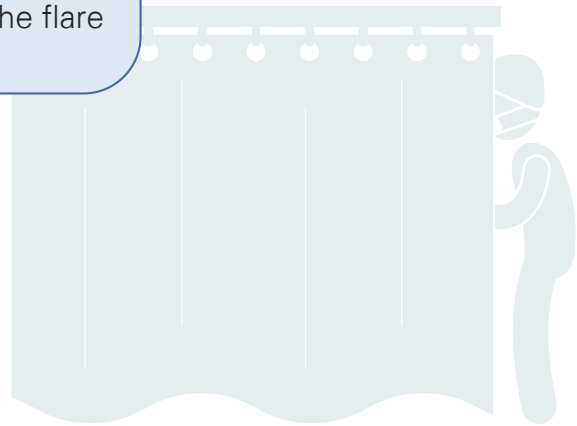
INTERIM STEPS

- If the patient's symptoms are reported via remote care, the patient is asked to come to the clinic for a more detailed consultation
- If already admitted as an in-patient, then the IBD team sees the patient on the ward and takes over care as appropriate
- Investigations such as blood tests, diagnostic imaging and further tests (*e.g.* faecal calprotectin) are conducted to confirm the flare
- Treatment plan is agreed and started immediately

3

WHAT HAPPENS NEXT

- The patient's progress is monitored regularly (*e.g.* weekly to bi-weekly), often using brief phone clinics and self-reporting
- Steroids are tapered down quite quickly (*e.g.* within 3 weeks) and stopped at 12 weeks maximum
- Treatment plans for patients are revised to reduce the likelihood of future flares



PATIENT JOURNEY – FLARE MANAGEMENT

ATTRIBUTES OF GOOD CARE

1 WHAT DOES GOOD CARE LOOK LIKE?

- Patients are fully aware what 'normal' looks like, so they can recognise and report symptoms that may indicate a flare
- Patients work closely with their IBD treatment team and report any change in their symptoms as soon as it occurs. They are then seen promptly either by a specialist or an IBD nurse for further assessment
- IBD physicians identify unusual symptoms and conduct tests every 2-3 months to keep close watch over bio-markers that could indicate a flare
- Patients' flares are managed immediately after the patient reports symptoms, with the goal to control the flare via medication within a maximum time frame of 10-12 weeks
- Clear guidelines to limit the use of steroids are in place
- MDT discussions are used for complex treatment decisions (*e.g.* whether to proceed to surgery)
- After a flare the treatment that the patient receives is reviewed and if necessary new treatment options are discussed. The treatment plan and its goals are updated after each flare

PATIENT JOURNEY – FLARE MANAGEMENT

COMMON BARRIERS AND SUCCESSFUL INTERVENTIONS

2 WHAT ARE THE COMMON BARRIERS TO GOOD CARE?

- Availability and/or reimbursement of tests that can help diagnose flares (*e.g.* faecal calprotectin)
- Care services may not be joined up (*e.g.* the IBD service may not be automatically made aware that a patient has attended the ED)
- Patients may lack awareness and consider up to five bowel movements per day 'normal' and not report these as symptoms of flares
- No MDT available for discussion of complex cases
- The interface between private sector and public sector care providers can cause confusion when the patient is passed between the two

3 WHAT ARE SOME OF THE SUCCESSFUL INTERVENTIONS?

- IBD team liaises with ED clinicians to develop a protocol that ensures IBD patients are treated in consultation with IBD specialists
- Education for patients to allow them to identify when their condition is deteriorating and consequently seek prompt advice from their IBD centre

FLARE MANAGEMENT – SUCCESSFUL INTERVENTIONS

Introduction of a telephone hotline for patients to get advice on change of symptoms

What was the objective?

- To improve patient identification of flares, and reduce response time to changes in condition by offering a quick and accessible source of specialist advice

What was achieved?

- A hotline staffed by IBD nurses was set up, giving patients access to a quick source of advice they could access when their condition changed

How was it achieved?

- Alongside other duties, the specialist IBD nurse started now manages a telephone hotline which patients were encouraged to use for advice, to place any queries that they had about their treatment, and for information on how to respond to any noticed change in their condition
- The IBD nurse would use her meetings with IBD patients to build up trust and rapport, and encourage them to see the hotline as an extension of these face-to-face meetings

How did the centre measure success?

- Anecdotally, patients felt more secure in their treatment and less anxious about changes in their condition, since they were aware that they could receive ad-hoc help whenever needed

ASAN MEDICAL CENTER 서울아산병원

세브란스 SEVERANCE

Key factors to consider when replicating this intervention

- Availability of time for the IBD nurse or other staff member to manage the hotline and associated cost
- Required level of medical expertise to deal with patient queries over the phone

FLARE MANAGEMENT – SUCCESSFUL INTERVENTIONS

Optimising care through the introduction of a care protocol for patients admitted with Acute Severe Colitis

What was the objective?

- To improve emergency treatment given to patients presenting with Acute Severe Colitis (ASC)

What was achieved?

- A set of protocols describing best practice treatment for patients with ASC were created and made accessible to hospital doctors to refer to on admission of IBD patients

How was it achieved?

- A retrospective case note audit was done on patients previously admitted with ASC, which highlighted that best practice guidelines were not always followed
- A local care protocol was developed for staff to follow when admitting patients with ASC

How did the centre measure success?

- The protocol lead to all IBD presentations to the ED being discussed with the gastroenterology department, with one member of the gastroenterology team always available for advice

Royal Adelaide Hospital

Key factors to consider when replicating this intervention

- Requirements to establish standardised processes to ensure that protocols are accessed and followed by ED staff on patient presentation
- Limitations that may prevent the delivery of best practice care, such as availability of speciality staff at all hours

SURGERY

PATIENT JOURNEY – DETAILED DESCRIPTION

1

FIRST EXPERIENCES

- IBD physician and surgeon discuss surgical options and their implications on the patient's lifestyle long before surgery is conducted
- Reasons for surgery are discussed in an MDT or at joint clinics, and the decision to proceed to surgery is reached collaboratively with the patient

2

INTERIM STEPS

- IBD physician and surgeon communicate surgical options to the patient jointly and ensure that the patient's views are understood
- Surgeon spends time with the patient to clearly explain to them the procedure specifics and any aftercare that will be required

3

WHAT HAPPENS NEXT

- Surgery is conducted and patient receives necessary aftercare
- Patient is trained how to care for their wounds and (if required) stoma by an appropriately trained stoma nurse
- Post-operative medical therapy is reviewed and if applicable, recommenced as soon as appropriate

PATIENT JOURNEY – SURGERY

ATTRIBUTES OF GOOD CARE

1 WHAT DOES GOOD CARE LOOK LIKE?

- Wherever possible, the potential need for surgery has been discussed with the patient at an earlier stage of the disease, and the patient is aware of the risks and benefits that surgery can offer
- Medical therapy has been fully optimised prior to consideration of surgery
- MDT meeting has been used to discuss complex surgical treatment, and surgery is planned collaboratively and proactively within the MDT meeting
- Once the decision for surgery is taken patients receive psychological care as needed, both before and after surgery
- The surgeons have extensive IBD experience and are trained in advanced laparoscopic techniques
- Together with the treating IBD specialist, surgeons meet patients several times before the surgery and try to build a rapport with the patient
- After the surgery the patient receives comprehensive training on how to care for their wounds and stoma (if applicable)

PATIENT JOURNEY – SURGERY

COMMON BARRIERS AND SUCCESSFUL INTERVENTIONS

2 WHAT ARE THE COMMON BARRIERS TO GOOD CARE?

- Treating IBD physicians and surgeons have insufficient opportunities to communicate with one another or do not routinely discuss surgical interventions
- Treating IBD physicians and surgeons do not have enough time to discuss surgery with the patient
- Surgery is undertaken before medical therapy has been fully optimised
- There are not enough resources to introduce dedicated stoma nurses to spend time training and informing patients after their surgery
- The psychological implications of having a stoma are underestimated and patients receive insufficient support

3 WHAT ARE SOME OF THE SUCCESSFUL INTERVENTIONS?

- Introduction of MDT meetings to ensure that surgical decisions are discussed amongst the whole treatment team
- Joint working between IBD gastroenterologists and surgeons, both for in-patient ward rounds and out-patient clinics
- Introduction of dedicated stoma nurses on the surgical wards to train patients on stoma usage and maintenance
- Introduction of a dedicated stoma and pouch clinic

SURGERY – SUCCESSFUL INTERVENTIONS

Early conversations with patients about surgery with clear messages from both surgeons and gastroenterologists

What was the objective?

- To reduce patient apprehension and misunderstanding about surgical treatment options

What was achieved?

- Gastroenterologists and surgeons have agreed to talk about surgery as an important treatment option and not just as a last resort in case of failure of medical management

How was it achieved?

- IBD physicians and surgeons take part in regular MDT meetings and agreed to position surgery (especially laparoscopic surgery) as a positive treatment option for some patients
- Patients will usually meet the surgeons early in their treatment, even if there is not a current indication for surgery, in order to reduce potential patient anxiety about surgery
- IBD physicians and surgeons conducted (and still) conduct ward rounds together to ensure that patients are aware of the option of surgical treatment and feel integrated in any decision for surgery in a timely manner

How did the centre measure success?

