



cutting through complexity



Optimising the Patient Pathway:

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

Findings from Dubai, Kuwait, Qatar and Saudi Arabia

GBL/HUG/0915/0564

This study was commissioned and solely funded by AbbVie as part of their QUANTUM initiative.

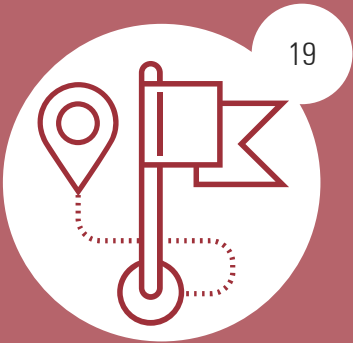


AbbVie had no role in the design and conduct of the study, collection, management, analysis and interpretation of data, or preparation, review and approval of this report.

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OUR APPROACH



KEY FINDINGS



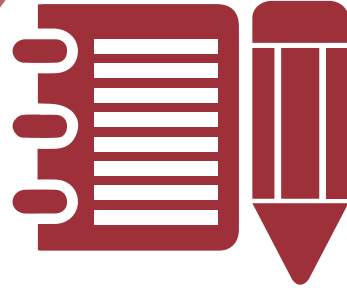
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Glossary

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





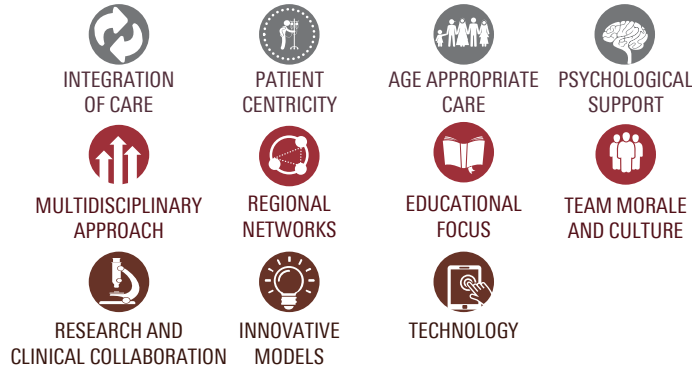
EXECUTIVE SUMMARY

EXECUTIVE SUMMARY

Several sources were used to meet the objectives of this project

BUILD ON THEMES IDENTIFIED IN PREVIOUS REPORT FROM 8 CENTRES ACROSS EUROPE & CANADA

Build on themes developed during Vita 1



VISIT ONE SITE EACH IN DUBAI, KUWAIT, QATAR & SAUDI ARABIA

Sites in Dubai, Kuwait, Qatar and Saudi Arabia



Inflexion points along the patient pathway



MAP THE PATIENT PATHWAY & RELEVANT INTERVENTIONS

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 Dubai, Kuwait, Qatar and Saudi Arabia
- 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



MULTIDISCIPLINARY APPROACH



REGIONAL NETWORKS



EDUCATIONAL FOCUS



TEAM MORALE AND CULTURE

FORWARD-THINKING MINDSET



RESEARCH AND CLINICAL COLLABORATION



INNOVATIVE MODELS



TECHNOLOGY

We have added to these themes based on our wider experiences from additional centres in Dubai, Kuwait, Qatar and Saudi Arabia

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** the patient to be an active partner in their disease management
- ➔ However, the **degree to which patients want to influence decisions** about their care does vary depending on age and culture
- ➔ For example, younger, well informed patients tend to want to be involved in treatment decisions whereas older patients may want their doctor to **make decisions on their behalf**
- ➔ This can in particular be observed in Dubai and Saudi Arabia, where doctors report that young patients use the internet as a source of information and sometimes ask to change their treatment accordingly



CULTURALLY APPROPRIATE CARE

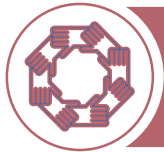
- ➔ Perhaps most notably in Dubai and Kuwait, we recognised that great care is not only age appropriate but also **culturally appropriate**
- ➔ Culture can have a **strong influence** on the expected roles of the doctors, nurses and other IBD team members
- ➔ Patient behaviours are equally influenced by cultural backgrounds, in particular the willingness to share symptoms openly with a treating doctor and attitudes 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
- ➔ Culturally, **psychological support can sometimes be hard to accept**
- ➔ In all countries that were visited, **family support plays a key role** in offering additional psychological care
- ➔ This means that patients may see a psychologist, but also that the psychologist and/or the treating doctor would see the patient and their family to discuss how to support the patient in the most effective way

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**
- ➔ Creating an ambience of trust that enables specialists to have **regular ad-hoc consultations** with each other is crucial
- ➔ However, the degree of **formality during colleagues' interactions varies** between countries
- ➔ For example, Qatari specialists **prefer to be formally consulted** and invited for multi-disciplinary team meetings, whereas Kuwaiti doctors **adopt a more informal approach**



PEER-TO-PEER CHALLENGE

- ➔ A strong team morale and collaborative culture enables doctors and nurses to provide **respectful challenge** to their colleagues
- ➔ Furthermore **it can facilitate 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 Qatar and Saudi Arabia, leading hospitals have a **formalised peer-review process**
- ➔ However in Kuwait peer-to-peer review is **less formalised** and takes place in a more spontaneous manner

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 a website or dedicated telephone line
- ➔ Patients also report **less anxiety** when they can refer to **'frequently asked questions' (FAQ)** webpages, or a point of contact on the telephone that answers their most urgent questions and discusses common symptoms
- ➔ Patients' attitudes towards the use of technology **vary slightly by country** but all visited centres in the region report great success through using webpages or telephone hotlines, which have improved patient attendance rates, and reduced cancelled procedures and emergency admissions



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

FIRST SYMPTOMS



FIRST SYMPTOMS

- 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 phase of treatment

SURGERY

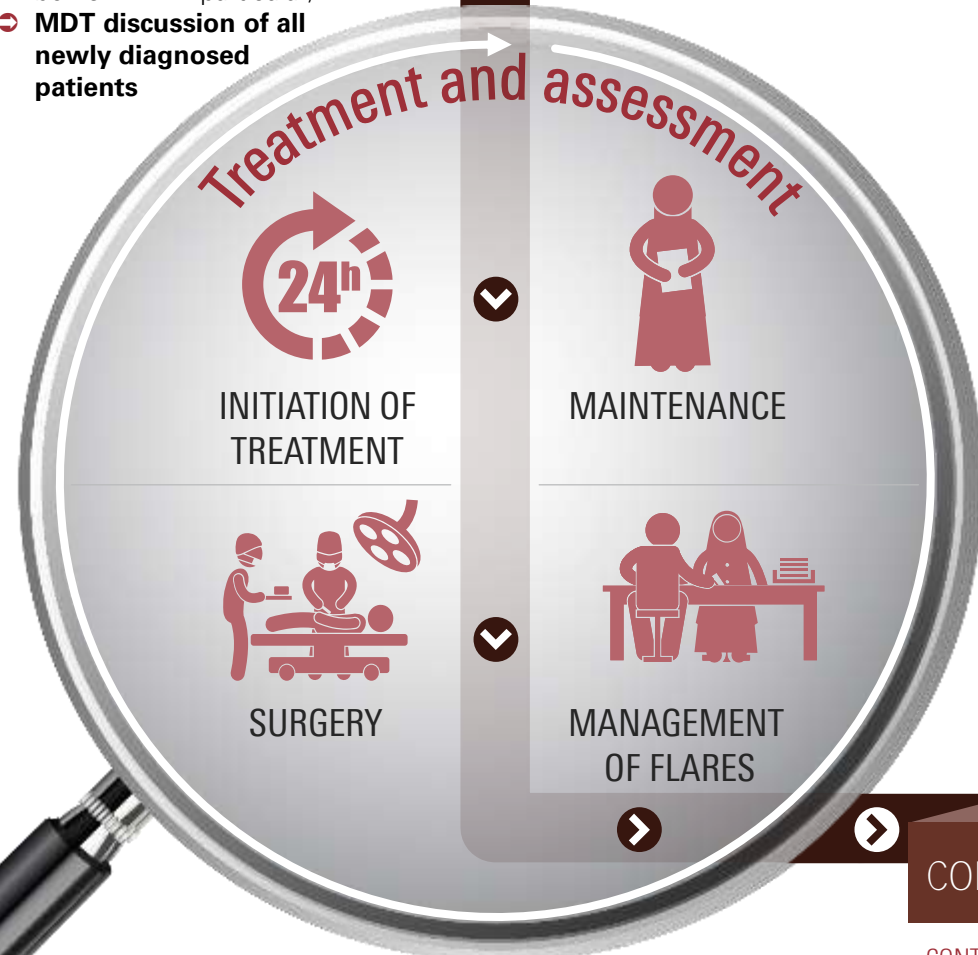
- Surgeons should have early involvement in patient management, and ideally should have extensive IBD experience
- Early decisions regarding surgical interventions in perianal disease
- Ideally, all surgical decisions should be discussed in an MDT setting

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



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

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 symptoms
- 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

ESTABLISH A STRONG IBD TEAM

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

Mubarak Al-Kabir Hospital in Kuwait was recently established with a team of specialist staff who all have excellent training and credentials from international institutions

IMPROVE DELIVERY OF CARE THROUGH REGULAR AND OBJECTIVE PEER REVIEW

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

Hamad Medical Corporation in Qatar has bi-monthly MDT meetings with a range of cross-speciality staff to ensure all views are captured

AND BEYOND!

- ➔ Foster a culture of continuous improvement

All centres have improvement programmes in place and try to regularly identify new areas where they can train staff and increase patient satisfaction



USE STEP-WISE INTERVENTIONS

START

ENSURE PATIENT FLOW FROM COMMUNITY REFERRALS

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

Rashid Hospital in Dubai hosts IBD education days for other hospital departments, and is planning to reach out to community doctors

HIRE AND TRAIN SPECIALISED IBD NURSING PERSONNEL

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

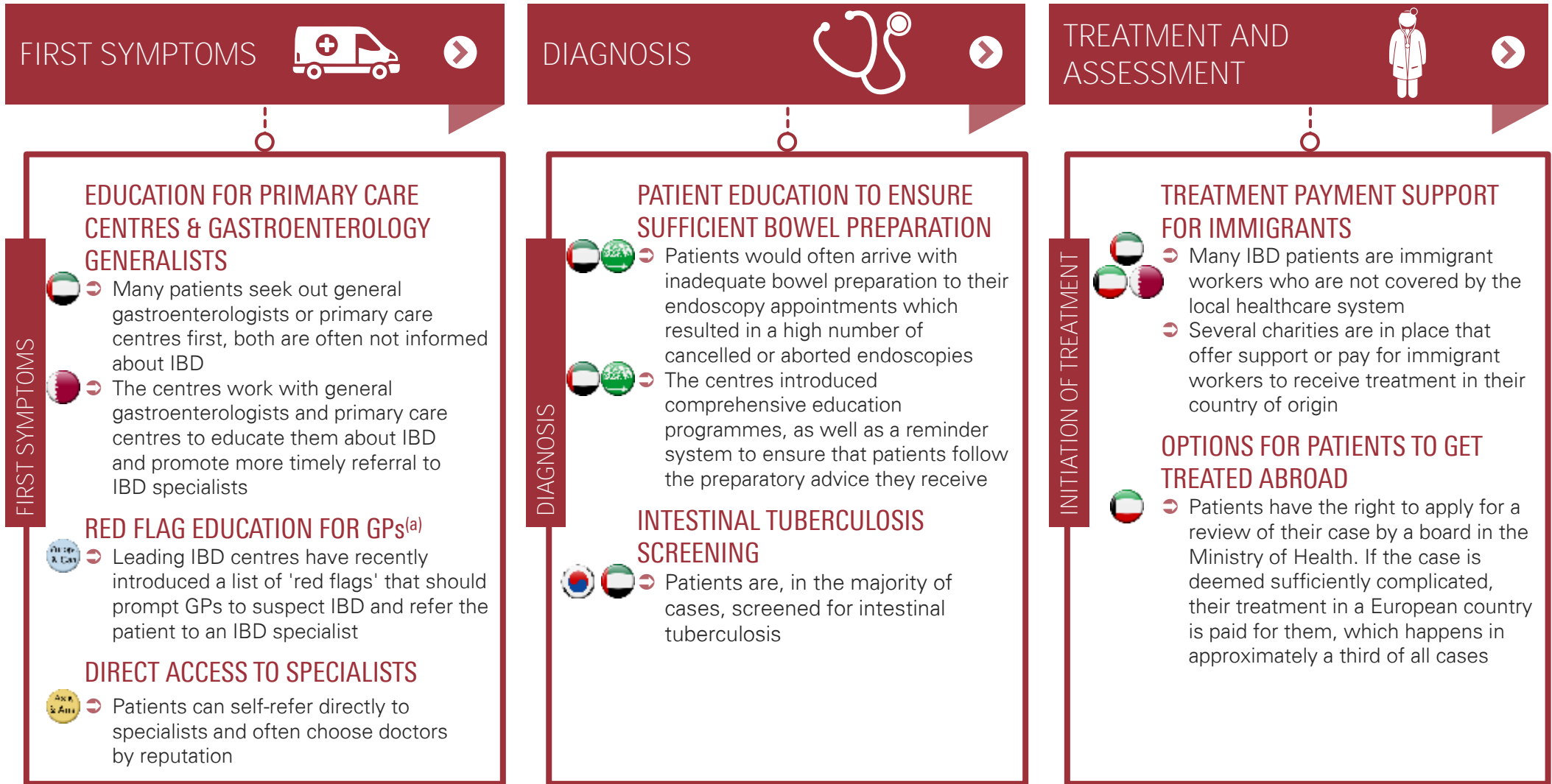
King Faisal Medical Centre in Saudi Arabia is funding the training of an IBD nurse at a leading healthcare university in the United States who will perform this role on completion of this training

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

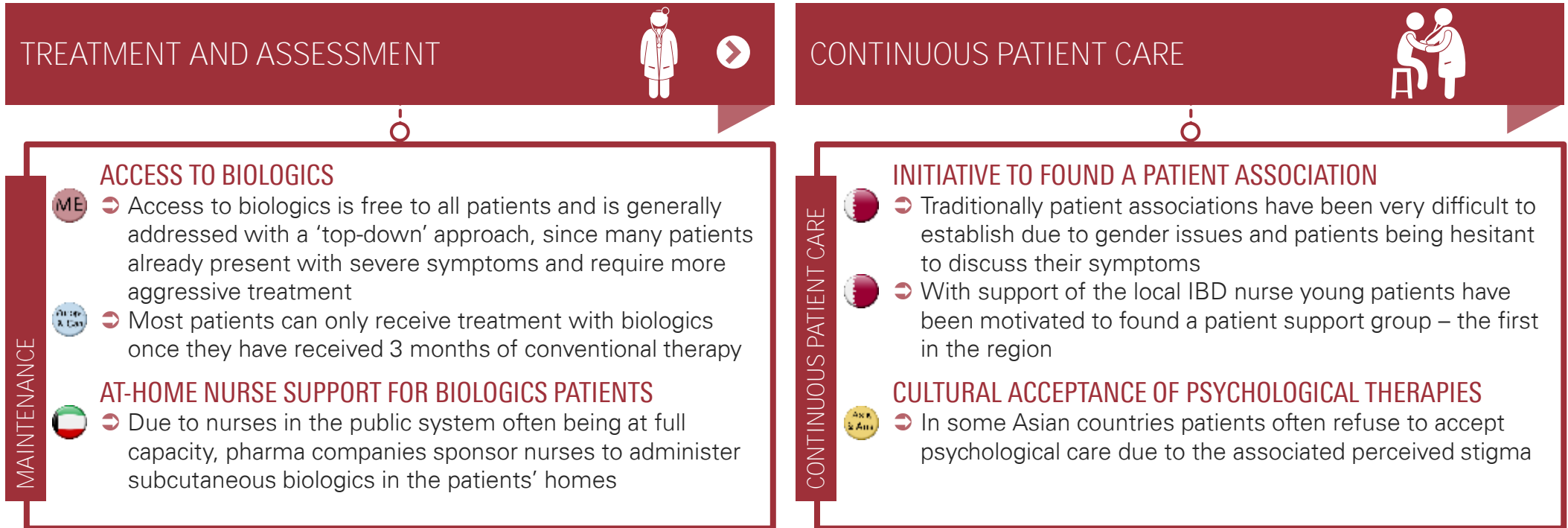
Hamad Medical Corporation's formal affiliations with John Radcliffe Hospital, Oxford, and UZ Leuven have led to sharing of research and joint training, and provides access to international specialist expertise