- Anecdotally, reduced patient anxiety about surgery was reported
- Increased numbers of joint team surgical decisions

Royal Adelaide Hospital

Key factors to consider when replicating this intervention

- Efficient ways for surgeons and IBD physicians to consult and communicate
- Opportunities that allow surgeons and IBD physicians to communicate jointly with patients (*e.g.* during ward rounds, joint clinics, ad hoc)

SURGERY – SUCCESSFUL INTERVENTIONS

Introducing a dedicated support system for stoma patients

What was the objective?

- To improve the satisfaction of patients with stomas, improve their management and care, and increase the efficiency of stoma treatment

What was achieved?

- Dedicated stoma nurse was introduced for stoma patient care and education, as well as the training of fellow nurses in stoma care
- Stoma nurse introduced informal network for stoma patients to exchange experiences and perspectives

How was it achieved?

- A dedicated stoma nurse was hired, and worked to connect patients who had received a stoma/pouch some time ago with patients who were just receiving a stoma. This was done in order to ease anxiety of the new patients and improve their satisfaction with the procedure

How did the centre measure success?

- Patients reported lower anxiety levels and higher satisfaction levels
- Fewer follow-up appointments were requested by stoma patients

TOHO UNIVERSITY NATURE LIFE MAN 東邦大学

Key factors to consider when replicating this intervention

- Training for dedicated stoma nurses
- Willingness of patients to participate in an informal knowledge and experience exchange with other stoma patients

CONTINUOUS PATIENT CARE

PATIENT JOURNEY – DETAILED DESCRIPTION

1

FIRST EXPERIENCES

- The patient is followed up closely (*e.g.* bi-monthly, through telephone or out-patient clinics, *etc.*) during their first 6 months of treatment
- Once the patient is comfortable and stable, frequency of follow-up appointments can be reduced

2

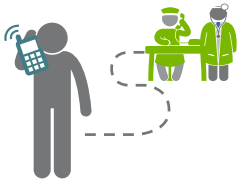
INTERIM STEPS

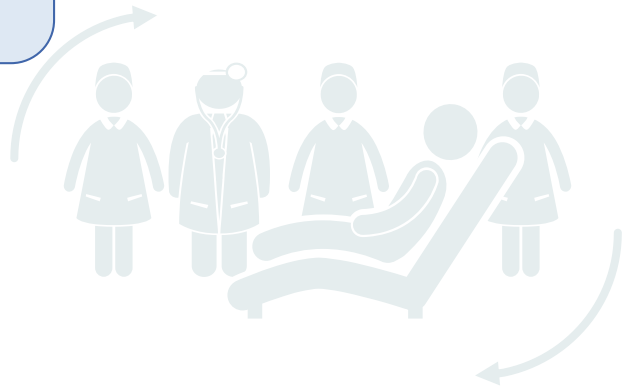
- The patient continues to check in with the IBD nurses, often via phone, and is aware of all the available care options (including access to psychological care)
- The patient makes the IBD centre aware of any key events in their life (*e.g.* exams, marriage and partnership, pregnancy)

3

WHAT HAPPENS NEXT

- If the patient reports a change in symptoms they are assessed promptly and treated accordingly as a flare case





PATIENT JOURNEY – CONTINUOUS PATIENT CARE

ATTRIBUTES OF GOOD CARE

1 WHAT DOES GOOD CARE LOOK LIKE?

- Regular (*e.g.* every 2-4 weeks) interaction with patient during the first 6 months of treatments, usually through a combination of telephone and out-patient clinics
- After this first period, the frequency of follow-up appointments is reduced (*e.g.* every 2-3 months), and the reduction of visits is aligned with the patient's symptoms (*e.g.* are they more or less stable) and the patient's preferences
- Patients are given several options to get in touch with the IBD centre (*e.g.* telephone hotline) and know who they can contact should they suffer a sudden worsening of symptoms during the non-working hours of the IBD centre
- Where necessary and helpful, psychological support is offered to ensure that the patient's psychological needs are met
- The IBD centre is aware of and sensitive to any key events in the patient's life (*e.g.* exams, marriage and partnership, pregnancy) and works with the patient to ensure that treatment is integrated as seamlessly as possible

PATIENT JOURNEY – CONTINUOUS PATIENT CARE

COMMON BARRIERS AND SUCCESSFUL INTERVENTIONS

2 WHAT ARE THE COMMON BARRIERS TO GOOD CARE?

- Patients may not adhere to follow-up regime due to lack of awareness or education
- Insufficient level of resources may prevent the centre from establishing a point of call (*e.g.* hotline) that patients can use to get in touch in times of need
- Lack of resources to establish psychological services
- Patients show reluctance to accept psychological services

3 WHAT ARE SOME OF THE SUCCESSFUL INTERVENTIONS?

- Introduce appointment schedule for patients who are transitioning from bi-monthly follow-ups during treatment initiation, to follow-ups every 2-3 months
- Introduce psychological care for patients and enable them to self-refer when needed
- Introduce hotline for patients to call if they need help/advice outside their regular appointments
- Other transition clinics to ease the move from paediatric care to adult care
- Develop specialist interface clinics, *e.g.* for patients who also see rheumatologists, obstetric clinics, psychological therapies etc.

CONTINUOUS PATIENT CARE – SUCCESSFUL INTERVENTIONS

Introduction of a psychological medicine forum and counselling service

What was the objective?

- To anticipate, identify and treat any psychological comorbidities of patients with bowel disease

What was achieved?

- A multi-disciplinary forum was introduced to focus on strategies to manage patients' psychological issues associated with IBD and other bowel conditions

How was it achieved?

- A regular forum consisting of 20-30 participants, including senior liaison psychiatrists, behavioural therapists, pain specialists, psychiatry and gastroenterology trainees, psychologists, IBD nurses and dieticians was established
- The forum members discussed issues that patients might suffer from, and how to help overcome these
- A dedicated weekly counselling service for patients was also introduced

How did the centre measure success?

- Strong anecdotal evidence of improved patient well-being, psychological and general well-being
- Awareness of psychosocial issues associated with both IBD and functional gut conditions amongst the IBD treatment team was improved

ST VINCENT'S HOSPITAL MELBOURNE

Key factors to consider when replicating this intervention

- Selection of forum members who are available and willing to participate
- Effective way to reach out to patients in need of psychological support *e.g.* counselling over internet forum, face-to-face consultations
- Financial investment required to establish a psychological support forum and/or counselling service (note: size of investment will depend on local requirements)

CONTINUOUS PATIENT CARE – SUCCESSFUL INTERVENTIONS

Introduction of a dedicated support forum for parents of adolescent IBD sufferers

What was the objective?

- To improve the management of IBD adolescent patients by offering support to the patients' parents

What was achieved?

- Nurses established a dedicated support group for parents of adolescent IBD patients

How was it achieved?

- Parents of IBD patients were contacted and asked to participate in a patient group dedicated to informal discussion and exchange of mutual experiences and tips

How did the centre measure success?

- The intervention is relatively new, but parents have reported anecdotally that they feel less anxious and more happy as a result of the parents' support forum

Key factors to consider when replicating this intervention

- Willingness of parents to participate in the forum
- Availability of nursing or counselling staff to facilitate the forum

DETAILED SITE VISITS

Royal Adelaide Hospital

Adelaide, Australia

Royal Adelaide Hospital

Royal Adelaide Hospital

Our visit revealed a number of detailed specifications about the Royal Adelaide Hospital's operations

IBD treatment team

Fortnightly **MDT** meetings comprising IBD physicians, surgeons, radiologists, dieticians and pathologists

Two **IBD nurses** supported by three part-time nurses, who coordinate care, provide admin support, educate and correspond with patients, and participate in research

Two specialist **radiologists** who participate in the MDT

Multiple **allied health** professionals' support, including an allocated 0.5 FTE dietician and two stoma nurses from the surgery department

Patient services

Access to six free sessions of **psychological support** through the GP, though the enrolment process is cumbersome; IBD team developing a case for a hospital-based programme

Paediatric patients treated in paediatric hospital. No official transition clinic in place, though team is planning to introduce a protocol in the future

Outreach to GPs and generalist gastroenterologists in the catchment area through regular gastroenterology events and giving *ad-hoc* advice on patient treatment and diagnosis

Access to **biologics** restricted until after 3-month course of conventional treatment is completed or has failed, or patient suffers from fistulas, with high administrative burden

Selected treatment approaches

Surgery undertaken proactively and not always as a last resort. Surgeons work closely with IBD physicians and meet patients early

Endoscopies done in three IBD dedicated rooms by experienced endoscopists

Additional points of relevance

Research is a particular strength, with the team focusing on clinical care models and psychological and social issues caused by IBD, as well as participating in and conducting other IBD research