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

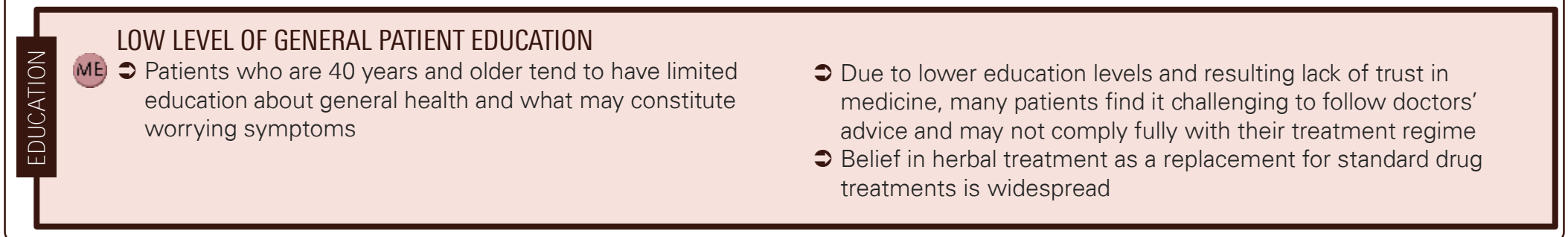


(a) For a study that identified early 'red flags' for Crohn's disease, see: Danese S, Fiorino G, et al. Development of Red Flags Index for Early Referral of Adults with Symptoms and Signs Suggestive of Crohn's Disease: An IOIBD Initiative, JCC, 2015
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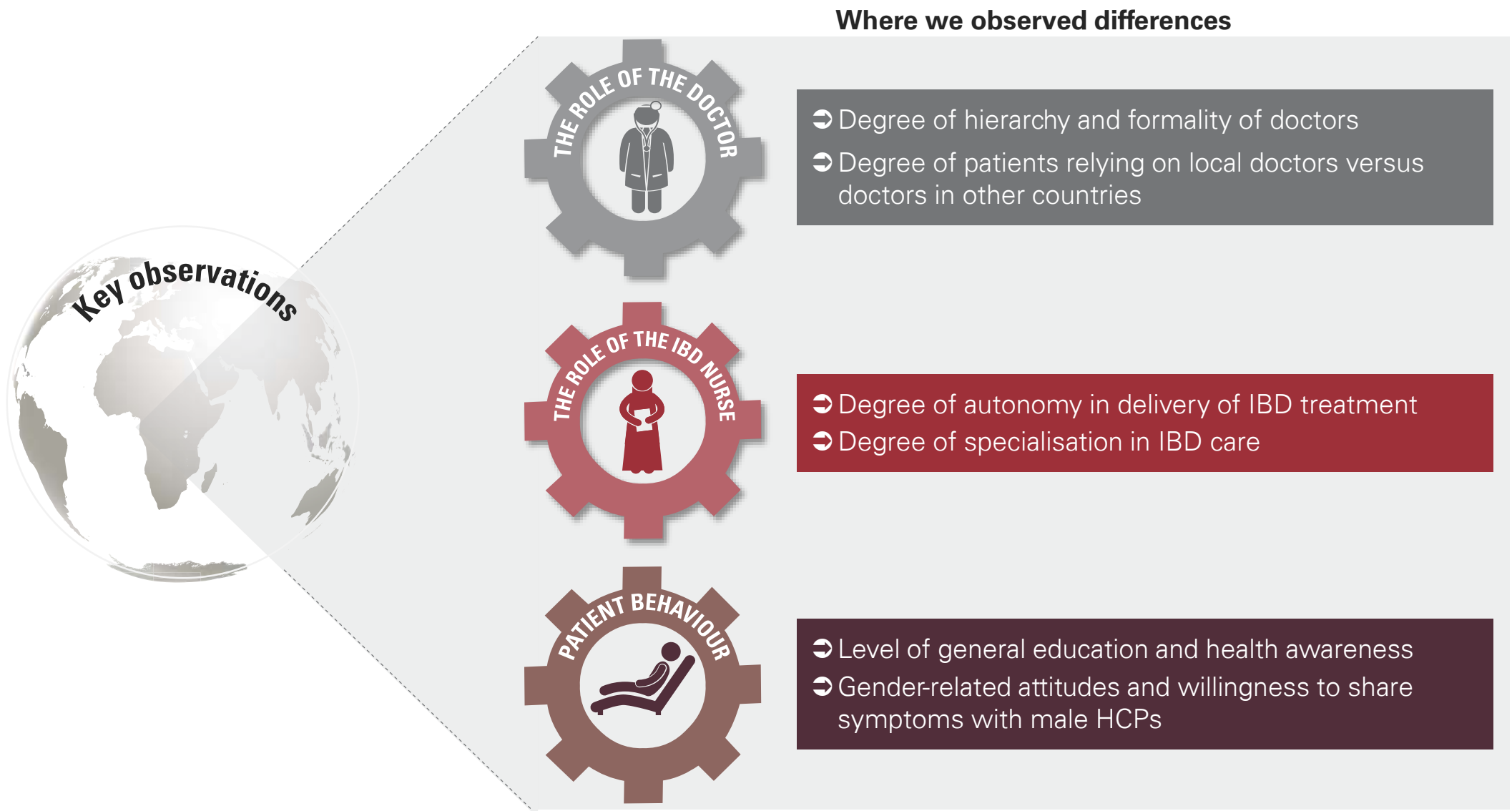
For each stage of the IBD pathway we also observed unique features for all the countries we visited (2/2)



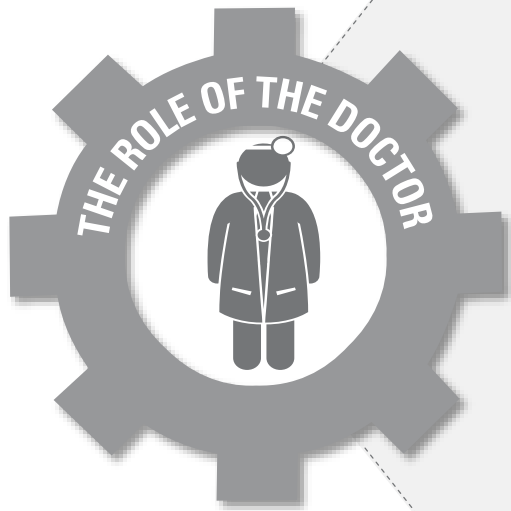
OTHER UNIQUE FEATURES FROM ACROSS THE PATIENT PATHWAY



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



The observed role of the doctor is similar across the four countries in the Middle East region that we visited, but there are significant contrasts compared with other geographies



- ⇒ Doctors are well respected and tend to have a more formal relationship with patients, especially in cases of a female patient being treated by 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

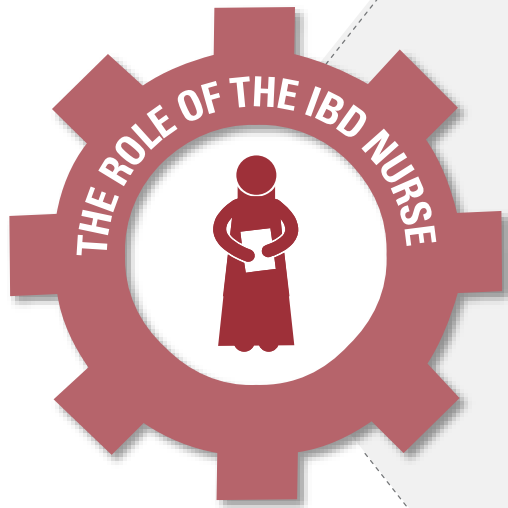


- ⇒ Doctors tend to have a friendly and informal relationship with patients
- ⇒ Publicly funded systems often do not have enough senior doctors to see to all patients, a factor in the development of extended nursing roles



- ⇒ The role of doctors varies between Japan, South Korea and Australia
- ⇒ Doctors in Japan and South Korea are very well respected and as a result tend to have a more formal relationship with their patients
- ⇒ In Australia doctors tend to have a very friendly and informal relationship with patients

IBD nurse roles vary across the Middle East region, Europe and Canada, and the Asian-Australian region in terms of their autonomy and degree of IBD specialisation



➔ General gastroenterology nurses (not IBD specialised) support the clinics with:

- Informal roles (e.g. patient counselling)
- Some care coordination activities such as scheduling of imaging and follow-up appointments
- Have a limited or no role in patient treatment decisions



➔ Dedicated IBD nurses in place:

- Play an active educational and pastoral role
- Capture patient data and coordinate treatment appointments
- Have often been trained abroad (UK and America)



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



- ➔ The role of IBD nurses varies by country. In general IBD nurses have a high degree of specialisation and autonomy
- ➔ Japan is an exception to this rule where generalist nurses work with IBD specialists but are not allowed to carry the title 'IBD nurse'



Patient behaviours are similar across the Middle East region, but there are some significant differences when compared to other regions



ME

- ⇒ Patients tend to have lower levels of general education and healthcare awareness, and consequently seek treatment late and take less ownership of their treatment regime. This is especially true of patients over 40
- ⇒ 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, preferring instead to share them with a female doctor or nurse

Europe & Can

- ⇒ Patients are normally well-educated and healthcare aware. They are happy to educate themselves and take ownership of their treatment regime
- ⇒ Female patients normally feel comfortable with being treated by a male doctor. A small proportion, however, feel embarrassed and prefer to share symptoms with a female doctor or nurse

Asia & Aus

- ⇒ Patients in South Korea and Japan are very well educated and take active ownership of their disease
- ⇒ Patients in Australia may live in rural areas and seek advice infrequently, which may lead to worsened symptoms, poorer engagement and later presentation to the doctor



OUR APPROACH

In this report we capture findings from four IBD centres in Dubai, Kuwait, Qatar and Saudi Arabia



RASHID HOSPITAL, DUBAI



- ➔ ~750 IBD patients across Dubai
- ➔ Four gastroenterologists
- ➔ Three surgeons
- ➔ One IBD nurse, supported by 12 general nurses

MUBARAK AL-KABIR HOSPITAL, KUWAIT



- ➔ Unknown number of IBD patients across the Rhallaway Sector, Kuwait (population of 1.3m)
- ➔ Two IBD-focused gastroenterologists
- ➔ Two general gastroenterologist surgeons
- ➔ No IBD nurses, but 94 general nurses in the gastroenterology unit

HAMAD MEDICAL CORPORATION, QATAR



- ➔ ~550 IBD patients across Qatar
- ➔ Three gastroenterologists
- ➔ Four surgeons
- ➔ No IBD nurses, but 25 general nurses in the gastroenterology unit

KING FAISAL MEDICAL CENTRE SAUDI ARABIA



- ➔ ~1,200 IBD patients across Riyadh and remote Saudi Arabia
- ➔ Two gastroenterologists
- ➔ Two surgeons
- ➔ No IBD nurses, but 32 nurses in the gastroenterology unit

➤ FIRST SYMPTOMS



➤ DIAGNOSIS



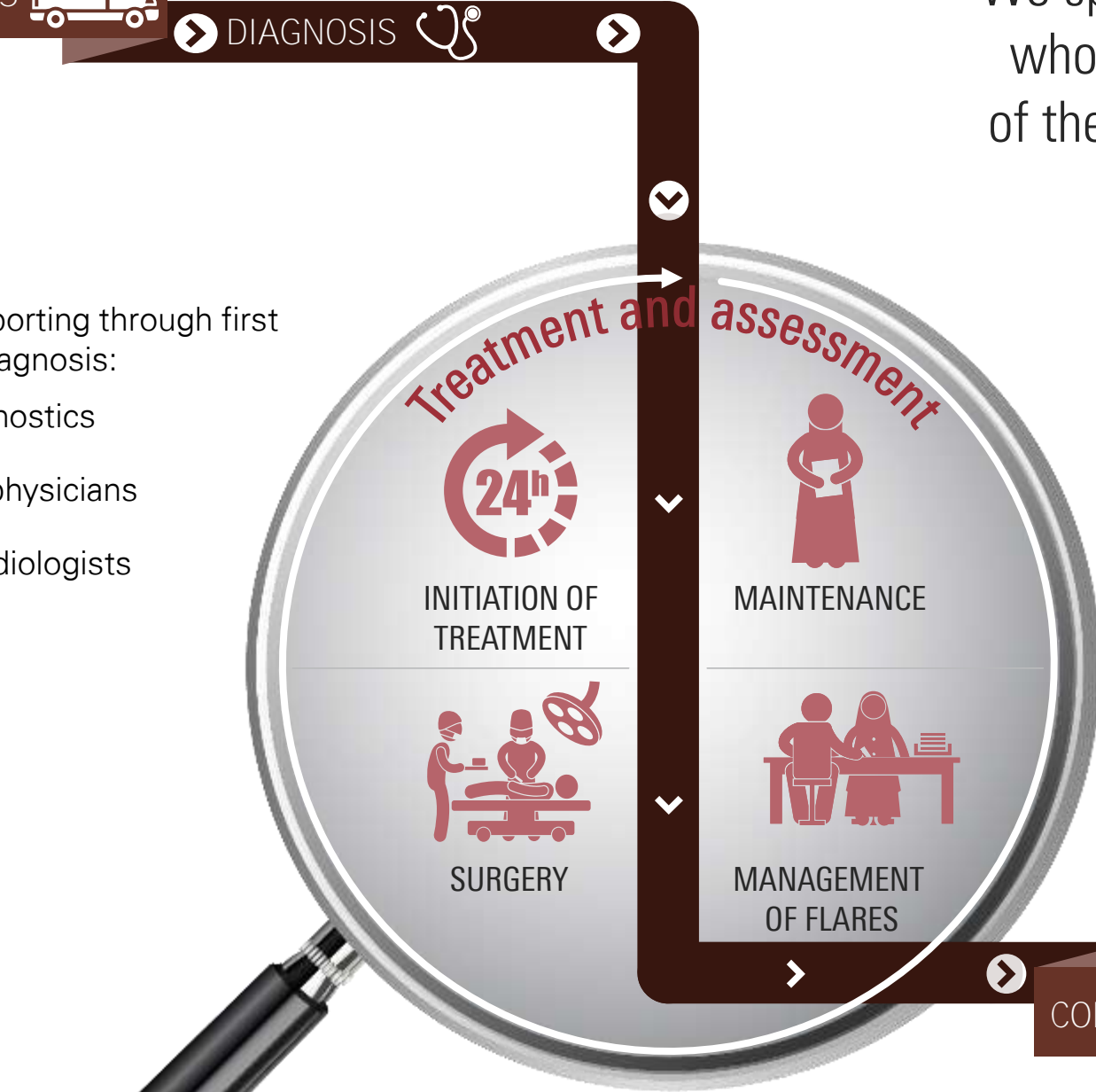
We spoke with staff members who are involved in all steps of the IBD patient pathway...

Practitioners supporting through first symptoms and diagnosis:

- 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




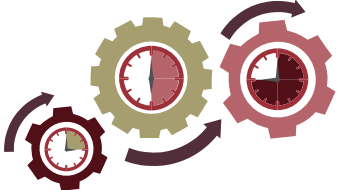
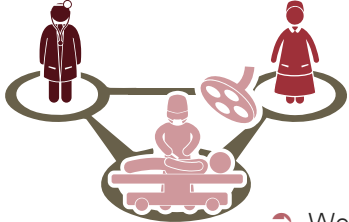



CONTINUOUS PATIENT CARE











...and observed their interactions, collecting centre data where possible

What did we observe?