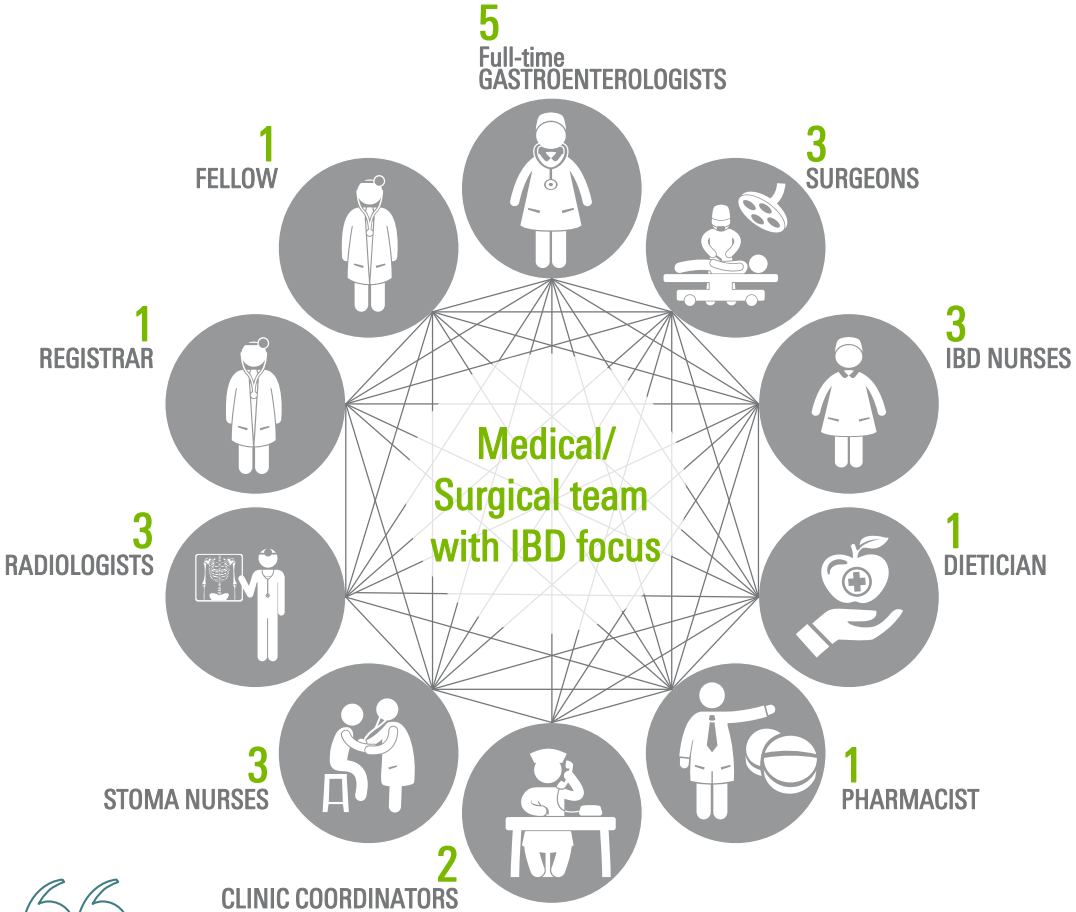
Despite the lack of a formal IT system, nurses record and track patient data in an Excel spreadsheet

Royal Adelaide Hospital – SUMMARY

Royal Adelaide Hospital

Greater Adelaide region

~800 active patients



No matter what your entry point into the system [medical or surgical], your care should be the same.
(Matt Lawrence, colorectal surgeon)

KEY FEATURES OF CENTRE:

- Strong leadership that emphasises patient focus for a very large patient population, despite being over-burdened with the volume at times
- IBD nurses who successfully coordinate care for patients
- Regular cooperation and meetings between all the departments that are involved in IBD treatment (GI department, pathology, imaging, nurses and GI surgery)

Being outward focused, in addition to running the internal aspects well, ultimately helps deliver better care to more people than units concerned only with own results, data or prestige.
(Professor Jane Andrews)

Royal Adelaide Hospital – SUMMARY

Royal Adelaide Hospital

STRENGTHS

Highly cohesive and multi-disciplinary team, with experienced and skilled staff

Systematic peer review and challenge encouraged by an open culture and strong processes

Good balance between generalist and specialist IBD care, with the IBD department allowing less complex cases to be managed by general gastroenterologists

KEY INFLEXION POINTS FOR PATIENT CARE

Speed and transitioning of referral from primary care, as slow referral due to a lack of knowledge of IBD can result in disease progression

Access to early escalation of therapy, such as surgery and biologics, can help improve outcomes

Ongoing support, education and follow-up with patients is important for treatment compliance, flare recognition and overall well-being

SUCCESSFUL INTERVENTIONS

A culture of data collection enables the centre to coordinate and organise care, conduct research and create business cases to use for service improvement or expansion

Members of the IBD team educate other gastroenterology colleagues on how to comply with the administrative requirements to access publically funded biologic treatments for patients

Patients are involved in treatment decisions and educated on the importance of adherence and disease management

Royal Adelaide Hospital

Royal Adelaide Hospital

What would you change if you had the opportunity?

ADDITIONAL IBD SPECIALIST

Why?

Currently, team members and colleagues from other specialties rely heavily on Professor Andrews for guidance and decisions on serious cases. As the team grows and more cases are referred to the centre, Professor Andrews will require support

How?

The management team is about to appoint another part-time consultant gastroenterologist with a specialist interest in IBD

IMPROVE REFERRAL FROM COMMUNITY

Why?

Some of the practitioners in both the city and the rural areas are unaware of the latest evidence in IBD care and the need for specialist advice, and can on occasion manage patients for too long before referring them for specialist opinions at RAH

How?

A better dialogue with GPs, generalist gastroenterologists and general surgeons of the city could help better identify IBD and teach them when to refer for specialist input

What would you advise a less specialised centre to implement, in order to improve their standards?

STRATEGIC DATA COLLECTION

Why?

Collecting data enables a centre to coordinate and organise care as well as to conduct research, as outcomes can be tracked and monitored. A rigorous approach to data collection enables units to create business cases to use for service improvement or expansion

How?

Although there is no EHR or integrated patient database in place, the IBD nurses still take ownership of capturing patient data by designing an excel spreadsheet which they update weekly. It allows them to flag when results come back as abnormal and patients need to be seen quickly

BEING OUTWARDS FOCUSED

Why?

The management of IBD, although mainly addressed by gastroenterologists, includes a wide range of other specialists in the centre and outside

How?

Beyond running the internal aspects of the team, Professor Andrews believes it is important to try to change care for people outside the university

ST VINCENT'S HOSPITAL
MELBOURNE

St Vincent's Hospital

Melbourne, Australia

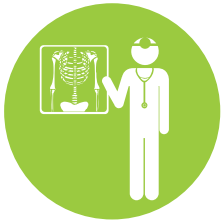
St Vincent's Hospital

Our visit revealed a number of detailed specifications about St Vincent's Hospital's operations

IBD treatment team

Weekly **MDT** meetings that are attended by physicians, surgeons, IBD nurses, pathologist, radiologist, psychologists, registrars and fellows

The team is strong and comprises **three IBD nurses** with a full-time principal IBD nurse who is supported by part-time nurses



Among the radiologists working at St Vincent's Hospital, **two radiologists** who have an interest in IBD regularly participate at the weekly MDT

Multiple **allied health** professionals such as dieticians, stoma nurses and behavioural therapists support the team and interact regularly with doctors

Patient Services

The gastroenterology team runs a weekly **psychological medicine forum** that includes 20-30 participants: senior liaison psychiatrists, behavioural therapists, pain specialists, psychologists, IBD nurses and dieticians

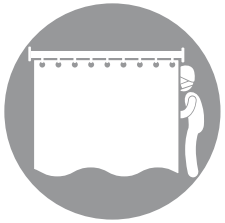
The St Vincent's IBD team has become a **quaternary centre** in the country for patients with IBD who would like to become **pregnant**; physicians focus on pregnancy management and also discuss fertility issues with patients

A **tele-health clinic** was set up in 2014 to provide patients with ongoing care while reducing the number of visits to the hospital

The national payer, Medicare, requires physicians to demonstrate that patients are not controlled on conventional IBD therapies for 3 months after initiation of the treatment before **biologics** are reimbursed

Selected treatment approaches

Surgery is discussed freely with patients – the attitude of the IBD team is that surgery is part of the management of IBD and not just an option after the failure of medical therapy (although this is still the case for some patients)



Endoscopies are performed by the gastroenterologists on Monday afternoons following the IBD clinic which takes place in the morning