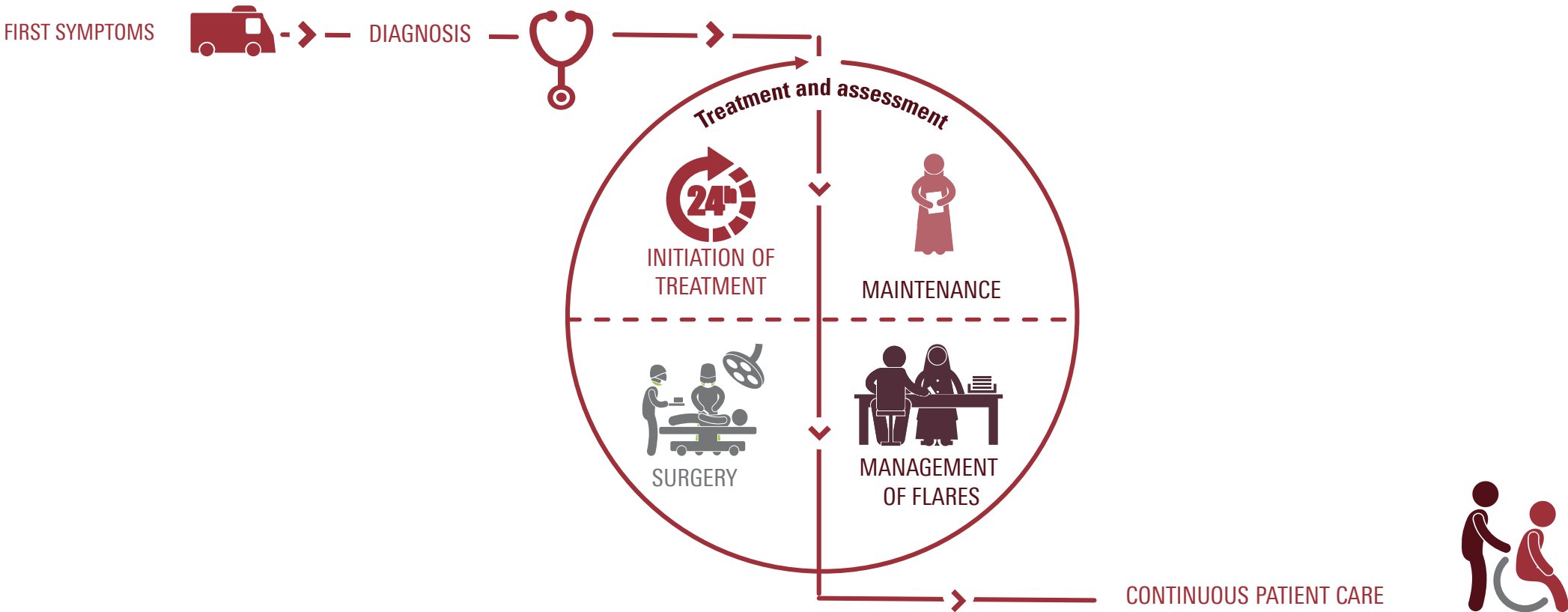
<p>PROCESSES </p>	<p>TEAM INTERACTION </p>	<p>PREMISES </p>
 <p>⇒ We wanted to observe the day-to-day activities of the members of the IBD teams we visited</p>	 <p>⇒ We aimed to assess the level of interaction between the members of the IBD team</p>	 <p>⇒ We wanted to understand the patient experience and asked our hosts to walk us through the IBD services on a typical patient journey</p> <p>⇒ 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</p>

What data did we collect?

<p>PROCEDURES </p>	<p>EDUCATIONAL MATERIAL </p>	<p>FORMS FROM IBD DATABASES </p>	<p>DETAILS OF PATIENT NUMBERS </p>
 <p>⇒ 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</p>	 <p>⇒ To understand the patient experience, we asked the centres to share any educational material that they give their patients, and their families and carers</p>	 <p>⇒ 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</p>	 <p>⇒ We could only estimate patient volumes as many centres did not collect operational data which distinguished an IBD diagnosis from GI pathologies</p>

We then consolidated our findings from the four 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 four 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

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

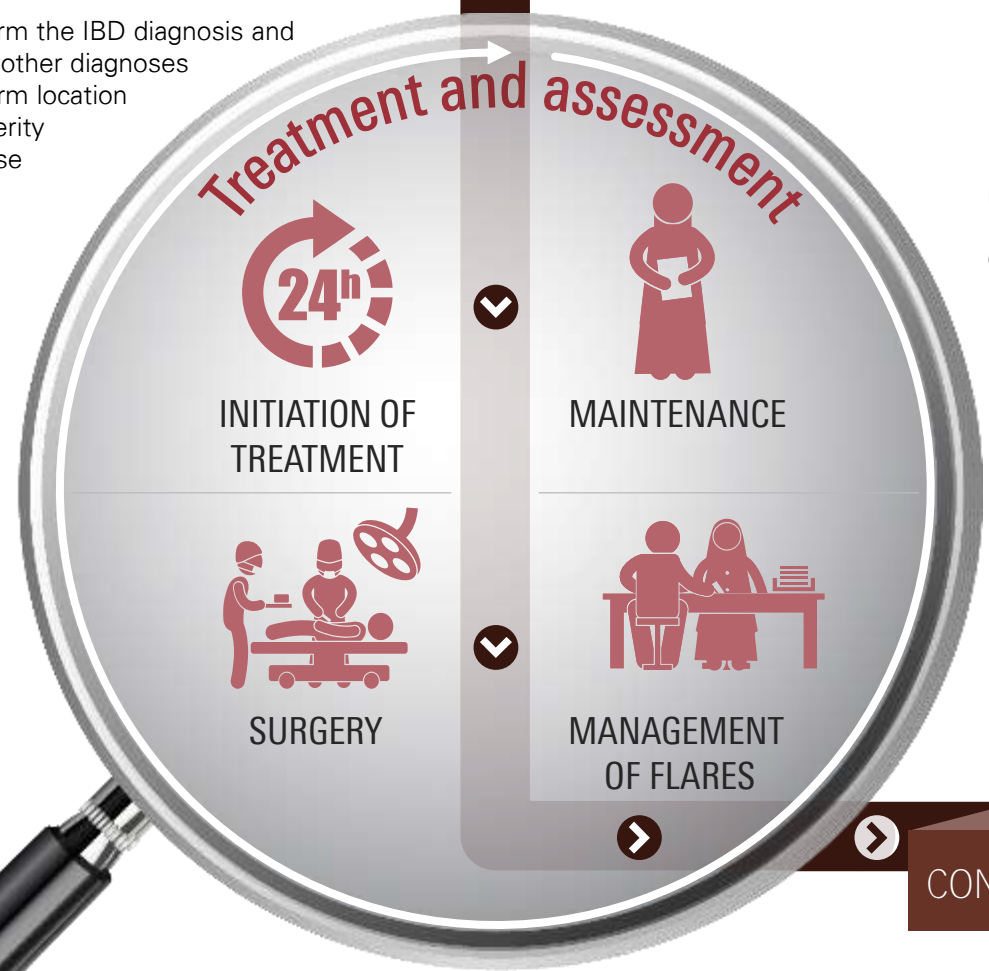
DIAGNOSIS

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



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 the 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. I may go to see a practitioner of 'traditional medicine' before seeing a doctor. I am becoming more worried about my symptoms and the impact on 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.



INITIATION OF TREATMENT

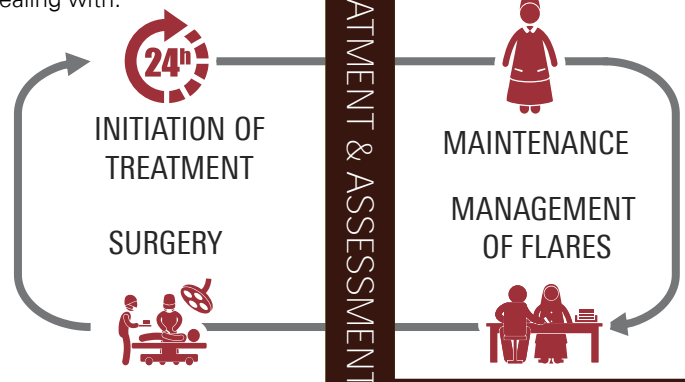
I am prescribed a short course of steroids and some longer term anti-inflammatory drugs. The nurse tells me that depending on the severity of my condition, I may require a range of other treatments. I have heard of patients who had to be fed through a tube or had to have an operation. Initially I worry about side effects and whether the medication will help me, but the nurse reassures me and offers me some helpful information on my treatment. I also worry about which food to eat, Food is an important part of my social life so I am sent to see a dietician. Her advice is very helpful and I leave the appointment reassured.

DIAGNOSIS



DIAGNOSIS

I hesitate to see a doctor and first go to see a general internal medicine specialist. I am not sure whether I trust his opinion so I make an appointment with another doctor as well. After several months I am sent to see an IBD specialist. I give a blood and a stool sample for a range of tests, I undergo imaging tests and have a colonoscopy. The colonoscopy worries me especially and I am not sure how to prepare for it, but the nurse spends a lot of time explaining everything to me. 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 since I finally know what I am dealing with.



SURGERY

Surgery worries me as I hear it is the last resort in the treatment of inflammatory bowel disease, with lifelong consequences, 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. I feel a bit ashamed to discuss this with my doctor so first try to get in touch with a nurse in 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



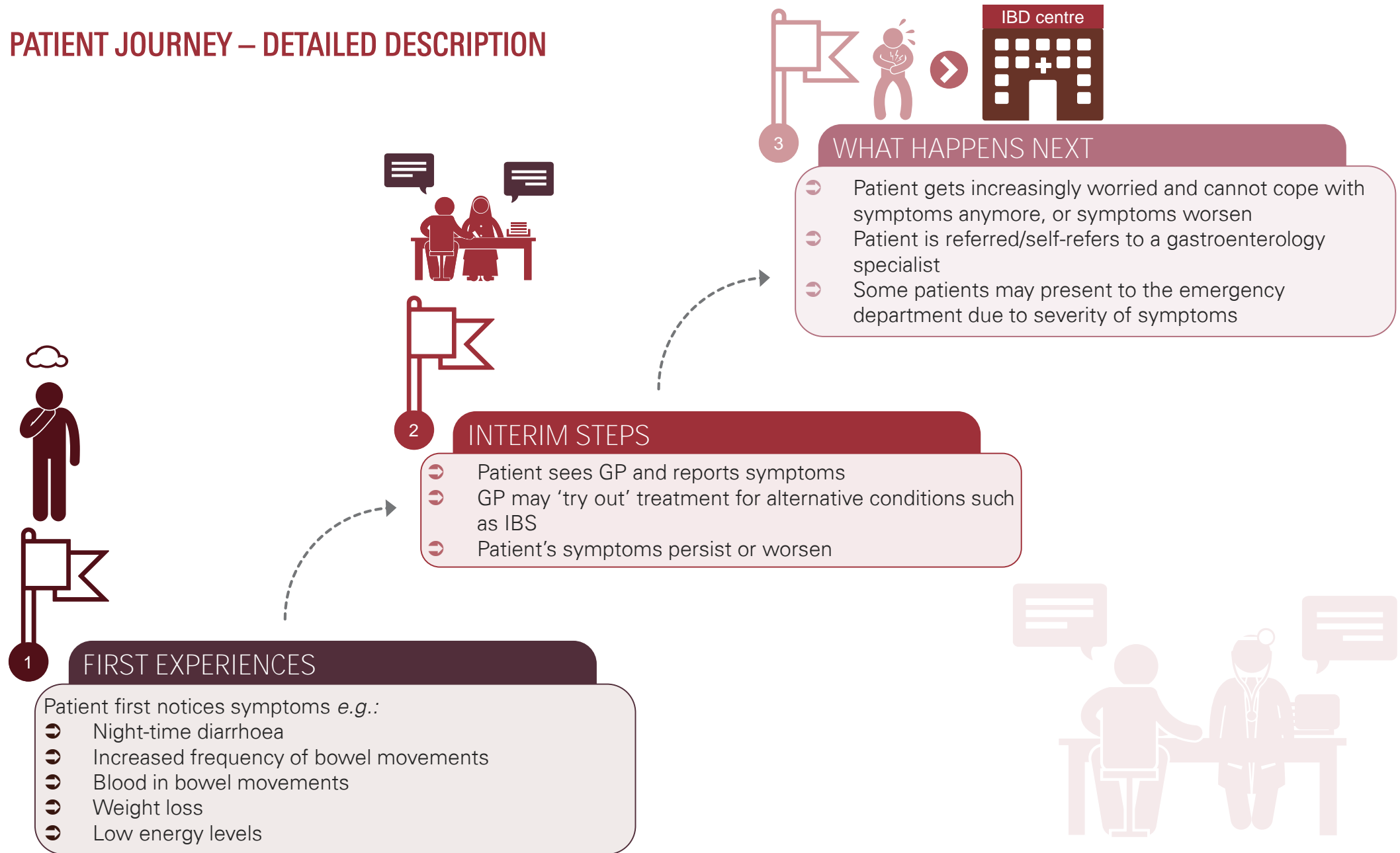
CONTINUOUS PATIENT CARE

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, monitoring, and by putting me in touch with therapy and group support services.



FIRST SYMPTOMS

PATIENT JOURNEY – DETAILED DESCRIPTION



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?

- ➔ Patient outreach programs to increase awareness of IBD indicating symptoms
- ➔ Outreach to general hospitals to ensure that internal medicine generalists, who are often initially consulted by the patients, are educated about IBD symptoms
- ➔ Patient education via videos on YouTube to increase patient trust in formal medicine (instead of traditional local medicine) and encourage patients to self refer

(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

Outreach programs to diverse communities to maximise IBD awareness

What was the objective?

- ➔ To improve IBD awareness among immigrant communities

What was achieved?

- ➔ The needs of different communities were addressed by launching a range of outreach programmes in several languages

How was it achieved?

- ➔ Qatar has an ethnically and socio-economically diverse population, with many foreign workers
- ➔ Hamad Medical Centre ensured that IBD educational material was accessible in Urdu and Hindi in addition to Arabic and English, in order to raise awareness amongst the large immigrant population of the country
- ➔ The hospital also hosts IBD awareness days for patients, and the team is beginning to extend outreach into local schools and universities in order to improve recognition of IBD and reduce the stigma associated with the condition

How did the centre measure success?

- ➔ Greater awareness of IBD among all demographics



Key factors to consider when replicating this intervention

- ➔ Demographics and needs of populations in the catchment area, to prioritise resources

FIRST SYMPTOMS – SUCCESSFUL INTERVENTIONS

Using YouTube videos to increase community education and improve trust

What was the objective?

- ➔ To improve IBD awareness and encourage patients to seek medical rather than alternative traditional local medicine treatment

What was achieved?

- ➔ Senior staff recorded educational YouTube videos to increase community awareness of IBD and improve trust amongst patients

How was it achieved?

- ➔ Due to anxiety issues and lack of education, patients tend to 'doctor shop' as well as seek out alternative treatment options. Both activities delay effective and timely treatment
- ➔ To combat this, the senior staff recorded multiple IBD education videos on YouTube. These were accessed by more than 130,000 people in the region

How did the centre measure success?

- ➔ Patients come to the clinic better informed and demonstrating greater trust in staff
- ➔ According to the centre lead they have seen a 5-10% change in awareness levels of patients on treatment options since the launch of the video series

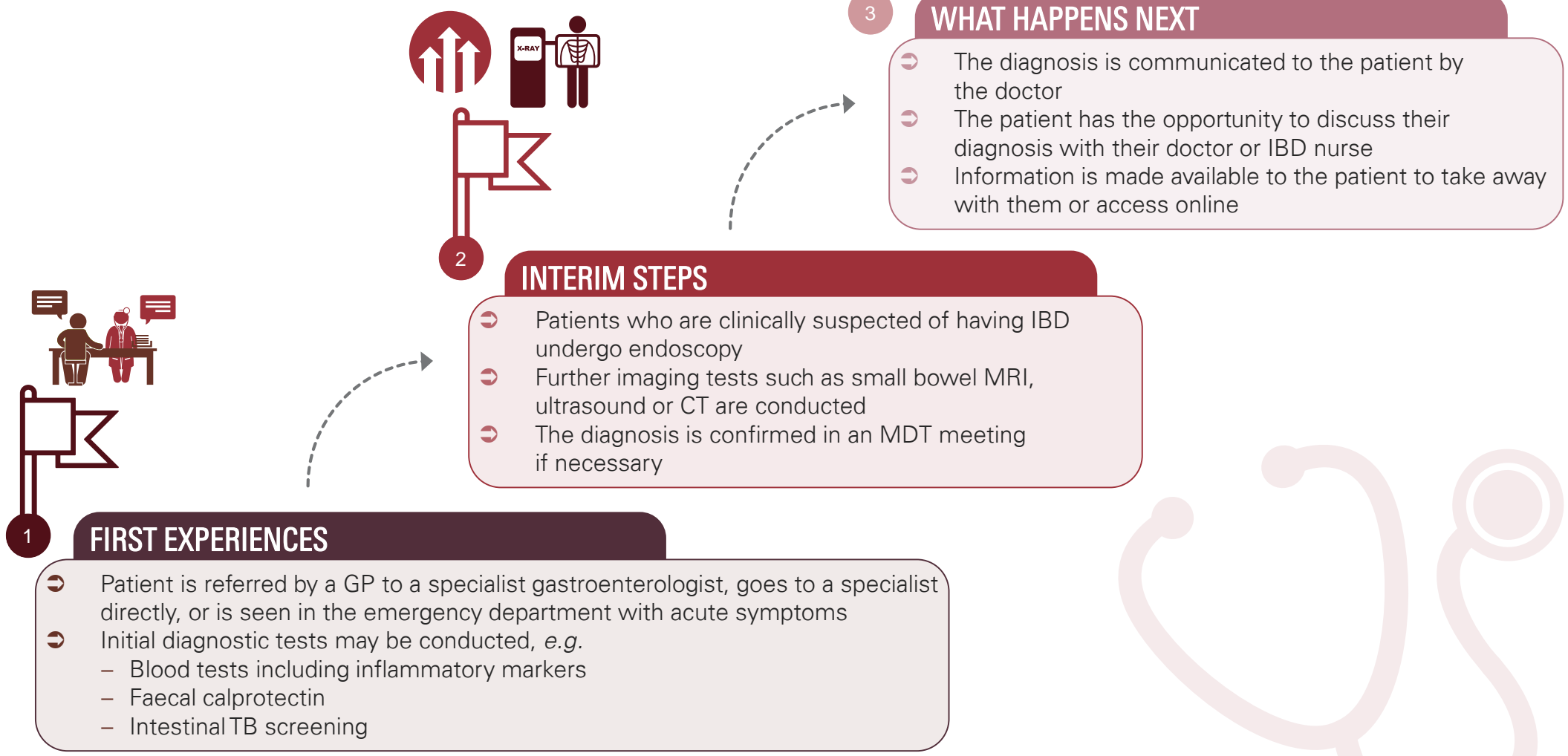
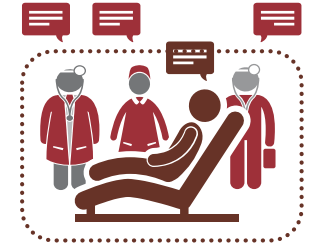
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Key factors to consider when replicating this intervention

- ➔ Quality control process for videos (e.g. compatibility with external communications policy)
- ➔ Needs of the target audience when determining the content and level of sophistication of the videos

DIAGNOSIS

PATIENT JOURNEY – DETAILED DESCRIPTION



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 testing mechanisms 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 conducted to ensure that potential surgical treatment options are understood and that the patient's anxiety about symptoms 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 creating delays and inconvenience for patients)
- ➔ Delayed access to specialist IBD advice in acute presentations to the ED
 - 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
- ➔ Due to cultural sensitivities, female patients may not be comfortable discussing symptoms and issues with male doctors

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
- ➔ Nurse-led patient bowel preparation programmes to reduce cancellations of endoscopies

DIAGNOSIS – SUCCESSFUL INTERVENTIONS

Nurse programme to improve patient bowel preparation for endoscopies, in order to reduce appointment cancellations

What was the objective?

- ➔ To reduce cancellation of endoscopy appointments, improve speed to diagnosis, maximise use of endoscopy equipment and improve patient outcomes

What was achieved?

- ➔ King Faisal Hospital began a nurse-led programme to ensure that patients were properly prepared for their endoscopies

How was it achieved?

- ➔ Patients were prepared for endoscopies through the Nurse Advisor Programme, a systematic programme of nurse/patient engagement
- ➔ This was enabled by nurses being trained by gastroenterology specialists, to prepare patients for endoscopies, and inform them about the procedure and potential side effects

How did the centre measure success?

- ➔ Patient treatment completion levels, number of scheduled appointments not cancelled/rescheduled and where treatment was administered as expected, rose from 80% in 2011 to 92% in 2013
- ➔ By reducing missed appointments, trust between staff and patients was increased and the likelihood of patients seeking alternative therapies was reduced



Key factors to consider when replicating this intervention

- ➔ Current appointment cancellation rates due to improper preparation to justify programme
- ➔ Capacity of nurses to manage programme
- ➔ Where the intervention fits in the current patient journey to endoscopy

DIAGNOSIS – SUCCESSFUL INTERVENTIONS

Creating a collaborative multi-disciplinary team to support diagnosis

What was the objective?

- ➔ Improve diagnosis accuracy and treatment effectiveness through increased staff collaboration

What was achieved?

- ➔ Diagnoses are now made quickly and accurately through the MDT approach by involving other departments, with dietitians, nurses, pharmacists and surgeons all supporting IBD specialists at all stages of the patient pathway

How was it achieved?

- ➔ With formal MDT meetings every 2 weeks, with representatives from all aspects of IBD care participating, and with access to electronic patient records
- ➔ By encouraging discussion and peer challenge in order to determine the best diagnosis and treatment for each patient in turn

How did the centre measure success?

- ➔ Involvement of the MDT allowed more prompt and accurate differential diagnoses to be made, improving not only patients' disease progression, but also their attitude towards the treating team

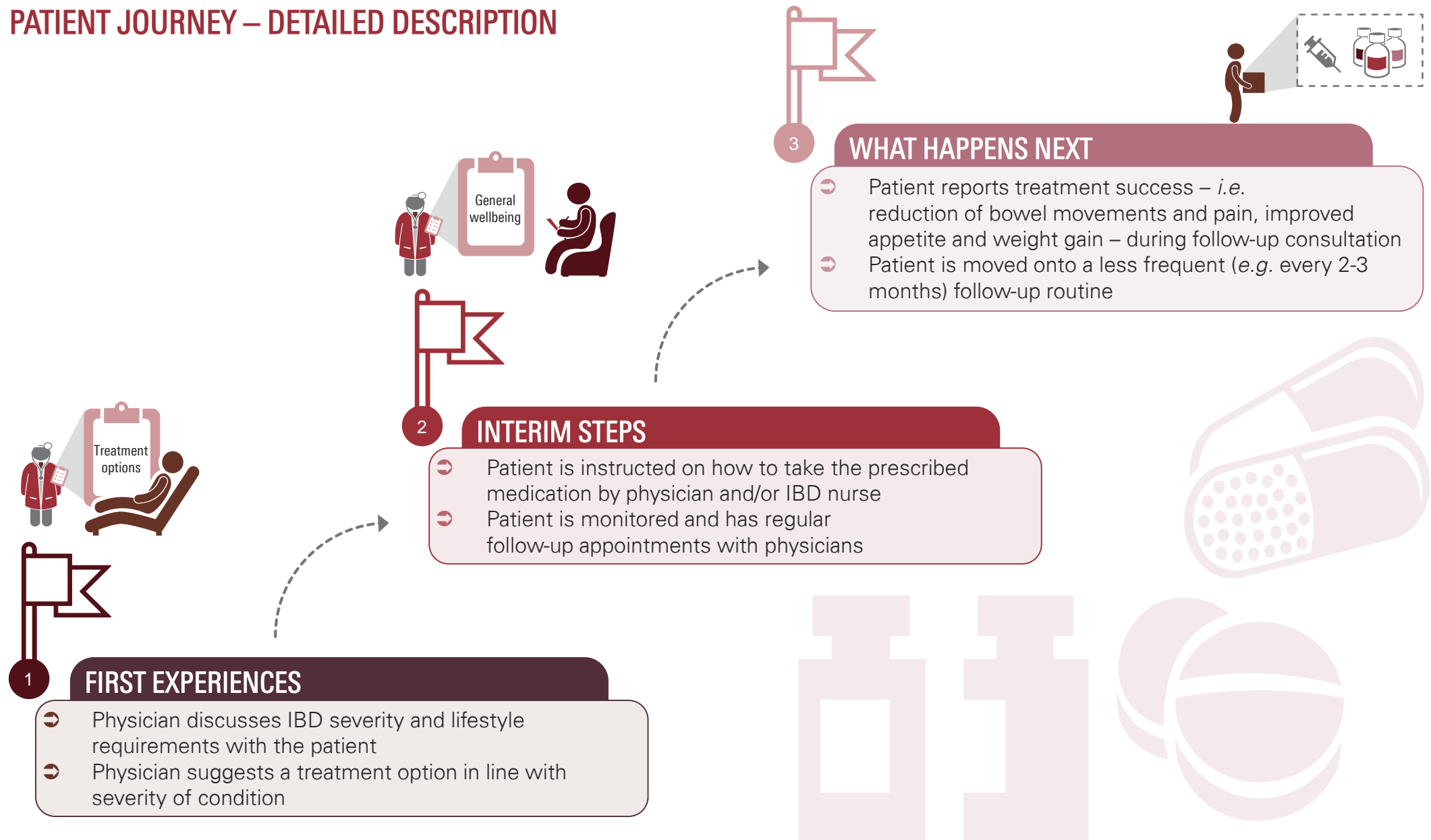


Key factors to consider when replicating this intervention

- ➔ Time required to prepare and run weekly meetings
- ➔ 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



(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 their 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 potential side effects)
- ➔ After a short period of time the patient is 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 and to be able to recognise them during follow-up appointments. 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 medication
- ➔ Psychosocial issues that may affect compliance are not recognised and addressed; limited or no access to psychological support services
- ➔ Treating IBD physicians and/or IBD nurses are not aware of the lifestyle implications of the different treatment options
- ➔ Lack of consideration of indirect 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?

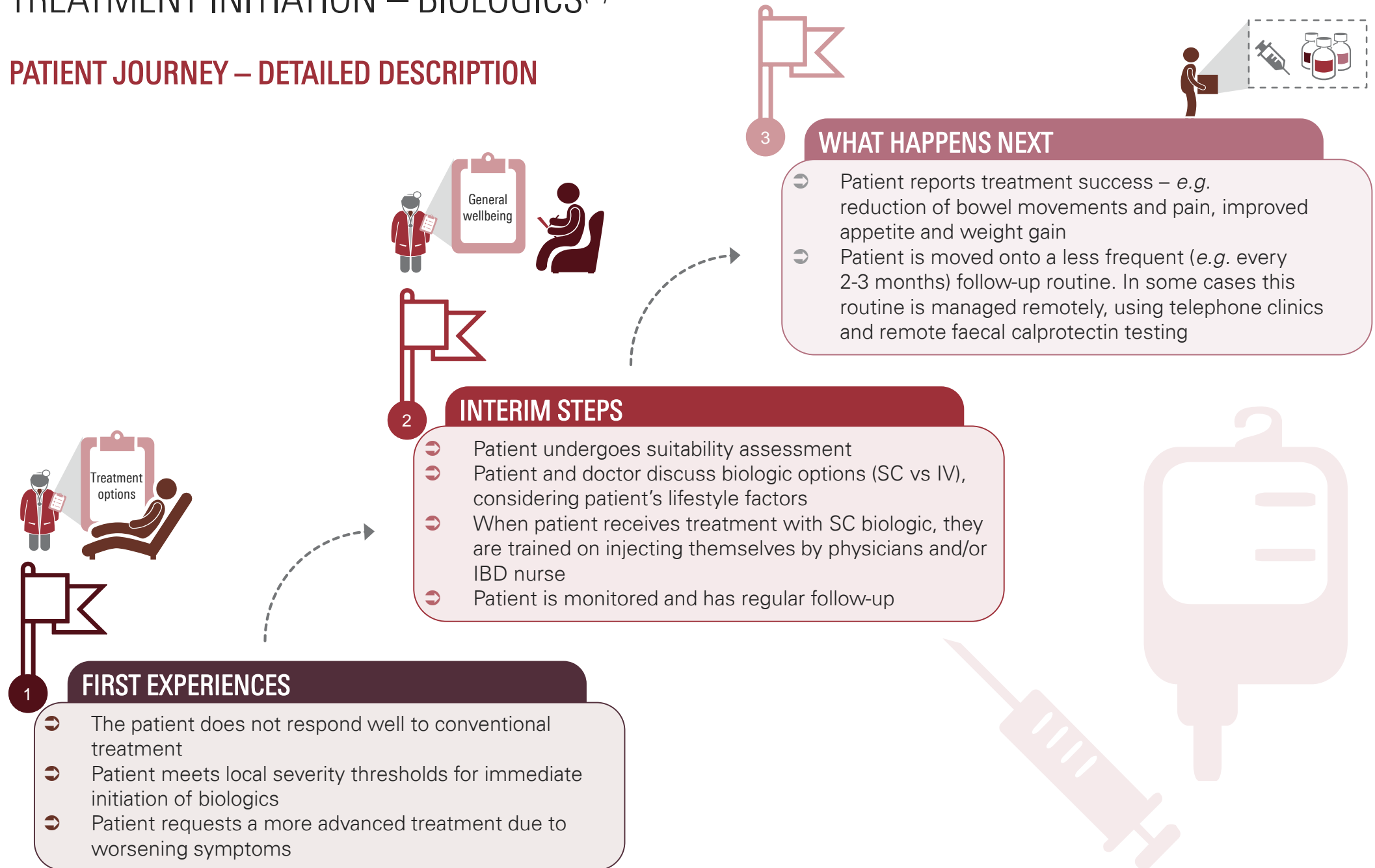


- ➔ Train a dedicated nurse who can educate patients on their treatment and/or create enough time for physicians to explain the treatment to patients
- ➔ Implement treatment plans that are goal-based and time-bound
- ➔ Ensure opportunities for treatment plans to be peer-reviewed, through MDT discussions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



(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 discuss the treatment success or potential side effects
- ➔ When patient is prescribed SC biologics, patients 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 do not optimise conventional therapy before suggesting a biologic
- ➔ Lack of adequate facilities such as infusion rooms for proper administration of certain biologics
- ➔ Limitations on reimbursement of biologics for some patients (*e.g.* migrant workers) which results in a significant administrative burden for the hospital and patient
- ➔ Patients fear needles and have trouble self administering and adhering to treatment
- ➔ Patients are reluctant to start biologic therapy due to misinformation (*e.g.* rumours that biologics can increase the risk of cancer)
- ➔ Insufficient staff to train patients on self-administration of treatment to an appropriate level

3

WHAT ARE SOME OF THE SUCCESSFUL INTERVENTIONS?



- ➔ Train a dedicated nurse who can educate patients on their new drug 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 that discussing patients' lifestyle and treatment preferences are part of the treatment choice decision
- ➔ Partner with seconded industry nurses so that biologic treatments are delivered by experts

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

TREATMENT INITIATION – SUCCESSFUL INTERVENTIONS

Integrating seconded pharmaceutical nurses into the IBD team

What was the objective?

- ➔ Nurses in the public system were working at full capacity and often did not have the required training to educate patients on biologics use
- ➔ To address this, pharma companies decided to pay for pharmaceutical nurses who would work in the hospital and train patients on how to use biologics

What was achieved?

- ➔ Pharmaceutical nurses on secondment from pharmaceutical companies to KFSH are fully integrated into the IBD team to help with patient education and the usage of biological treatments

How was it achieved?

- ➔ Pharma companies worked with the centre to identify the need for additional support and then paid for additional nurse support

How did the centre measure success?