Additional points of relevance

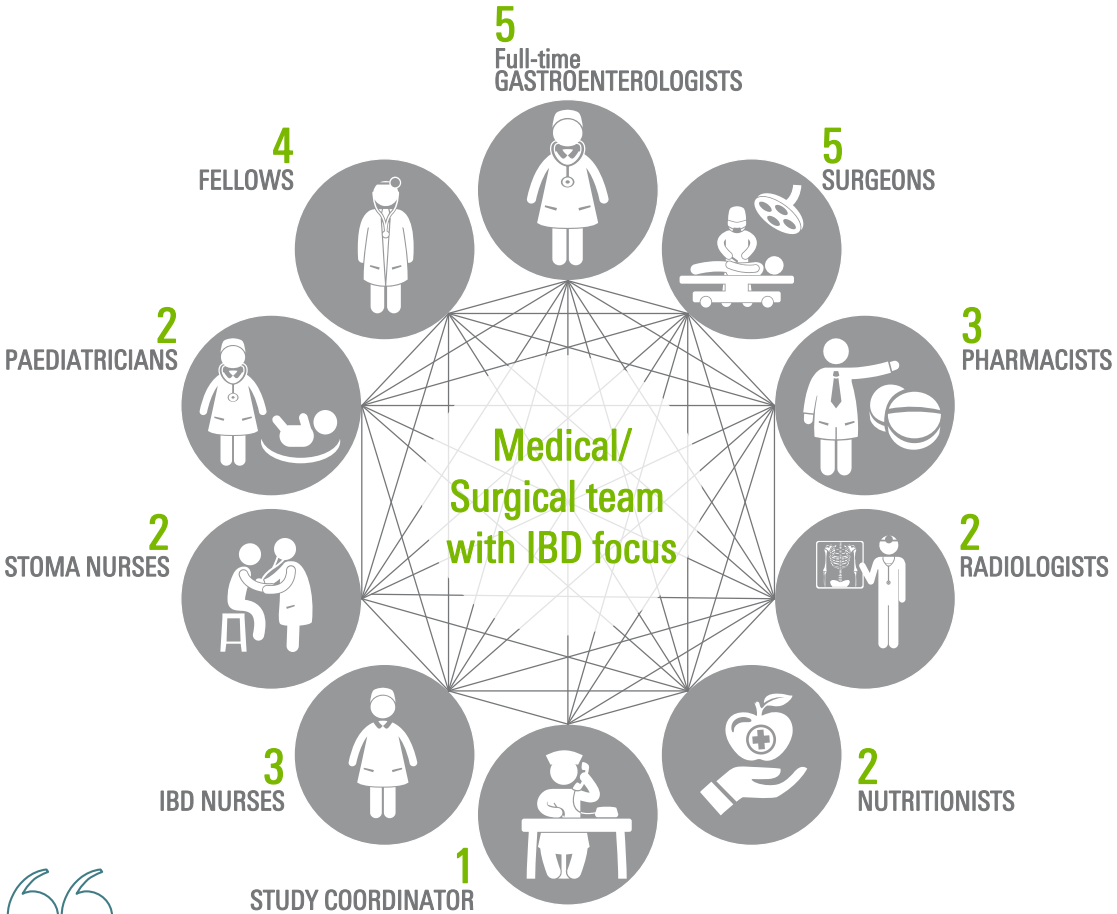
Research is well embedded in the day-to-day activities of the IBD team. IBD physicians also act as supervisors for IBD fellows who currently are doing their PhDs

The IBD team can refer people for an **'e-medicine'** service, a self-counselling tool available online to help patients cope with their disease

St Vincent's Hospital – IBD TREATMENT TEAM

Melbourne and suburbs, tertiary centre for Victoria

~2,000 active patients



By us doctors and nurses working with them, our patients realise that they have power and with power comes responsibilities.
(Dr Sally Bell)

KEY FEATURES OF CENTRE:

- St Vincent's Hospital was the first IBD centre in Australia, created in early 1990s, as a result of a shared interest of a group of physicians and surgeons to produce a combined service; now it has significant critical mass in terms of patients and clinical expertise
- Successful use of tele-health and outreach clinics
- Psychological medicine forum and dedicated support services

A world-class centre requires three things: clinical excellence, a strong research pedigree and a culture of teaching and training.
(Professor Kamm)

St Vincent's Hospital – SUMMARY

STRENGTHS

Weekly MDT meeting attended by approximatively 20 people including registrars, radiologists, pathologist and surgeons

Large number of IBD patients, many of whom are challenging cases. This provides 'critical mass' which helps maintain quality of care

All cases are discussed at the MDT and the management of these cases undergo intense peer review. A range of opinions are exchanged and challenging discussion is encouraged

KEY INFLEXION POINTS FOR PATIENT CARE

Making a diagnosis as soon as possible is important, and both GPs and the gastroenterology community around the centre do not always refer patients to see a specialist when potential signs of IBD occur

In the first 2 years after diagnosis, it is critical to work with the patient intensively – by educating the patient up front you can better equip them to deal with a chronic disease

It is important to recognise when treatment is not working and move to 'plan B' rapidly. It is also important to understand that surgery is one of the tools of the management of the disease, not a standalone intervention or treatment of last resort after the failure of medical therapy

SUCCESSFUL INTERVENTIONS

The IBD team can refer people for an 'e-medicine' service, a self-counselling tool available online to help patients cope with their disease

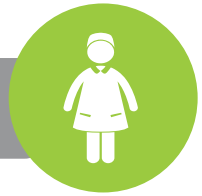
One of the part-time IBD nurses dedicates most of her time to enable a swift handling of the biologics administrative burden. She ensures that the right tests are performed and the results are documented so the paperwork can be completed on time to ensure that patients are able to access therapy as soon as possible

St Vincent's set up a tele-health clinic that is run for patients who are in more remote locations. The clinic is run by an IBD physician and the IBD nurse, both of whom interact with patients via Skype during pre-agreed appointments. These sessions are designed to supplement the clinic visits, and to provide an update of treatment and progress

St Vincent's Hospital

What would you change if you had the opportunity?

ADDITIONAL IBD NURSES



Why?

The IBD nurses at St Vincent's are very highly regarded, and are seen to improve outcomes and compliance. However, they are stretched for capacity and require more support with an additional IBD nurse

How?

Create a business case for more funding and then work on recruiting, hiring and training more specialised IBD nurses as funding becomes available

MONITOR IMMUNOSUPRESSANTS

Why?

Patients taking immunosuppressants require close monitoring for good care. This is currently challenging, as there is no dedicated blood test recording system

How?

The staff at St Vincent's are currently designing a booklet with pathologists to record blood test results so the patient on immunosuppressants can refer to them on subsequent visits

What would you advise a less specialised centre to implement, in order to improve their standards?

SURGERY DECISION MAKING

Why?

Surgery can be very helpful in improving quality of life, but it has been observed that patients can be reluctant to undergo operations and consequently suffer from an unnecessary deterioration of their condition

How?

Improve surgical decision making through the use of MDT discussions and help patients understand the impact surgery will have on their lives from an early stage of their treatment process onwards

PEER REVIEW

Why?

A centre needs to understand what it can do well; where it is unable to treat more complex patients, it should seek advice externally

How?

The department should have a culture that encourages peer challenge of patient management, and be willing to accept advice from external experts

Fukuoka University Chikushi Hospital

Fukuoka, Japan

Fukuoka University Chikushi Hospital

Our visit revealed a number of detailed specifications about Fukuoka University Chikushi Hospital's operations

IBD treatment team

Weekly and ad-hoc **MDT** meetings attended by physicians, surgeons, IBD nurses, pathologist, radiologist, psychologists, registrars and fellows

The team is strong and comprises **five GI nurses with an interest in IBD**, all of whom work with IBD patients and the doctors treating them

Among the radiologists working at Fukuoka University Chikushi Hospital, **one radiologist** has an interest in IBD and regularly attends the weekly MDT where participants can share their opinions with the rest of the team

Multiple **allied health** professionals such as dieticians, leucocytapheresis technicians and stoma nurses support the team and interact regularly with doctors

Patient services

Motivated by their own experiences IBD nurses have recently started a **self-help forum for parents** of children that suffer from IBD

The centre focuses on a **close and regular re-evaluation of patients –** doctors follow-up with patients at least every 3 months and not only conduct standard tests but also make sure that they ask a comprehensive set of questions to understand the patient's condition

In order to **successfully manage patient expectations,** doctors at the centre try to build strong rapport and make sure that the patients understand that their condition needs to be managed carefully for the rest of their lifetime

Biologics are widely available and patients can choose which biologic they prefer

Selected treatment approaches

Strong focus on **patient experience** and interaction with IBD specialist team; strong focus on seeing the lifelong nature of the condition and where possible scheduling **surgery** so that it is least disruptive to the patient (*e.g.* not during final school exams, or before a marriage)

Endoscopies are performed by gastroenterologists or other endoscopy experts if necessary

Additional points of relevance

Yearly 'homecoming days' for patients to discuss the newest developments in IBD treatment as well as their own care and treatment success

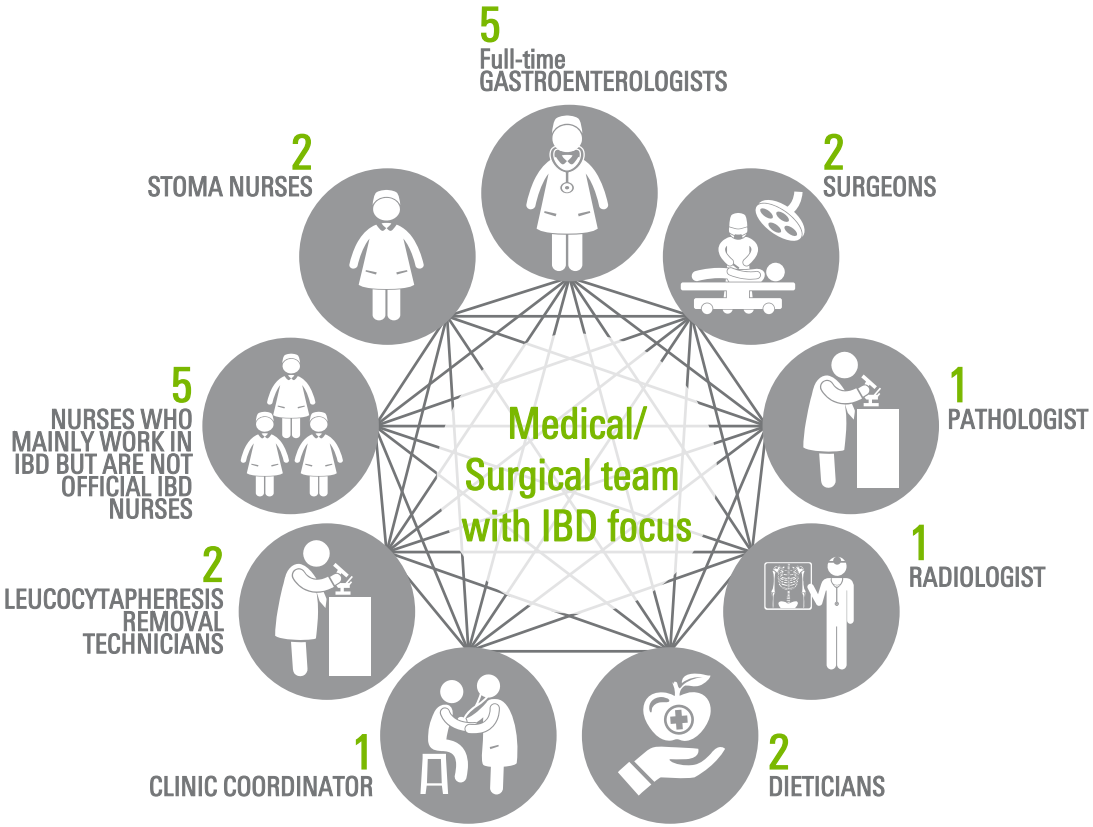
Information sessions for community doctors held almost monthly (depending on demand; sometimes held less frequently)

Research is currently conducted in all clinical IBD fields and in collaboration with study groups across Japan

Fukuoka University Chikushi Hospital – IBD TREATMENT TEAM

Whole Kyushu Island

~1,300 active patients



KEY FEATURES OF CENTRE:

- Strong patient focus for a very large patient population, despite being over-burdened with the volume at times
- Regular cooperation and meetings between all the departments that are involved in IBD treatment (gastroenterology department, pathology, imaging and GI surgery)
- Strongly motivated nursing staff who try to focus on the needs of patients and their families

I take time to have an in-depth consultation with my patients. They can also call me if their symptoms change. This is key to establishing a long-term relationship of trust.
(Professor Matsui)

We work with other teams in the hospital if we are unsure; this normally helps to establish a prompt and accurate diagnosis.
(IBD GI specialist)

Fukuoka University Chikushi Hospital – SUMMARY

STRENGTHS

Close working multi-disciplinary team who are extremely motivated and work very hard to improve their knowledge of IBD

Very active and engaged nurse population who have initiated IBD educational meetings for gastroenterology nurses and other interested nurses in the hospital

Patient centricity, with patients given some treatment choice, and educational and outreach days conducted regularly

KEY INFLEXION POINTS FOR PATIENT CARE

Quick differential diagnosis and prompt initiation that aim to avoid disease progression

Patients are far more likely to take ownership of their condition if they have a positive relationship with their doctor. Clear communications allow for realistic patient expectations about the condition and the realisation that it requires lifelong treatment

Regular follow-ups of established patients that include a thorough discussion of the patients' symptoms, to ensure that any potential signs of complications/flare ups are captured

SUCCESSFUL INTERVENTIONS

The clinic holds yearly 'homecoming days', where patients can come and discuss the newest developments in IBD treatment as well as their own care. They can also exchange tips and stories on an informal basis

The centre has established a culture that accepts IBD as a lifelong condition and tries to accompany patients through the most important phases of their life. They achieve this through using active advice and disease management

Dedicated team training initiatives to focus on achieving high patient satisfaction scores help to put patients at the centre of everything that the treatment team does. This engenders a culture of continuous improvement

Fukuoka University Chikushi Hospital

What would you change if you had the opportunity?

FOCUS ON FEMALE PATIENTS

Why?

Female patients are often hesitant to share their symptoms openly. As a result their quality of life can be worse than it needs to be

How?

In order to integrate the female patient perspective, female nurses try to pay special attention to what these patients report, and share any unusual symptoms mentioned with the treating doctors. Dedicated education sessions for female patients would be a very helpful supplement to this activity

INTRODUCE SPECIALIST NURSE

Why?

Currently, nurses are trained informally by the doctors, and try to train themselves wherever possible (there is a great spirit of patient centricity and service improvement amongst the nursing staff). However there is no dedicated IBD nurse

How?

The creation of dedicated IBD nurse roles would reflect the specialist status that many nurses have obtained through their training, and would also ease the burden on the existing GI nurses

What would you advise a less specialised centre to implement, in order to improve their standards?

STRONG EXPERTISE OF STAFF AND DOCTORS

Why?

The centre is a key one for patients in the Kyushu region (although there are others available). It is consequently important that all doctors and staff are highly trained, so that primary care doctors continue to feel confident in referring patients to this centre, and patients feel secure in the knowledge of receiving high-quality treatment

How?

There is a strong focus on training doctors and staff in Fukuoka University Chikushi Hospital, which has allowed the centre to build its strong reputation during the last 10-15 years

MULTI-DISCIPLINARY APPROACH

Why?

Whilst an IBD expert is of crucial importance, they cannot work alone. A strong team approach is necessary to make an IBD centre successful

How?

Making sure that the different departments (*e.g.* radiology, pathology, GI and surgery) work together closely is an approach that is fully established at the centre and determines its accurate diagnosis approach

東邦大学

Toho University Sakura Medical Centre

Greater Tokyo, Japan

Toho University Sakura Medical Centre

Our visit revealed a number of detailed specifications about Toho University Sakura Medical Centre's operations

IBD treatment team

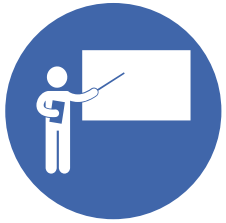
Weekly and (if needed urgently) *ad-hoc* **MDT** meetings comprising gastroenterologist, radiologist, pathologist and GI surgeon

Two to three **GI nurses** who work with IBD patients and who, amongst other duties, accompany the doctors on ward rounds, and educate and support patients

Endoscopies performed close to the consultation rooms, usually by IBD specialist doctors, every 1-2 years for regular patients

Surgery discussed freely with patients and only performed after certain threshold breaches, in close collaboration with physicians and allowing for patient life events

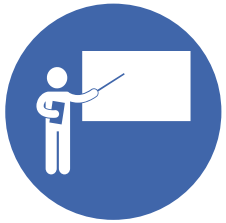
Patient services



Research undertaken in several fields, with the hospital having an extensive clinical research programme

Fully reimbursed **biologics** with little administrative burden; choice of biologic given to patients with nurses conducting one-on-one training on how to administer

Hospital-wide **psychiatric** service available but rarely used by patients due to stigmatisation. However the IBD department works to acknowledge and address psychological needs



Outreach and education clinics for both community doctors and patients through 'homecoming days' held at least once per year, during which patients are informed about latest IBD treatment developments and can also discuss their treatment progress

Selected treatment approaches

Multiple **allied health** professionals' support, including one IBD experienced dietician, two leukocytapheresis technicians and three stoma nurses who interact regularly and frequently with doctors

One specialist **radiologist** who participates in the MDT, with patients having full access to and a slight preference for MRI

Additional points of relevance

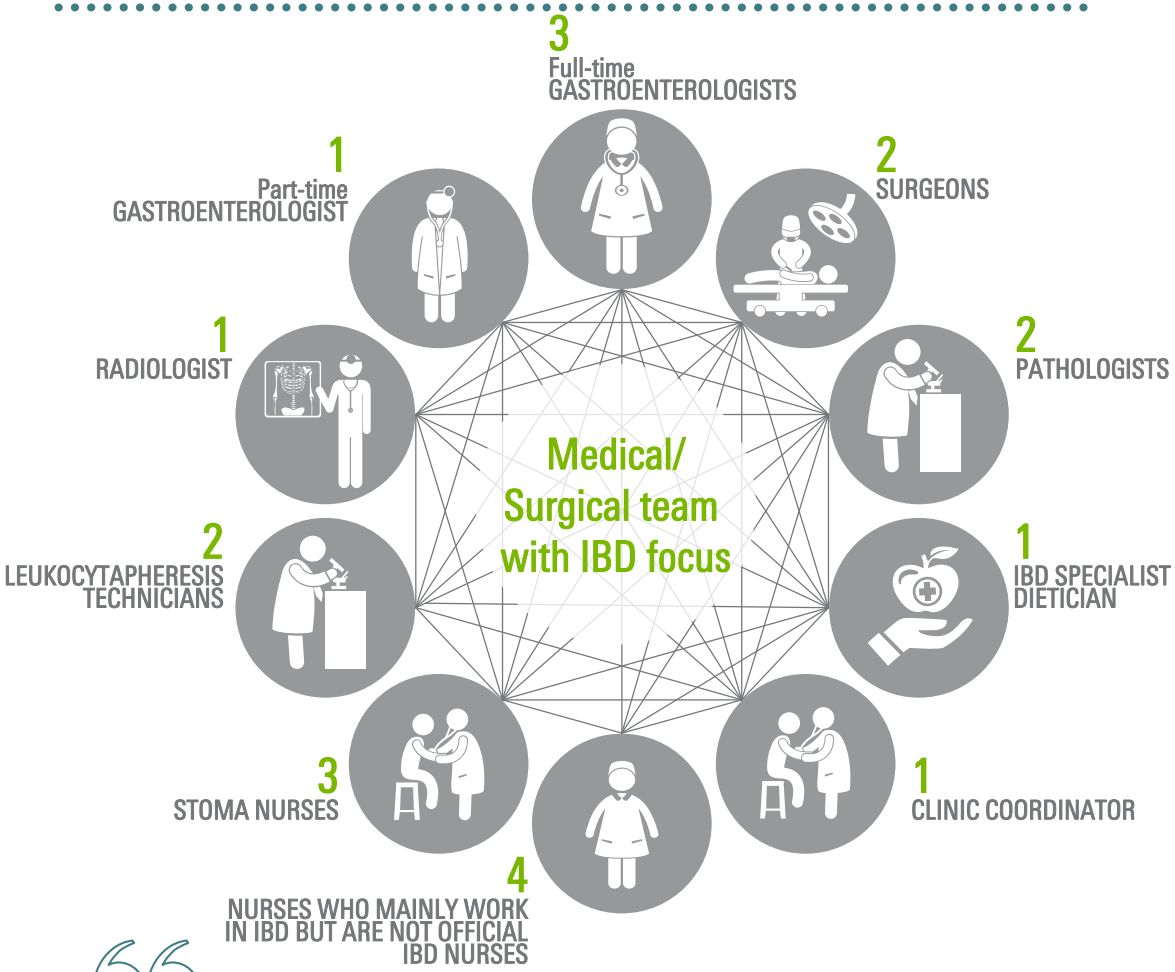
Paediatric patients mostly treated by paediatric specialists, though Professor Suzuki treats a number of adolescent patients, with the team taking care to address the emotional needs of younger patients