- ➔ Success was not formally measured, but higher patient satisfaction and improved capacity for the nursing staff was reported



Key factors to consider when replicating this intervention

- ➔ Potential conflicts of interest
- ➔ Communication channels between seconded nurses and doctors to ensure that patient feedback on their condition is captured
- ➔ Limitations on the care that the seconded nurse can give to patients

TREATMENT INITIATION – SUCCESSFUL INTERVENTIONS

Partnerships with industry to administer biologic treatments in patients' homes

What was the objective?

- ➔ To improve the compliance levels and overall quality of life of patients, in a cost-effective way

What was achieved?

- ➔ The hospital was able to improve ongoing care for patients through localised treatment and ongoing education
- ➔ This initiative also helped to cover some of the functions of the missing dedicated IBD nurse

How was it achieved?

- ➔ Pharmacists and nurses sponsored by pharmaceutical companies worked with doctors to educate patients and administer treatment locally in patients' homes

How did the centre measure success?

- ➔ Success has not been officially measured, but a strong increase in patient satisfaction has been mentioned by the treating doctors and the remotely working nurses

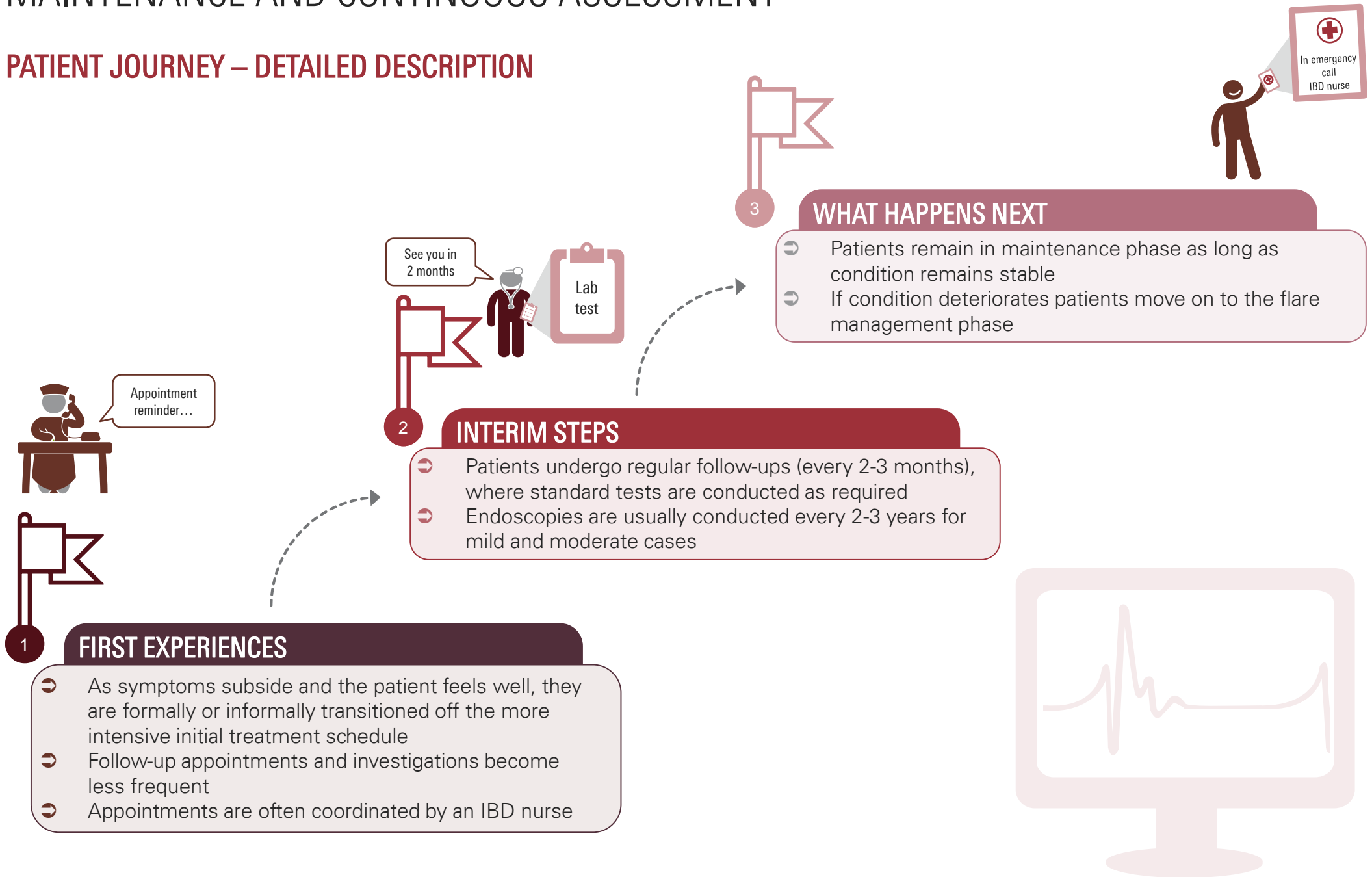
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Key factors to consider when replicating this intervention

- ➔ Restrictions on the type of treatment that can be given
- ➔ Communication channels between sponsored nurses and regular nurses and doctors, to ensure that the patient's condition is monitored properly

MAINTENANCE AND CONTINUOUS ASSESSMENT

PATIENT JOURNEY – DETAILED DESCRIPTION



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 patient files 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 of their treatment routine and adhere to it
- ➔ 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

MAINTENANCE AND CONTINUOUS ASSESSMENT – SUCCESSFUL INTERVENTIONS

Developing initiatives to deliver continuous care to patients living far from the hospital

What was the objective?

- ➔ To treat IBD sufferers living in rural areas at some distance from the hospital

What was achieved?

- ➔ A number of different initiatives were set up to allow patients living in rural areas to access high-standard treatment

How was it achieved?

- ➔ Capabilities of rural primary care centres were improved by sending specialist staff on occasional visits to the centres to train general practitioners in IBD care
- ➔ Rural patients were able to have medicines delivered to their homes through partnerships with couriers
- ➔ A video conference clinic is currently being set up to allow for the management of stable patients without the need for laborious travel to King Faisal Medical Centre

How did the centre measure success?

- ➔ Patient compliance and satisfaction was improved



Key factors to consider when replicating this intervention

- ➔ Capability of courier service to safely transport expensive medicines
- ➔ Ability of patient to self-report own condition accurately through video conferences

MAINTENANCE AND CONTINUOUS ASSESSMENT – SUCCESSFUL INTERVENTIONS

Identified patient to lead the first patient association in the region

What was the objective?

- ➔ Patient associations are uncommon in the Middle East region, due to a traditional separation of the different genders in public and patients' hesitance on sharing symptoms
- ➔ The centre strongly believed in the positive effects of a patient association (e.g. share burden of disease, exchange tips, have social interaction with other patients) and wanted to found a patient association

What was achieved?

- ➔ A young female patient who was very well regarded amongst fellow patients was identified and trained to set up a patient association

How was it achieved?

- ➔ The IBD nurse of the centre regularly holds patient education sessions and discussion rounds, and used this opportunity to discuss her idea for a patient association and identify potential candidates who could set up and lead such an association

How did the centre measure success?

- ➔ This is a relatively new intervention so success has not yet been measured

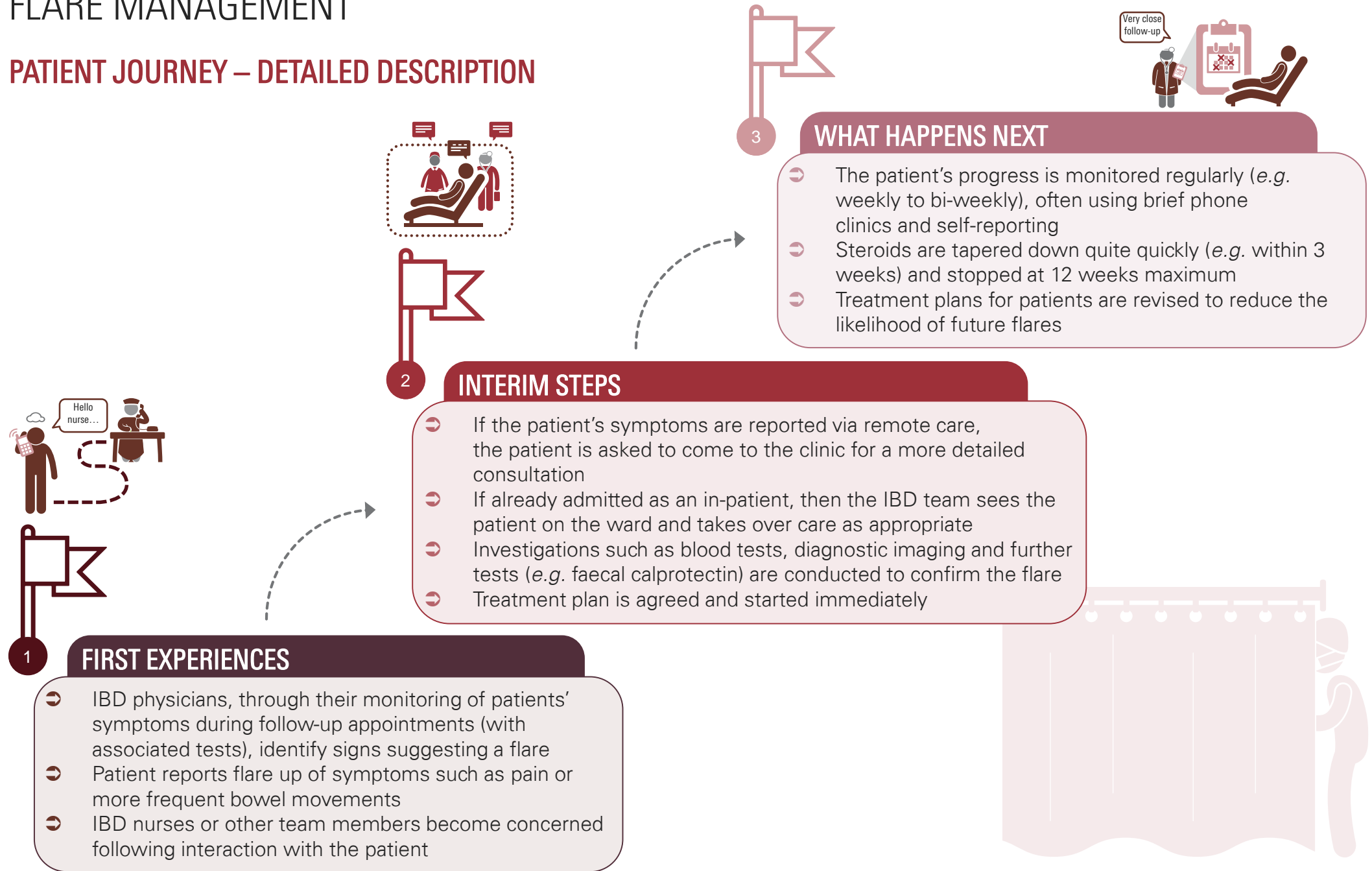


Key factors to consider when replicating this intervention

- ➔ Willingness of patients to participate in a patient association
- ➔ Availability of staff to discuss the idea of a patient association with existing patients, as well as to then support a patient who may wish to take a leading role in the new patient association

FLARE MANAGEMENT

PATIENT JOURNEY – DETAILED DESCRIPTION



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 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 and public sector care providers can cause confusion when the patient is passed between the two
- ➔ Whilst most doctors are aware about the dangers of extensive steroid use there are limited or no published guidelines on steroid use in place

3

WHAT ARE SOME OF THE SUCCESSFUL INTERVENTIONS?



- ➔ Allow patients to contact doctors directly over the phone in emergencies so that they receive timely advice on how to manage any condition changes, from specialist physicians who they trust
- ➔ Education for patients allows them to identify when their condition is deteriorating and consequently seek prompt advice from their IBD centre

FLARE MANAGEMENT – SUCCESSFUL INTERVENTIONS

Emergency call system for patients

What was the objective?

- ➔ To give patients access to advice on the phone so that they would not have to attend the ED unnecessarily

What was achieved?

- ➔ A reduction in ED visits because patients felt that their questions were addressed by treating doctors

How was it achieved?

- ➔ All doctors were given a mobile phone. The phone number was given to patients in case that they wanted to speak to the doctor urgently
- ➔ On weekends and out of hours one dedicated doctor would keep his phone switched on so patients could reach someone for advice if needed

How did the centre measure success?

- ➔ Success was not measured, but a strong reduction in ED visits and increased patient satisfaction has been reported anecdotally

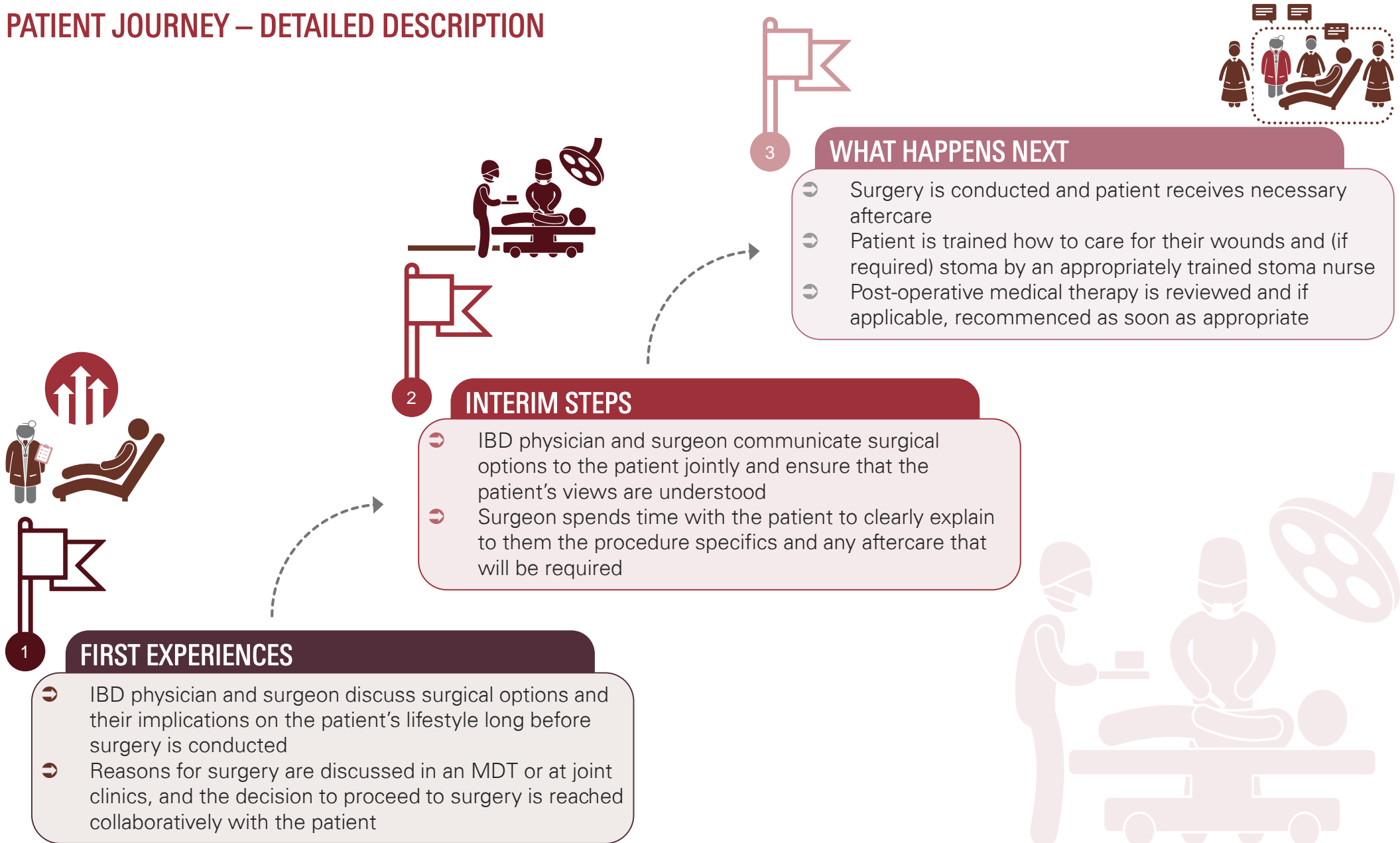
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Key factors to consider when replicating this intervention

- ➔ Willingness of doctors to make themselves available for patient calls, especially out of hours
- ➔ Cost of mobile phones

SURGERY

PATIENT JOURNEY – DETAILED DESCRIPTION



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
- ➔ The MDT meeting is 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 where needed, both before and after their 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

Ensure strong surgical presence and participation in the MDT

What was the objective?

- ➔ To ensure that surgeons have a strong position in the MDT, as they play an important role in IBD treatment due to many patients presenting quite late in the disease progression and consequently requiring surgery

What was achieved?

- ➔ Regular MDT attendance of surgeons and close cooperation between surgeons and IBD specialists

How was it achieved?

- ➔ The MDT schedule was designed to accommodate surgery times and the availability of surgeons
- ➔ IBD specialists invested a lot of time and effort to build a close relationship with the surgeons in their respective centres and encouraged them to contribute to the MDT (and outside the MDT whenever necessary)

How did the centre measure success?

- ➔ Success was not measured, but improvements on joint surgical decision making were reported



Key factors to consider when replicating this intervention

- ➔ Efficient ways for surgeons and IBD physicians to consult and communicate
- ➔ Role of surgeons and IBD specialists in the respective healthcare system

SURGERY – SUCCESSFUL INTERVENTIONS

Introducing a dedicated support system for stoma patients

What was the objective?

- ➔ Ensure that stoma patients receive sufficient psychological care and education to actively own their condition

What was achieved?

- ➔ A dedicated stoma nurse was introduced for stoma patient care and education, as well as for the training of fellow nurses

How was it achieved?

- ➔ The nurse informally linked up patients who had had a stoma/pouch for some time with patients who were just receiving one, in order to ease anxiety of the new patients and improve their patient satisfaction

How did the centre measure success?

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

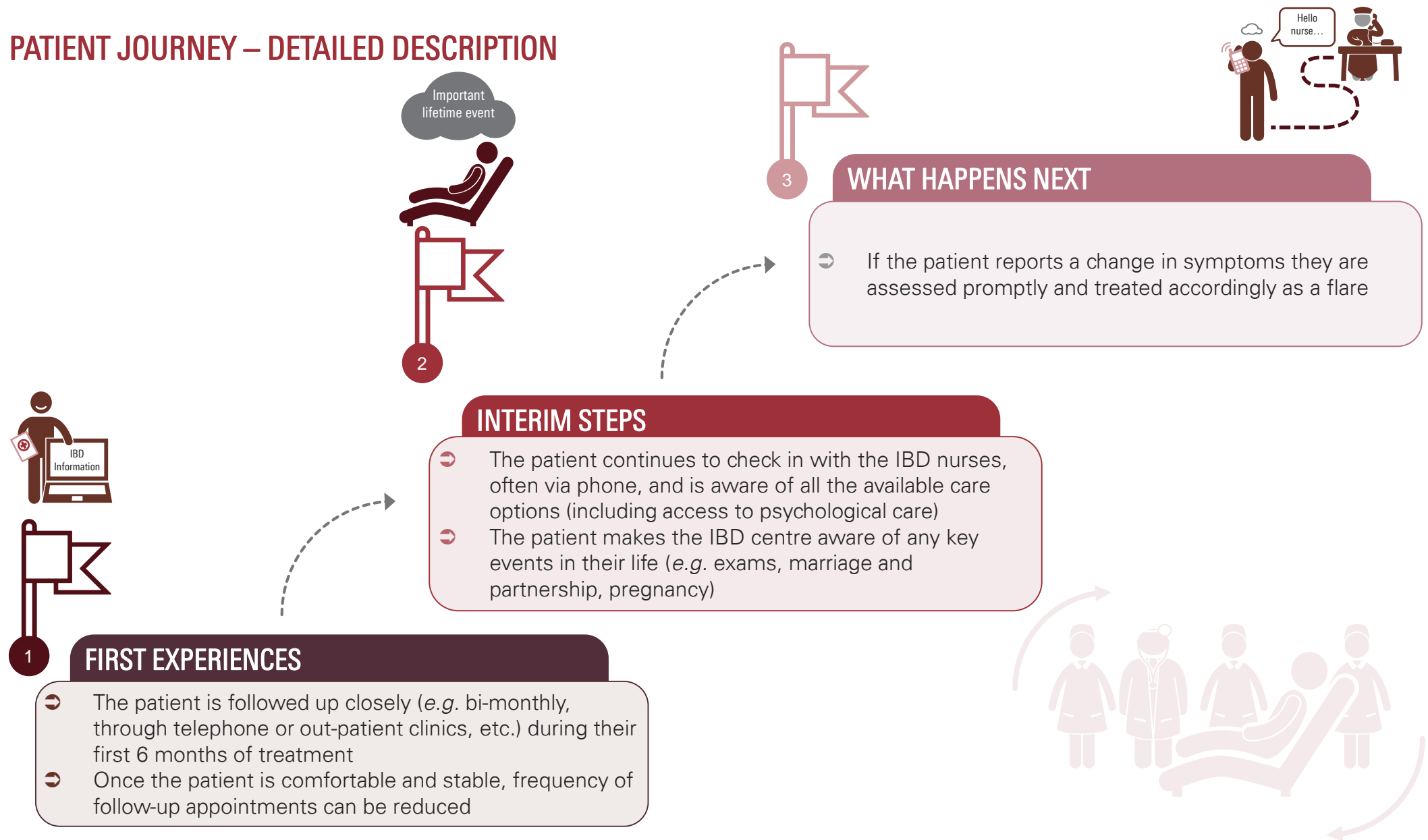


Key factors to consider when replicating this intervention

- ➔ 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



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), 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
- ➔ Lack 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?



- ➔ Instituting an Electronic Medical Records system to ensure that patient records are up to date and easily accessible for all treating specialists, to ensure continuity of care
- ➔ Developing a transition clinic to ease the move from paediatric to adult, with initiatives to increase the age of transition
- ➔ Many of the IBD specialists in the Middle East countries have separate phone numbers/mobile phones which they share with their patients – this helps easy and quick access in emergencies

CONTINUOUS PATIENT CARE – SUCCESSFUL INTERVENTIONS

Using electronic patient records to ensure continuity of care

What was the objective?

- ➔ To improve efficiency of treatment and diagnosis accuracy, and ensure continuity of care for patients

What was achieved?

- ➔ An integrated Electronic Medical Record system was developed to allow medical staff quick and easy access to patients' records

How was it achieved?

- ➔ Hamad Medical Corporation developed an integrated, digital system of patient records that stored all imagery and reports relating to the patients' treatment
- ➔ This system was accessible to all treating staff the patients encountered on their journey

How did the centre measure success?

- ➔ Medical staff have easy access to up-to-date patient records, enabling accurate diagnosis and continuity of care
- ➔ It is especially useful for IBD patients in remission, who may go 2-3 months between appointments and tests, as it ensures that treating staff have an up-to-date patient history



Key factors to consider when replicating this intervention

- ➔ Data retention laws
- ➔ Data security risks and patient concerns
- ➔ IT hardware and data management system available
- ➔ Financial and logistical effort to set up and EMR database

CONTINUOUS PATIENT CARE – SUCCESSFUL INTERVENTIONS

Create a patient-centric approach to adolescent care and adolescents transitioning into adult care

What was the objective?

- ➔ To create helpful guidelines to regulate the transitioning age and procedure for a patient to move from adolescent to adult care

What was achieved?

- ➔ The age of transition was increased from 12 years to 14-16 years
- ➔ A more formal transition process was established for paediatricians to liaise with adult care IBD physicians to discuss patients approaching transition age

How was it achieved?

- ➔ Evidence was presented to the respective ministries of health that showed that patients at the age of 12 were better provided for under paediatric care, and would not receive the standard and quality of care they required if treated by an adult-care IBD physician at this age
- ➔ Initiatives in the centres to establish a better defined transition process – *e.g.* adult-care IBD physicians actively reaching out to their paediatric colleagues to discuss how transition could be organised

How did the centre measure success?

- ➔ These initiatives are all fairly recent (<1 year) so success has not yet been measured



Mubarak Al-Kabir Hospital

Key factors to consider when replicating this intervention

- ➔ Organisational structures and referral guidelines within the centre

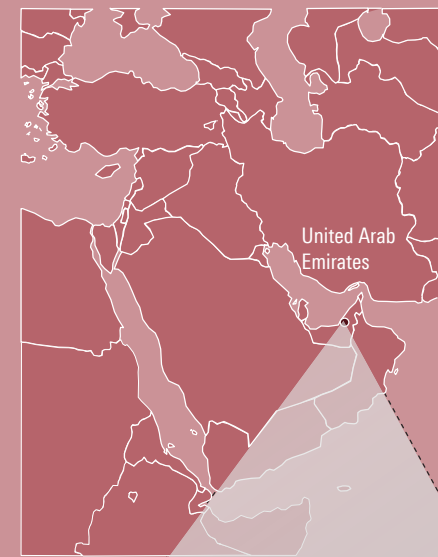
DETAILED SITE VISITS





Rashid Hospital

Dubai, UAE



Rashid Hospital

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

IBD treatment team



No formalised MDT, but **very good informal cooperation** between IBD specialists, radiologists and surgeons



Strong team with a **dedicated IBD nurse** who acts as an interface between patients and hospital as well as providing education and coordination



One **radiologist** has an interest in IBD in the hospital, and patients have full access to MRI, fluoroscopy, CT scans and ultrasound



Allied health professionals such as a dietician and a stoma nurse support the team, particularly in relaying information from female patients who may be reticent with male doctors

Patient services



Patients have access to hospital **psychologists**, but most of this burden is carried by the IBD clinical team itself



There is a **paediatric** gastroenterology facility within the hospital that treats IBD patients until the age of 13 or 14. Parents can accompany their children until they reach the age 18



Staff are aware that **female patients** will potentially require more delicate engagement from male doctors to fully engage with diagnosis and treatment, with a female gastroenterologist currently being recruited to improve treatment for female patients

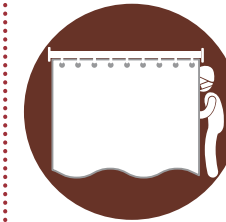


Biologics are available to all patients free of charge if required, and doctors have the flexibility to use either the 'bottom-up' or 'top-down' approach as they see fit

Selected treatment approaches



Surgeons are included in regular conversations with the IBD specialist team. Strict benchmarks are used to determine whether or not **surgery** should take place, with medical treatment being explored first



Endoscopies are performed by all gastroenterologists with a team of endoscopy nurses

Additional points of relevance



There are **IBD awareness days** for patients at the hospital. The team is also beginning to extend outreach into local schools and universities, in order to improve recognition of IBD and reduce the stigma associated with the condition



Research is currently not being conducted, but the centre has worked hard on building an IBD patient database which could form the basis for future research

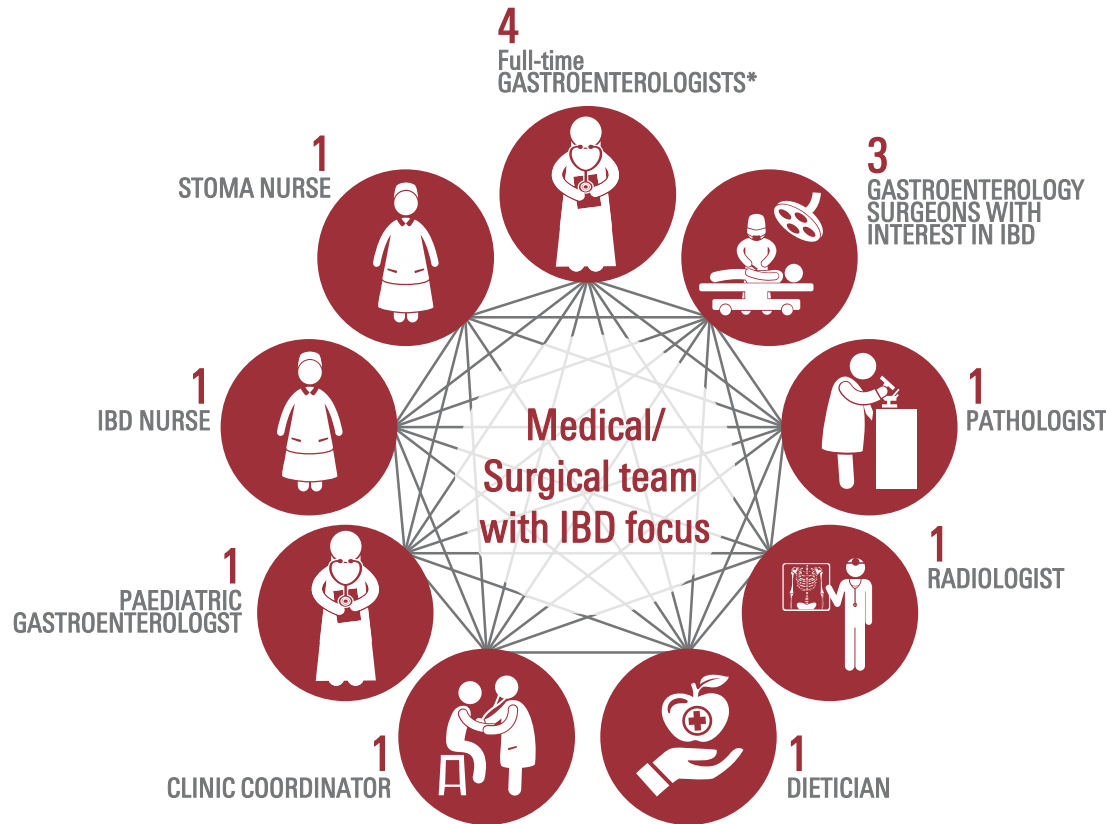
Rashid Hospital – IBD TREATMENT TEAM



All of Dubai



~750 active patients



KEY FEATURES OF CENTRE:

- Enthusiastic staff who try to address the needs of their multicultural patient population
- Special attention to the needs of female patients through nurse training and female gastroenterologists
- Adherence to ECCO treatment guidelines
- Leveraging full capabilities of EMR
- Emphasis on patient outreach and education



I think it is very helpful that I am a female IBD specialist – many patients ask specifically for me and feel much more open when it comes to discussing their symptoms with me.

(Dr. Al Meera)

* 11 Gastroenterologists in the whole hospital, but four that focus on IBD





All our staff undergo a very comprehensive and regular training programme. This ensures the excellence and patient centricity we are so well known for.


(Dr. Al Awadhi)


Rashid Hospital – SUMMARY

STRENGTHS


 High importance placed on training staff to a very high level to deliver excellent care to patients, with funding provided for training


 Strong focus on patient education and engagement, with staff mitigating difficulties arising from local behaviours (e.g. doctor shopping) through initiatives such as patient education sessions


 Presence of an IBD specialist nurse who provides specific expert knowledge, regular patient contact and a consistent interface, and a coordination point for patients and staff


 Presence of a female gastroenterologist. This allows for comprehensive care of female patients who, due to local culture, are often reticent about speaking to male doctors about their symptoms

KEY INFLEXION POINTS FOR PATIENT CARE


 Better awareness of IBD amongst the general population aids early diagnosis and reduces the stigma that accompanies chronic illness


 The long-term nature of IBD care means that clinical staff have to rely on written records to maintain effective treatment, discuss cases and maintain consistency of care


 The handover of paediatric patients to adult care poses particular challenges, with the potential for the loss of patient trust just as the patient enters puberty


 Patient diagnosis should not be made in isolation; views should be debated and challenged in order to achieve an accurate diagnosis as early after patient presentation as possible

SUCCESSFUL INTERVENTIONS

 There are IBD awareness days for patients at the hospital. The team is also beginning to extend outreach into local schools and universities, in order to improve recognition of IBD and reduce the stigma associated with it

 Investment in comprehensive Electronic Medical Records provide timely, accessible information on every patient. This enables consistent care and improves the research capabilities of the hospital

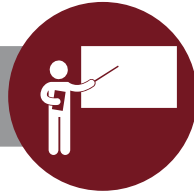
 Formal transition clinics are held for all patients aged between 14-18 years old, combining all adult and paediatric parties, enabling the retention of patient trust

 The unit has state-of-the-art medical equipment, with further investment planned to expand capacity and capability in a new hospital/building

Rashid Hospital

What would you change if you had the opportunity?