Formal and informal **patient support groups** where 'established' IBD patients pass on knowledge and tips during yearly homecoming days and education sessions

Toho University Sakura Medical Centre – IBD TREATMENT TEAM

Greater Tokyo

~2,000 active patients



KEY FEATURES OF CENTRE:

- Regular cooperation and meetings between all the departments that are involved in IBD treatment (gastroenterology department, pathology, imaging and GI surgery)
- Strongly motivated nursing staff who endeavour to educate themselves on IBD patients and their treatment
- Very motivated and charismatic clinic leader who built the centre from the ground up

I discuss all treatment options with my patients. It helps me to build rapport with them and as a result they trust me and talk to me freely about their worries and symptoms.
(Professor Suzuki)

We pay special attention to what's going on in our patients' lives and design their treatment around this. As a result they trust us and love talking to us and always take their medication!
(Senior nurse)

Toho University Sakura Medical Centre – SUMMARY

STRENGTHS

- Close working multi-disciplinary team
- Passionate staff with a willingness to proactively improve their own knowledge of IBD
- Patient centricity, with patients given some treatment choice, and educational and outreach days
- Strong reputation of head of IBD centre Professor Suzuki as an expert

KEY INFLEXION POINTS FOR PATIENT CARE

- Quick differential diagnosis to avoid disease progression
- Continual education of patients to encourage patient ownership of their condition, reducing anxiety and improving treatment adherence
- Consideration of life events (weddings, exams) when treating IBD to reduce disruption and improve quality of life

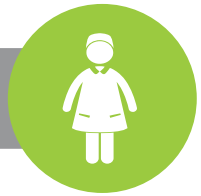
SUCCESSFUL INTERVENTIONS

- TUSMC uses the MDT approach for diagnosis as it is systematic, quick and allows the right level of involvement from other departments
- Doctors work closely with patients when choosing treatment options, and inform patients about surgical options early
- Doctors put special effort into acknowledging important times in patients' lives, and discuss ways to manage IBD while minimising disruption during these periods

Toho University Sakura Medical Centre

What would you change if you had the opportunity?

INTRODUCE SPECIALIST NURSE



Why?

Currently, nurses are trained informally by the doctors, and try to train themselves wherever possible (there is a great spirit of patient centricity and service improvement amongst the nursing staff). However there is no dedicated IBD nurse

How?

The creation of dedicated IBD nurse roles would reflect the specialist status that many nurses have obtained through their training, and would also ease the burden on the existing gastroenterology nurses

CREATE ROLE FOR NURSE IN MDT MEETING

Why?

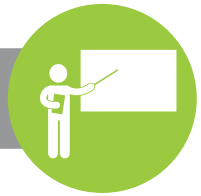
There is very good cooperation between nurses and doctors – an aspect raised by all interviewees. However nurses do not currently take part in the MDT meetings except on special occasions where the cases are unique or complex

How?

If possible, an official requirement should be put in place for a nurse to attend MDT meetings

What would you advise a less specialised centre to implement, in order to improve their standards?

TRAINING OF STAFF



Why?

Well-informed staff are key to achieving correct diagnosis and effective treatment. Patients also feel more reassured knowing that they are treated by up-to-date specialists

How?

Through inter-staff knowledge sharing. Prof. Suzuki built the IBD centre from the ground up, and attributes its current success to the effort he invested in training his staff, and educating them about IBD and IBD treatment

OUTREACH INTO THE COMMUNITY

Why?

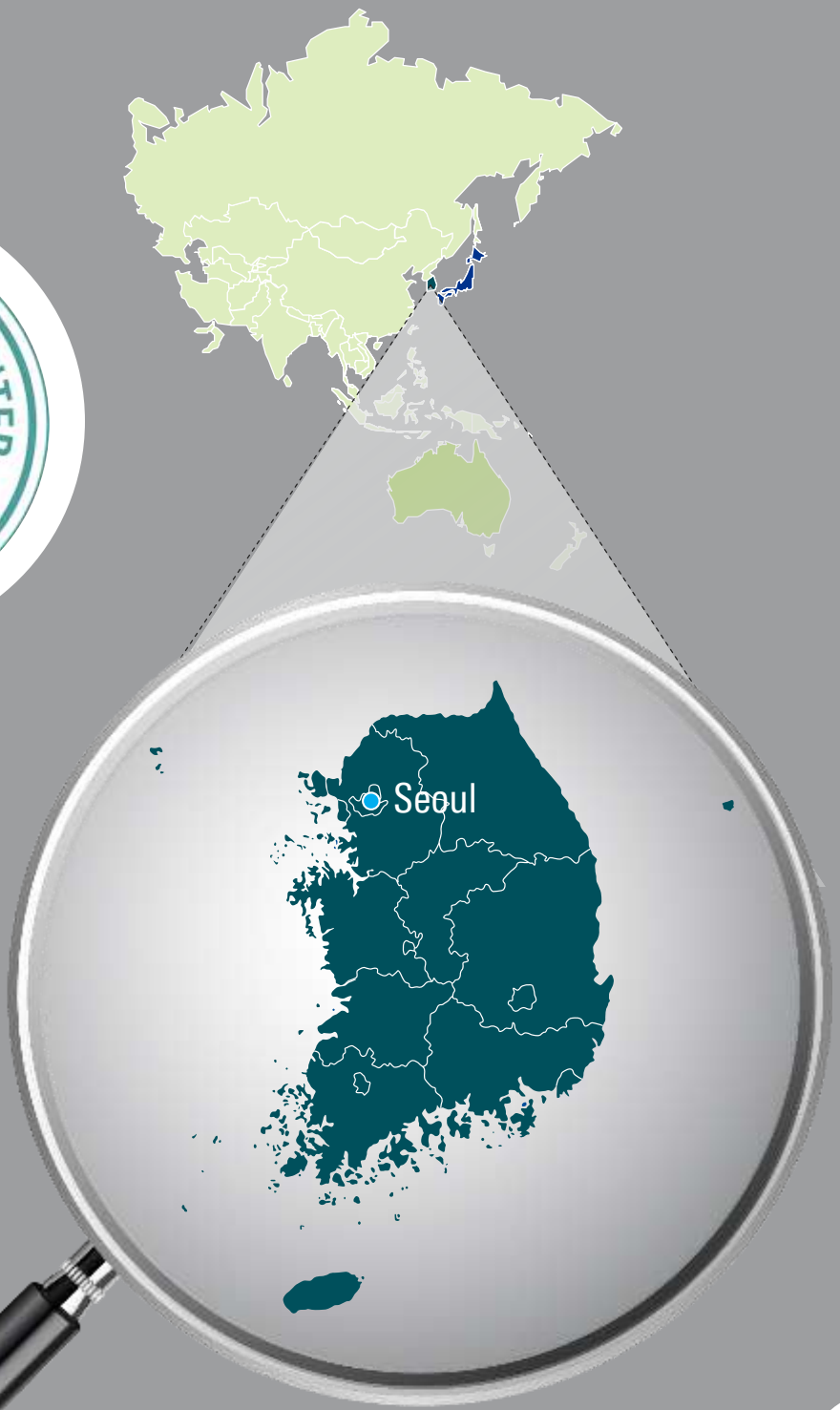
Regular communication with community doctors will ensure a lower mis-diagnosis rate and enhance the reputation of the centre

How?

It is important to introduce IBD and its treatment options to local GPs. In particular it is very relevant to introduce diagnostic criteria to help reduce mis-diagnosis and delayed referral of patients

Asan Medical Centre

Seoul, South Korea



Asan Medical Centre

Our visit revealed a number of detailed specifications about Asan Medical Centre's operations

IBD treatment team

Weekly and (if needed urgently) *ad-hoc* **MDT** meetings comprising gastroenterologists, radiologists, GI surgeons, pathologists and IBD nurses

Two dedicated **IBD nurses** supported by several gastroenterology nurses and interview nurses who meet patients before doctor consultations to capture their symptoms

Two specialist **radiologists** who participate in the MDT, with patients having full access to a range of imaging

Multiple **allied health professionals**' support, including one dietician and two stoma nurses who interact regularly and frequently with doctors

Patient services

Hospital-wide **psychiatric** service available but rarely used by patients due to stigmatisation

Paediatric patients treated by paediatric specialists until they are 17-19 years old, with a highly successful transition process into adult care

Outreach and education clinics for both community doctors and patients through regular training across the country

Some administrative burden for **biologics** which can be prescribed once a certain level of the Crohn's Disease Activity Index and Mayo score is achieved and conventional treatment is found to not work

Selected treatment approaches

Surgery discussed freely with patients and only performed after certain threshold breaches, in close collaboration with physicians and allowing for patient life events

Endoscopies performed close to the consultation rooms usually by IBD specialist doctors, 1-3 years for regular patients

Additional points of relevance

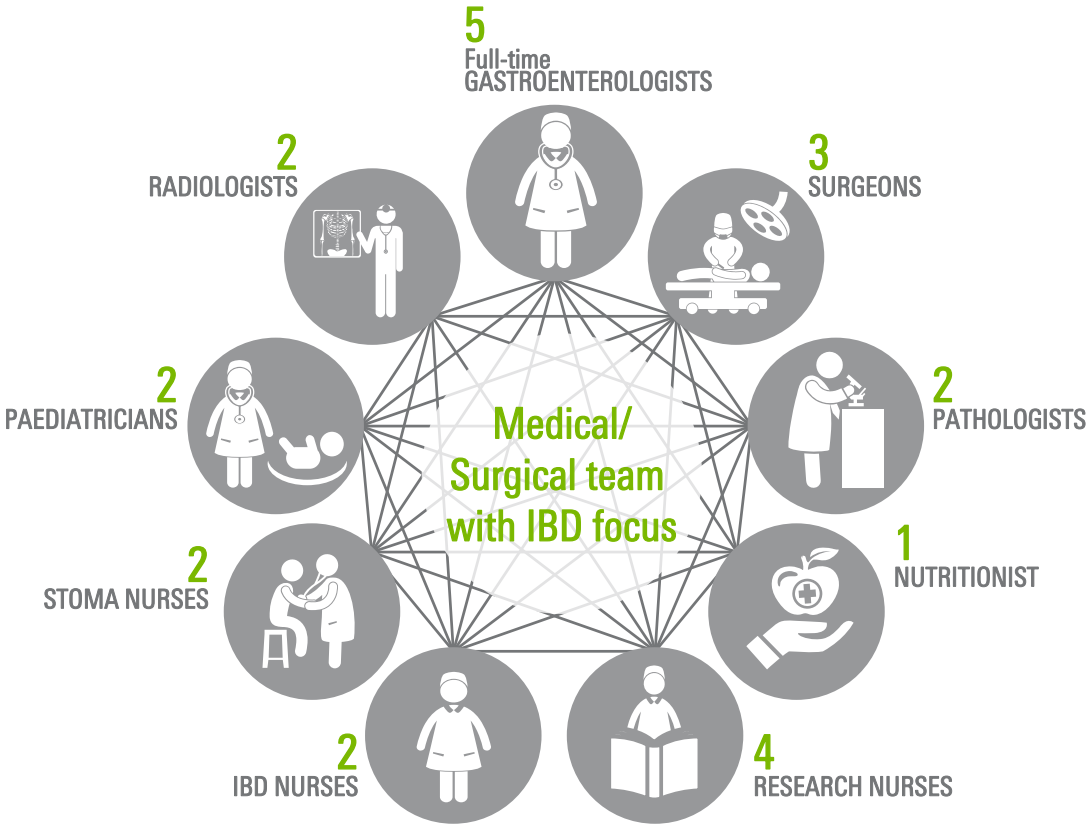
Research is a particular strength, with multiple research projects in drug treatment options and genetic IBD research

Technology is very advanced and multiple forms of technology are used to capture patient education, train doctors and educate patients on their treatment

Asan Medical Centre – IBD TREATMENT TEAM

Seoul and South Korea

~5,700 active patients



KEY FEATURES OF CENTRE:

- Strong patient focus for a very large patient population, despite being over-burdened with volume at times
- Strong focus on technical integration, especially in regards to using a long-established patient and imaging database for training and research
- The Centre conducts routine training programmes for doctors across the country

We have a long tradition of collecting data and referencing it where necessary. We are also used to working in an MDT – this allows us to be world class when it comes to differential diagnosis.
(Professor Yang)

Our patients really appreciate the effort we spend in informing and educating them. As a result they trust us and have high patient satisfaction levels.
(Professor Park)

Asan Medical Centre – SUMMARY

STRENGTHS

- Close working multi-disciplinary team, that has access to a unique EMR and IBD imaging database
- Patient centricity, with patients given some treatment choice, and educational and outreach days being conducted regularly
- Strong reputation as a key IBD research and treatment centre in South Korea

KEY INFLEXION POINTS FOR PATIENT CARE

- Quick differential diagnosis to avoid disease progression
- Providing insightful information to patients. This is important to prevent misinformation, causing patients to delay treatment and feel anxious
- Continuous communication channels with patients are important to prevent anxiety, improve compliance and monitor symptoms

SUCCESSFUL INTERVENTIONS

- Asan Medical Centre has a unique EMR system that tracks all patient data, and is updated by patients on self-service computers during follow-up appointments. This gives patients a sense of ownership and empowerment
- Asan Medical Centre has developed its own computer based IBD education programme that allows patients to obtain information on IBD and IBD treatment in an interactive way
- Dedicated team training initiatives, and a focus on achieving high patient satisfaction scores puts the patient at the centre of everything that the treatment team does

Asan Medical Centre

What would you change if you had the opportunity?

INTERACTIVE PATIENT INFORMATION

Why?

Currently, patients can access their information at self-service stations in the hospital, but it would be helpful if they could access them from home, or via their smartphone

How?

Create an interactive and web-based platform that patients can access remotely using a special password to guarantee the security of their data

BETTER INFORMATION FOR COMMUNITY DOCTORS

Why?

Regular communication with community doctors will ensure a lower mis-diagnosis rate and enhance the reputation of the centre

How?

It is important to introduce IBD and its treatment options to local GPs. In particular it is very relevant to introduce diagnostic criteria to help reduce mis-diagnosis and delayed referral of patients

What would you advise a less specialised centre to implement, in order to improve their standards?

BUILD A RESEARCH AND PATIENT DATABASE

Why?

A strong database will allow junior doctors to get a higher level of knowledge on IBD and will allow them to be better at the differential IBD diagnosis

How?

Start collecting patient data as soon as the centre is established, and ideally automate this data collection, *e.g.* via EMR

STRONG TEAM ETHIC AND PATIENT FOCUS

Why?

A team that is passionate about delivering great care for its patients and that works across departments and disciplines, will be more successful in treating IBD patients

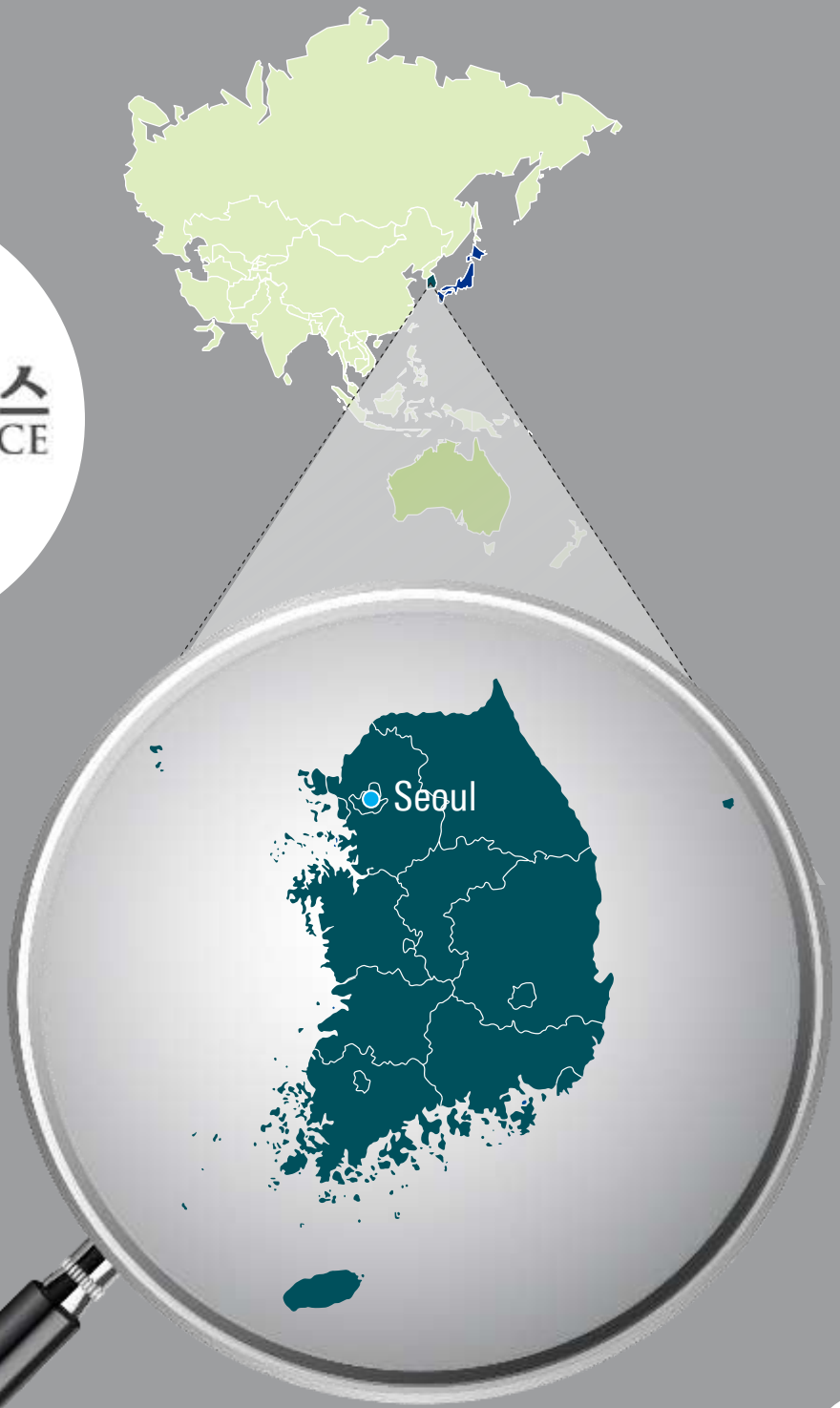
How?