CREATE MORE AWARENESS



Why?

There is a lack of IBD knowledge amongst medical staff in primary and secondary centres that can result in delayed or incorrect referrals, and treatment of comorbidities in ways that adversely affect ongoing IBD treatment

How?

The centre runs regular IBD education stands, where hospital staff and patients raise awareness of the disease

ESTABLISH A PATIENT ASSOCIATION



Why?

Creating a self-help network eases patients' psychological burdens by giving them the opportunity to share experiences with one another

How?

Build upon current successes – embed patient education days as part of IBD treatment, and encourage attendees to build self-help relationships with other patients

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

ENCOURAGE RESEARCH



Why?

Research increases both situational awareness of local IBD characteristics, which is critical to successful treatment, and improves overall clinical knowledge of IBD treatment

How?

The establishment of relationships with local universities/medical colleges and the funding of a fellowship will facilitate this practice

HIRE EXPERIENCED STAFF & IBD NURSE

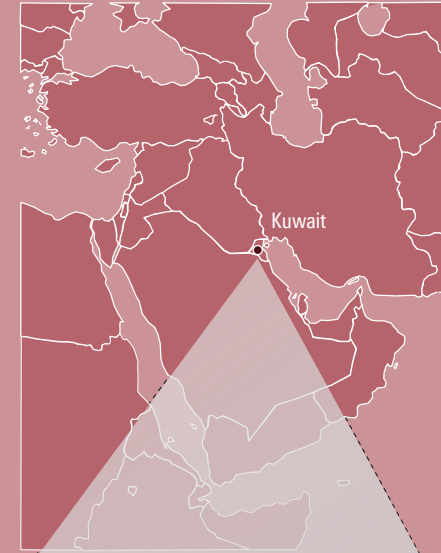


Why?

Staff with IBD experience will bring instant expertise that will cascade to all members of the local team, increasing a centre's capabilities, whilst an IBD nurse can provide a focal point and impetus for the entire team and their patients

How?

Recruit IBD-focused staff from neighbouring centres or overseas to give impetus to the development of a new IBD centre



Mubarak Al-Kabir
Hospital



Mubarak Al-Kabir Hospital

Kuwait City, Kuwait



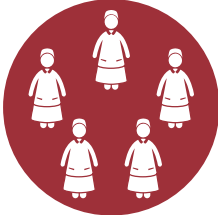
Mubarak Al-Kabir Hospital

Our visit revealed a number of detailed specifications about Mubarak Al-Kabir Hospital's operations

IBD treatment team



No formalised MDT; **ad-hoc discussions** between specialist doctors and surgeons as and when required, and on a patient-by-patient basis



Over 90 nurses aligned to the wider gastroenterology department. However, **no official IBD nurse** is currently employed at the centre



Of two **radiologists** in place, one has an interest in IBD, and patients have full access to MRI, some prefer due to fears of radiation

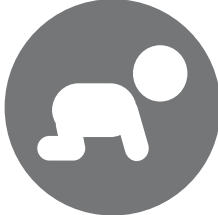


Allied health professionals such as a dietician support patients and participate in informal discussions with doctors when required. While there are no specialist stoma nurses, the gastroenterology nurses are experienced in dealing with stoma patients

Patient services



Patients have access to a hospital **psychiatrist**



There is a **paediatric gastroenterology** facility within the hospital that treats IBD patients until the age of 13, after which they are referred to adult care



Female patients are less forthcoming about symptoms with male doctors. The doctors are sensitive to this and usually try to build a good rapport to help the consultation run more openly



Kuwaiti nationals are reimbursed for **biologics**; other residents are sometimes subsidised by charities and drug companies

Selected treatment approaches



Surgery decisions in line with clear benchmarks, and on a patient-by-patient basis. They follow cross-department discussions, which in turn are facilitated by strong internal relationships



Endoscopies are performed very close to the consultation room to avoid extra effort for the patient, and are all publicly reimbursed

Additional points of relevance



A number of **outreach programmes** have included IBD education programmes for GPs, raising awareness of advancements in biologics within the hospital, and patient education through YouTube



There is little **IBD-specific research** undertaken by the unit. However, a gastroenterologist consultant is also a research fellow at the Faculty of Medicine, so there is potential for stronger links to be forged

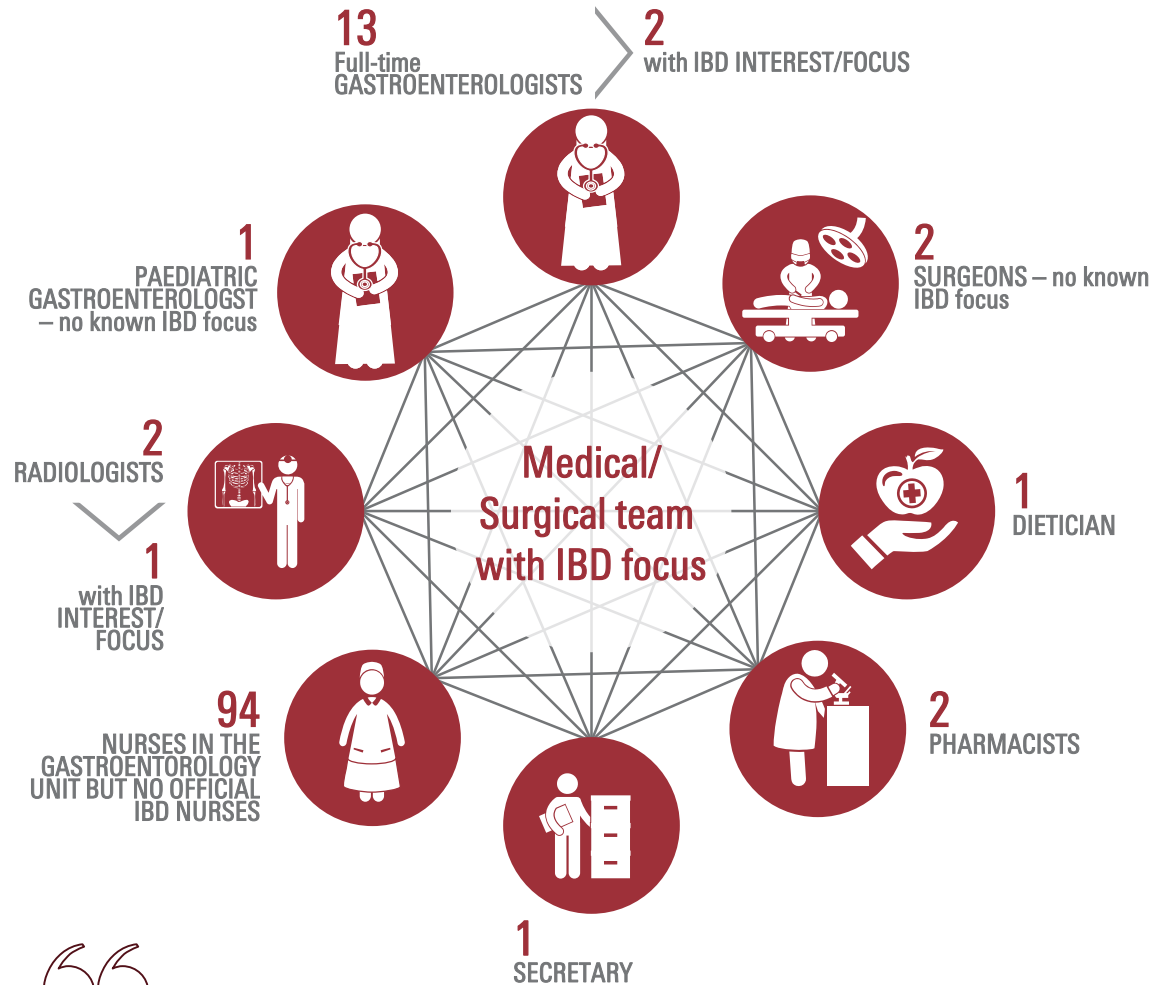
Mubarak Al-Kabir Hospital – IBD TREATMENT TEAM



Rhallaway Sector, Kuwait,



(No registry in place)



KEY FEATURES OF CENTRE:

- The department was established in 2012, with support from the Kuwait Ministry of Health and a private donor
- Staff demonstrate ownership and initiative, and are keen to improve
- World-class equipment, facilities and training of staff
- Cooperation with industry for the administration of medicines to patients




We work very hard to improve the visibility of our centre - our YouTube campaign has worked really well in this regard
(Dr. Al Fadhi)





The team works well and efficiently together and often discuss diagnoses. This creates greater accuracy and benefits the patient.
(Senior gastroenterologist)


Mubarak Al-Kabir Hospital – SUMMARY

STRENGTHS


 There is a high level of initiative and ownership demonstrated by staff; they actively take steps to identify areas for development, to ensure that the centre becomes an eminent example in the field of IBD care


 Staff education and training is very good. Due to a restriction in local training opportunities, the vast majority of physicians have received first-class training at specialist centres overseas

 Dr Al Fadhi, the centre director, is the driving force behind the centre. He has established strong working relationships with the Ministry of Health and the hospital, both of which have provided important support


 State-of-the-art medical equipment and facilities, achieved by longstanding financial support from local healthcare authorities


KEY INFLEXION POINTS FOR PATIENT CARE

 Timely and accurate referral from community doctors in polyclinics can ameliorate delayed treatment and worsened health outcomes

 Due to anxiety issues and lack of education patients tend to 'doctor shop' and seek out alternative treatment options, both of which can delay effective and timely treatment

SUCCESSFUL INTERVENTIONS

 Senior staff established outreach programmes in the community, which resulted in improved referral rates. The staff are now planning to improve cooperation further via developing a dedicated referral sheet

 Senior staff created IBD educational YouTube videos, which got more than 130,000 views, and resulted in better-informed patients who were keen to be treated at the clinic

What would you change if you had the opportunity?

CREATE A PATIENT DATABASE



Why?

Currently there is very little understanding of how many patients actively suffer from IBD, a fact which makes patient population development studies difficult

How?

A patient database combined with an EMR system would allow doctors to deliver more advanced treatment, and to share information with minimised administrative burden

ESTABLISH A PATIENT ASSOCIATION



Why?

It is very important for patients to share experiences with one another in order to mitigate the psychological effects of IBD; creating a self-help network eases the burdens of everyday life

How?

Build upon current successes – embed patient education days as part of IBD treatment, and encourage attendees to build self-help relationships with other patients

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

INCLUDE AN IBD NURSE IN THE TEAM



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 reflects the specialist status that many nurses have obtained through their training, and would also ease the burden on the existing GI nurses

ENCOURAGE STRONG TEAM COOPERATION

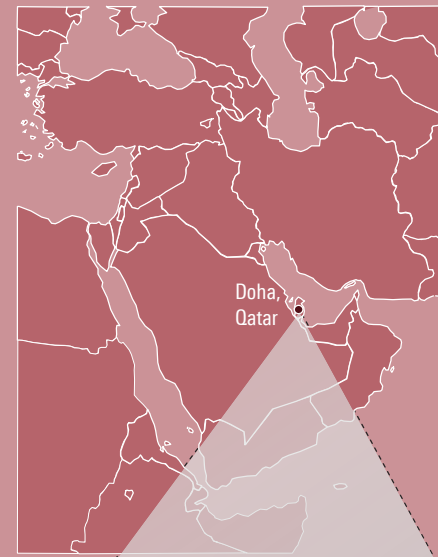


Why?

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, gastroenterology and surgery) work together closely through regular communication



HAMAD MEDICAL CORPORATION

DOHA, QATAR



Hamad Medical Corporation SUMMARY (1/2)



Our visit revealed a number of detailed specifications about Hamad Medical Corporation's operations

IBD treatment team



Monthly **MDT** meetings to discuss patients of concern, involving the entire IBD team



Strong team with a **dedicated IBD clinical nurse specialist** who acts as an interface between patients and hospital as well as providing education and coordination



Allied health professionals such as a dietician, pharmacist and a clinical nurse specialist in stoma care support the team, and are fully integrated into MDT team.



One specialist **radiologist** participates in MDT meetings, with patients having full access to MRI, fluoroscopy, CT scans and ultrasound

Offering patient-centric services



Patients have access to hospital **psychologists**, but most of this burden is carried by the IBD clinical and support team itself, with long-term personal relationships allowed to develop



There is a **paediatric gastroenterology** facility within the hospital that treats IBD patients until the age of 13 or 14. A transition clinic runs for 14–18 year olds, in order to minimise disruption. A paediatric clinical facility is also under construction, which will be completely digitalised. The clinic also trains a paediatric fellow in working with IBD patients



Staff are aware that **female patients** can require drawing out by staff to fully engage with diagnosis and treatment; for this reason, there is a clinical facility specifically for female patients under construction, the new facility will be completely digitalised

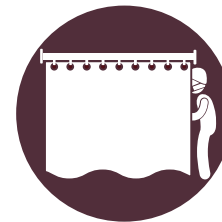


Biologics are available to all patients, free of charge for national population and highly subsidised for the expatriate population when required, and doctors have the flexibility to use either the 'bottom up' or 'top down' approach as they see fit

Selected treatment approaches



Decisions to proceed with **surgery** are made at the monthly MDT meeting, after consultation with the MDT team and the patient or on a patient-by-patient basis in an emergency. Patients are educated about all treatment options, including surgery, during their first "teaching"/ IBD educational session



Endoscopies are performed by all gastroenterologists with a team of endoscopy nurses

Additional points of relevance



There are **IBD awareness days** for patients at the hospital. The team is also beginning to extend outreach to local schools and universities in order to improve recognition of IBD and reduce the stigma associated with it



Local **research** is considered a vital part of long-term capability-building in IBD treatment, and is very much part of the hospital's culture, which has an attached medical college

Hamad Medical Corporation SUMMARY (2/2)

Our visit revealed a number of detailed specifications about Hamad Medical Corporation's operations

Outreach and patient education



HMC has an **outreach clinic** in place to improve rural referral rates, one in AlKhor hospital and one in Al Wakra hospital, to cover the North and South of the country



The team has worked extensively with **primary care physicians**, who can use a 24hr hotline to get in touch with IBD specialists at HMC



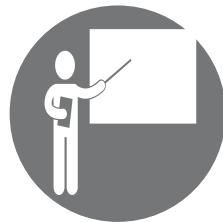
The team holds **educational sessions** that are organised by the IBD clinical nurse specialist, a coordinator and a senior doctor. During these patient education session, the team **uses videos** and clips from YouTube



Educational and preparatory material for patients, including patients undergoing endoscopies, is available in **multiple languages**, to reflect the local diversity

Patients also have access to a **hotline**, should they wish to reach the IBD centre urgently

Working with other centres



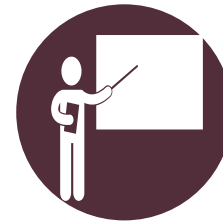
HMC Doha holds **joint teaching sessions** with experts from Oxford IBD Centre at John Radcliffe Hospital and Leuven IBD Centre.

In October 2015 HMC held a **2 day symposium** with Oxford IBD Centre, which was attended by numerous participants with a range of IBD sub-specialities



Together with Harvard University HMC Doha participates in a **joint research programme** that involved about 20 research scientists

Training staff

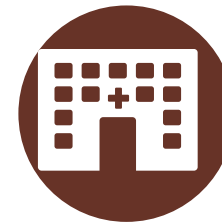


Last year HMC Doha held a **teaching session** for all hospital nurses and hospital dieticians that work with IBD patients



In addition to the IBD clinical nurse specialist the centre is currently recruiting an **IBD coordinator** that was trained at university level. For the upcoming year the post of an IBD dietician has been approved

Care protocols



Care protocols are routinely and widely used, in particular in regards to pregnancy and vaccinations of IBD patients.

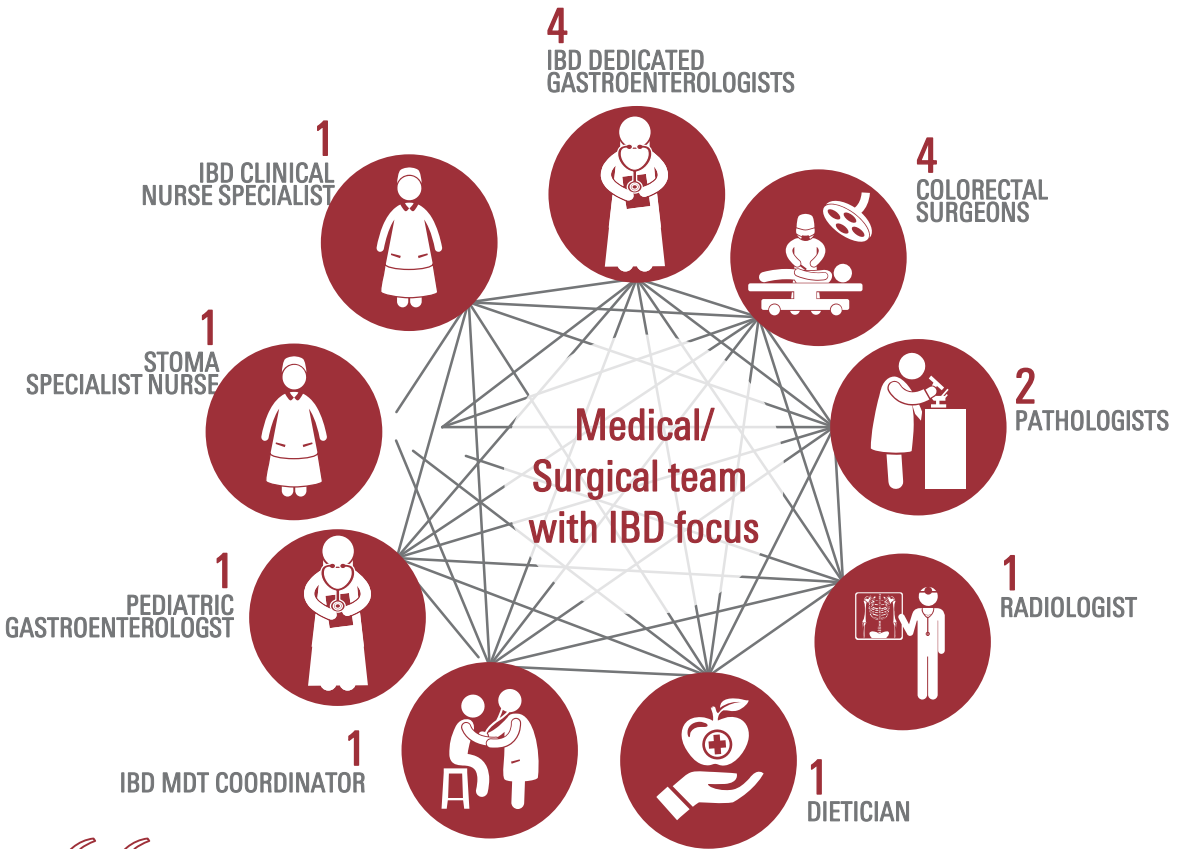
Emergency cases are also dealt with via a dedicated protocol which needs to be filled out before admitting urgent cases to the inpatient department



Calprotectin test are used regularly as part of a testing protocol

Hamad Medical Corporation IBD TREATMENT TEAM

All of Qatar ~550 active patients



KEY FEATURES OF CENTRE:


- Robust and systematic MDT approach
- Leverage full capabilities of EMR
- High levels of funding and government support
- Emphasis on patient outreach and education

*We want to reach out to schools and universities and remove the stigma of IBD.
(Senior Consultant)*


*Paediatric/adolescent patients pose a big danger for compliance levels, so it is of key importance to address them with extra care.
(Senior Consultant)*


Hamad Medical Corporation OFFERING PATIENT CENTRIC SERVICES

STRENGTHS


 High importance placed on delivering excellent care to patients, continuous training through collaborations with Kings College for nursing and Oxford Centre for doctors


 **Formal MDT meetings every month**, with representatives of all aspects of IBD care participating and access to electronic patient records


 Presence of an **IBD clinical nurse specialist** who provides specific expert knowledge, regular patient contact and a consistent interface and coordination point for patients and staff


 There is a **high level of initiative and ownership demonstrated by staff**; they actively take steps to identify areas for development, to ensure that the centre becomes an eminent example of good IBD care

KEY MOMENTS OF MEANING


 Better **awareness of IBD** amongst the general population will aid early diagnosis and reduce the stigma that accompanies chronic illness


 Presence of a **female gastroenterologist**. This allows for comprehensive care of female patients who, due to local culture, are often reticent of speaking to male doctors about their symptoms


 The handover of **paediatric patients** to adult care poses particular challenges, with the potential for the loss of patient trust just as the patient enters puberty


 Patient diagnosis should not be made in isolation; views should be debated and challenged in order to achieve an accurate diagnosis as early after patient presentation as possible

SUCCESSFUL INTERVENTIONS

 **Community awareness** of IBD is improved through the provision of educational materials in multiple languages

 HMC has a very comprehensive, modern, up to date **Electronic Medical Records System** using the latest generation of CERNER programmes which allows all multidisciplinary healthcare staff across the corporation from the primary healthcare centres to regional hospitals and tertiary hospitals to assess all patients' data, their latest test results, surgery history and IBD MDT decisions in a timely manner

 Formal **transition clinics** are held for all patients aged between 14-18 years old, combining all adult and paediatric parties, enabling the retention of patient trust

 Strong **affiliations with Oxford IBD Centre at John Radcliffe Hospital and Leuven IBD Centre** have led to sharing of research, the conducting of joint training, and opening access to specialist expertise. Experts from Leuven and Oxford visit the centre twice yearly to assess challenging cases

What would you change if you had the opportunity?

INCREASE AWARENESS
ACROSS IBD CENTRES



Why?

There is a knowledge deficit of IBD amongst medical staff in primary and secondary centres that can result in delayed or incorrect referrals, and treatment of comorbidities that adversely affects ongoing IBD treatment

How?

The centre runs regular IBD education stands for hospital staff and patients to raise awareness of the disease

CREATE AN IBD SPECIFIC
PATIENT REGISTER



Why?

Facilitate better local research and enable improved tracking of IBD patient trends to improve treatment over the medium to long term

How?

Establish a database through new or existing software modelled on the current GI database, but which allows clinical staff to focus only on IBD treatment

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

SEEK AFFILIATIONS WITH
CENTRES OF EXCELLENCE



Why?

A wealth of knowledge has been built up in IBD treatment and should be leveraged by developing centres to ensure they deliver best practice

How?

Affiliations with established IBD centres enable new treatment centres to ensure that they keep pace with developments in IBD treatment. It also allows them to act as a source of expert knowledge for complex cases to be referred to before local expertise is fully established

HIRE AN IBD NURSE



Why?

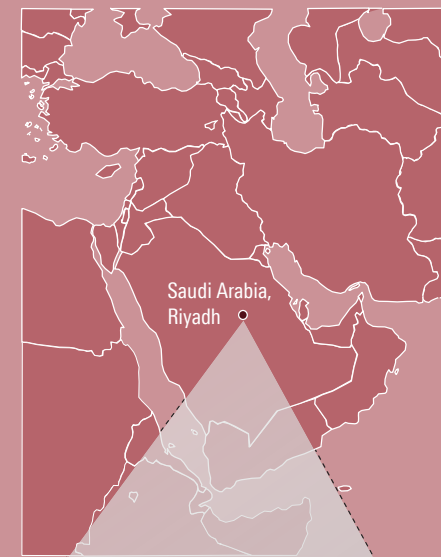
Staff with IBD experience will bring instant expertise that will cascade to all members of the local team, increasing a centre's capabilities, whilst an IBD nurse can provide a focal point and impetus for the entire team and their patients

How?

Recruit IBD-focussed staff from neighbouring centres or overseas to give impetus to the development of a new IBD centre



King Faisal Medical Centre Riyadh, Saudi Arabia





King Faisal Medical Centre

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

IBD treatment team



No formalised MDT, but **weekly imaging and pathology diagnosis meetings** with physicians and radiologists, and *ad-hoc* meetings between physicians and surgeons



Team of **GI nurses with good IBD experience** who share IBD nurse responsibilities, with a specialist IBD nurse currently being trained



Three specialist **radiologists** participate in regular diagnosis meetings, with access to MRI, fluoroscopy, CT scans and ultrasound



Allied health professionals such as a dietician, stoma nurses and seconded pharmacists from pharmaceutical companies support the team, particularly in relaying information from female patients to male HCPs

Patient services



Patients have access to hospital **psychologists**, but in recognition of culture, there is an emphasis on patient and family education and awareness, and on developing self-help networks between patients



There is a **paediatric** gastroenterology facility within the hospital that treats IBD patients until the age of 13 or 14. Parents can accompany children until they reach the age of 18



Female dieticians, nurses and pharmacists often receive reports from **female patients** about symptoms that the patients withhold from male HCPs; which they then try to feed back to the male HCPs

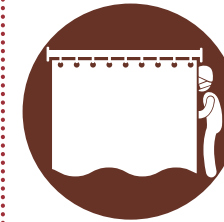


Biologics are available to all patients free of charge, with doctors considering the location of patients (e.g. local in Riyadh, or rural location) to determine which drug is prescribed

Selected treatment approaches



Decisions to proceed with **surgery** are made in line with international guidelines and on a patient by patient basis after discussion between physicians and surgeons



Endoscopies are performed by specialist gastroenterologists with a team of endoscopy nurses. All endoscopies are publically funded

Additional points of relevance



As patients come from a huge geographical area, the IBD centre has a number of **outreach initiatives** such as an IBD helpline, secondment of staff to remote clinics and delivery of medicines by courier



IBD **research** is currently not being conducted, but the presence of electronic health records do allow fellows to conduct their own research efficiently



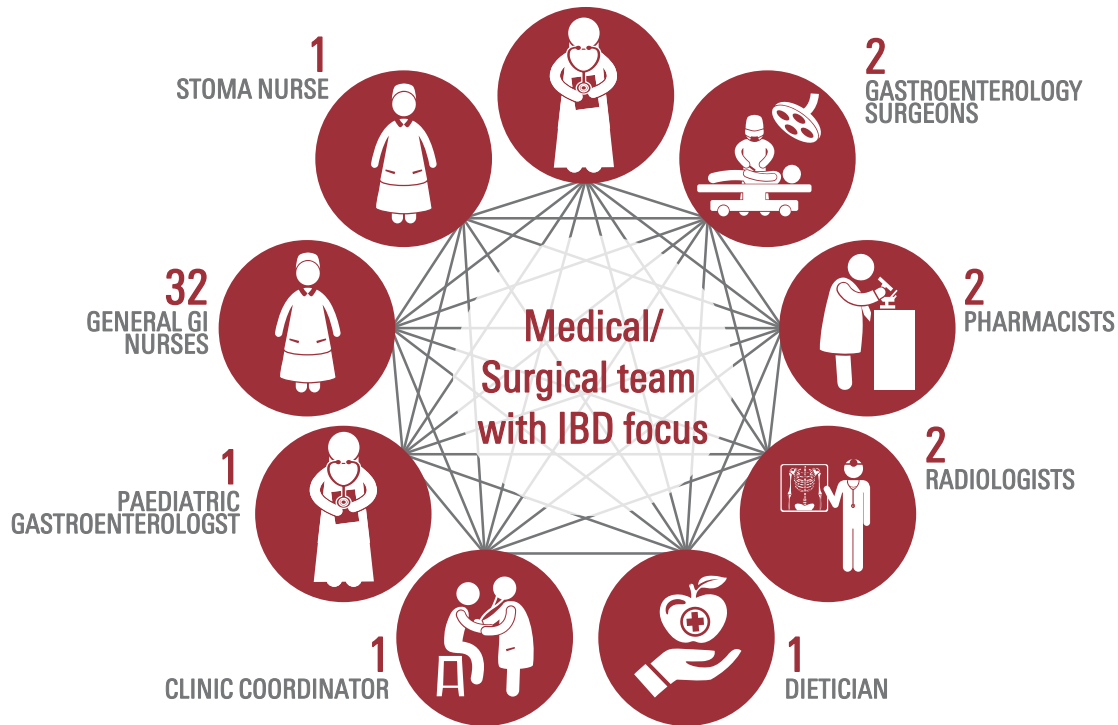
King Faisal Medical Centre – IBD TREATMENT TEAM



Riyadh and remote
Saudi Arabia

~1,200 active
patients

2
Full-time
GASTROENTEROLOGISTS



KEY FEATURES OF CENTRE:

- International staff, combining local and international expertise
- Extremely motivated staff who take pride in their patient centric work and are bound together by a strong team spirit
- Outreach programme to serve patients in remote areas



I am so proud to work at King Faisal – one word sums up our approach – excellence!
(Senior nurse)



We work really well together and often discuss diagnoses. This creates greater accuracy and benefits the patient.
(Radiologist, IBD focus)







King Faisal Medical Centre – SUMMARY





STRENGTHS

-  All staff members strive for excellence across all patient and non-patient facing functions, and staff are encouraged to undertake training sponsored by world-class institutions
-  Strong focus on patient education and engagement, with staff mitigating difficulties arising from local behaviours and expectations with initiatives such as patient education meetings
-  A multi-disciplinary approach is considered vital, with dieticians, nurses, pharmacists and surgeons all supporting IBD specialists in the provisions of comprehensive patient care at all stages of the patient pathway
-  State-of-the-art medical equipment and facilities, achieved by long-standing financial support from local healthcare authorities

KEY INFLEXION POINTS FOR PATIENT CARE

-  Better awareness of IBD amongst the general population will aid early diagnosis and reduce the stigma that accompanies chronic illness
-  The long-term nature of IBD care means that clinical staff cannot alone rely on memory and written records to maintain effective treatment. There is also the need to discuss cases amongst staff, so consistency of care can be maintained even if staff rotate
-  The handover of paediatric patients to adult care poses particular challenges, with the potential for losing patient trust just as the patient enters puberty
-  Patient diagnosis should not be made in isolation; views should be debated and challenged in order to achieve an accurate diagnosis as early after patient presentation as possible

SUCCESSFUL INTERVENTIONS

-  IBD awareness in remote primary care centres is being raised as a result of outreach programmes, to enable early diagnosis of IBD prior to referral to KFSH
-  Investment in comprehensive Electronic Medical Records provide timely, accessible information for every patient, enables consistent care and improves the research capabilities of the hospital
-  Formal transition clinics are held for all patients aged between 14-18 years old, combining all adult and paediatric parties, enabling the retention of patient trust
-  A systematic programme of nurse/patient engagement to ensure that patients were properly prepared for their endoscopies was instigated, raising patient treatment completion levels¹ from 80% in 2011 to 92% in 2013

Note 1. Patient treatment completion level refers to the number of scheduled appointments for treatment that were not cancelled or rescheduled, and where treatment was administered as expected



King Faisal Medical Centre

What would you change if you had the opportunity?

CREATE A POSITION FOR AN IBD NURSE



Why?

Current nurses at King Faisal Medical Centre are regarded highly, and are seen to improve outcomes and compliance. However, they are stretched and require more support through an additional IBD nurse

How?

A local nurse specialist is currently preparing to attend training in the USA and will return to King Faisal Medical Centre as a fully trained IBD nurse in 12 months' time

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 has reduced the mis-diagnosis rate by about 20%

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

SPECIALISED NURSING STAFF



Why?

An IBD nurse or a well-educated nursing staff with IBD focus increases the capabilities of an IBD centre. The nurse drives IBD nursing expertise, supports doctors clinically, and acts as the primary point of contact for IBD patients

How?

Well-trained and specialised nursing staff are key to delivering patient-centric treatment and to create more efficiencies for the treatment centres through effective patient care management

MULTI-DISCIPLINARY APPROACH



Why?

IBD is condition that requires the expertise of multiple well-trained medical professionals who have the opportunity to regularly exchange and challenge their respective professional opinions

How?

Ensure a climate that encourages open exchange of opinions and allows peers from different departments to meet regularly



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