Ensure that the whole team aligns to the ethic of delivering great care (*e.g.* through team value statements and rigorous team selection processes). Establish an MDT from the very outset of the centre's existence

세브란스 SEVERANCE

Yonsei Severance University Hospital

Seoul, South Korea



Yonsei Severance University Hospital

Our visit revealed a number of detailed specifications about Yonsei Severance University Hospital's operations

IBD treatment team

Weekly and (if needed urgently) *ad-hoc* **MDT** meetings comprising gastroenterologists, radiologists, GI surgeon, pathologist and occasionally the IBD nurse

One **IBD nurse** supported by several GI nurses, who meet established patients before doctor consultations and runs the IBD support hotline

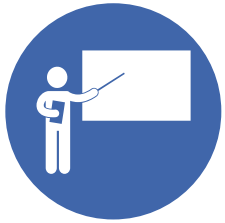
One specialist **radiologist** who participates in the MDT

Multiple **allied health professionals**' support, including one dietician and two stoma nurses who interact regularly with doctors

Patient services

Hospital-wide **psychiatric** service available but rarely used by patients due to fears of stigmatisation

Paediatric patients treated by paediatric specialists until they are 17-19 years old, with the following transition process having a high rate of success



Outreach and education clinics for both community doctors and patients through 'homecoming days' held at least once per year

Fully reimbursed **biologics** with little administrative burden; choice of biologic given to patients with nurses conducting one-on-one training on how to administer

Selected treatment approaches

Surgery discussed freely with patients and only performed after certain threshold breaches, in close collaboration with physicians and allowing for patient life events

Endoscopies performed close to the consultation rooms usually by IBD specialist doctors, every 1-2 years for regular patients

Additional points of relevance

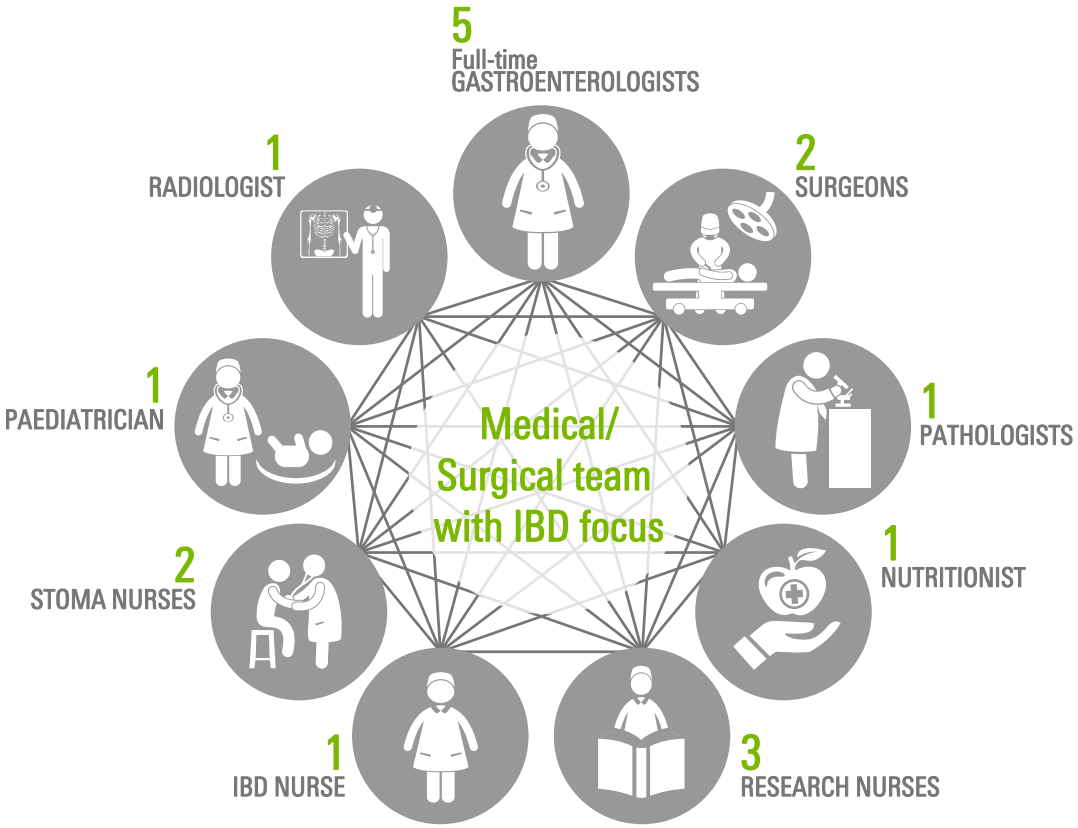
Research undertaken in several fields, particularly drug treatment options, and supported by two senior researchers and one research nurse

Technology used for patient education and communication, and Twitter and SMS used to update patients on appointments and check their well-being

Yonsei Severance University Hospital – IBD TREATMENT TEAM

Greater Seoul area

~2,000 active patients



KEY FEATURES OF CENTRE:

- Regular cooperation and meetings between all the departments that are involved in IBD treatment (gastroenterology department, pathology, imaging, nurses and GI surgery)
- Strong focus on paediatric care and successful patient transition from paediatrics to adult care
- Strong patient focus for a very large patient population, despite being over-burdened with volume at times

One of our key goals is a quick differential diagnosis, and we work across our multi-disciplinary team to achieve this.
(Professor Cheon)

Our patients know that when they come to see us that we will try our best to diagnose them quickly. That is what our centre is famous for.
(IBD GI specialist)

Patients are in true need of information. Our publications help them to address this. They can also call our hotline whenever they need – this really helps them to gain the security they need.
(IBD nurse)

Yonsei Severance University Hospital – SUMMARY

STRENGTHS

- Close working multi-disciplinary team
- Continuous quality control of care through peer review
- Patient centricity, with patients given some treatment choice, and educational and outreach days
- Strong reputation and rich history as the founding Korean IBD centre

KEY INFLEXION POINTS FOR PATIENT CARE

- Quick differential diagnosis to avoid disease progression
- Continual education of patients important to avoid misinformation and consequent treatment avoidance
- Continuous communication channels with patients important to prevent anxiety, improve compliance and monitor symptoms

SUCCESSFUL INTERVENTIONS

- YSUH conducts standard tests such as occult blood, faecal calprotectin and tests for parasites, while waiting for intestinal TB results, and uses the MDT
- Senior doctor regularly updates a blog containing the latest IBD information and seasonal advice. Blog is advertised to clinic patients
- The IBD nurse uses Twitter to communicate with patients and update them on information; SMS is used to remind patients about their appointments and check on their general well-being

Yonsei Severance University Hospital

What would you change if you had the opportunity?

BETTER ACCEPTANCE OF PSYCHOLOGICAL CARE

Why?

Patients in South Korea are currently not very accepting of psychological care and suffer from a higher emotional burden as a result

How?

Create more awareness and acceptance amongst patients and explain the connection between psychological/emotional well-being and perceived physical well-being

BETTER INFORMATION FOR COMMUNITY DOCTORS

Why?

Regular communication with community doctors will ensure a lower mis-diagnosis rate and enhance the reputation of the centre

How?

It is important to introduce IBD and its treatment options to local GPs. The centre is already holding yearly information sessions for regional doctors which they believe have reduced the mis-diagnosis rate by about 20%

What would you advise a less specialised centre to implement, in order to improve their standards?

MULTI-DISCIPLINARY APPROACH

Why?

A strong multi-disciplinary team is key to treating this condition. Consequently, having an MDT is imperative for creating a successful IBD centre

How?

Schedule regular MDT meetings involving physicians, surgeons, pathologists, radiologists etc. to discuss challenging cases

STRONG TEAM ETHIC AND PATIENT FOCUS

Why?

Putting patients at the centre of any treatment effort will enable services to be delivered in a better way and improve patient satisfaction

How?

The team regularly uses surveys and informal conversations to track what their patients want (*e.g.* more usage of MRI for diagnostic purposes to reduce exposure to radiation)

KPMG

cutting through complexity

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