



*cutting through complexity*



# **Guiding Principles and a Toolkit for the Improvement of IBD Care**

## **Autumn 2014**

Project I.D. 1587710

This study was commissioned and solely funded by AbbVie. 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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Inflammatory Bowel Disease (IBD) is a complex chronic disease which has a serious impact on patients. Although there are a number of treatment options available, IBD cannot be medically cured.



Currently, patients, their carers and physicians face significant challenges including ill-defined and fragmented care pathways, poor use of medical treatments, late diagnosis and late referral to specialist centres. There are wide variations in the quality of care patients receive, even within the same geographical locations.



KPMG carried out a study to help understand how to deliver excellent IBD care for patients and how to help improve care delivery across healthcare systems.



A team of clinicians and research scientists visited eight reference centres. During these visits, the team observed IBD care, collected data and interviewed healthcare professionals involved in the management of IBD patients.



The aim of this report is to help document best practice in IBD care and share these across other healthcare centres. No attempt has been made to rank the reference centres or to make judgements about medical decisions.



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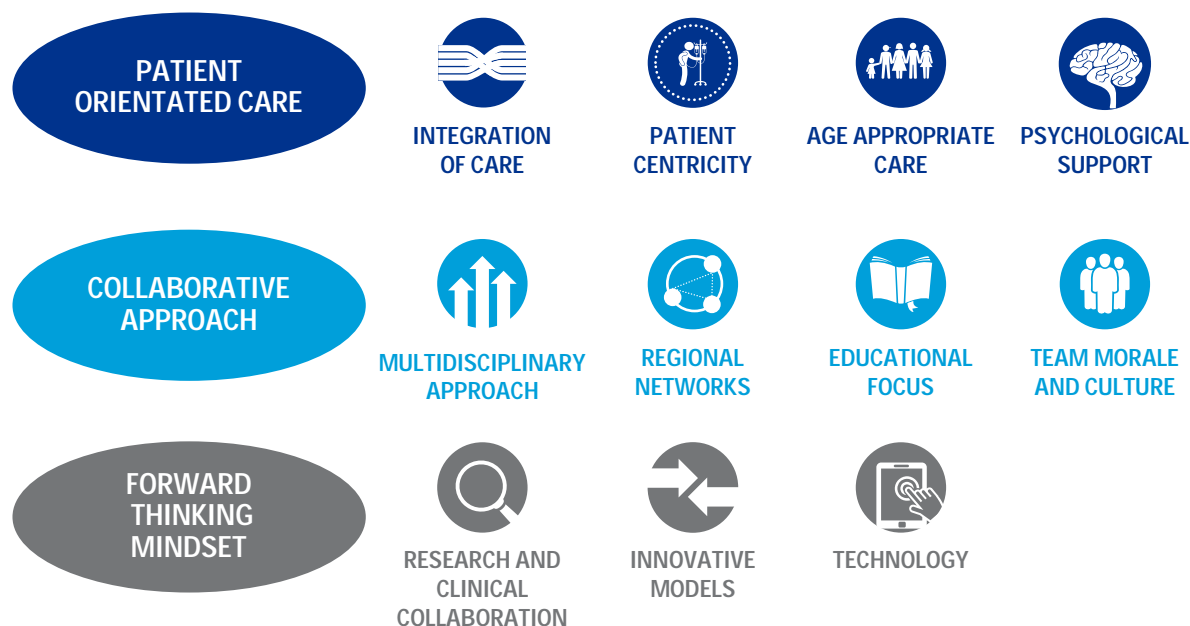


We identified three themes relating to good IBD care:

- Patient-oriented care
- Collaborative approach
- Forward thinking mindset

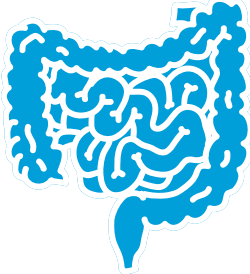


Each theme can be further divided into eleven subsections which are described in detail in this report:



# IBD IS A COMPLEX CHRONIC DISEASE WHICH HAS A SERIOUS IMPACT ON PATIENTS

1/2 CONTEXT



## What is IBD?

The term IBD (Inflammatory Bowel Disease) is mainly used to describe two conditions, Crohn's disease (CD) and ulcerative colitis (UC), both of which are chronic diseases which cause inflammation in the wall of the gastrointestinal tract.

- **UC** affects the colon (large intestine)
- **CD** can affect the entire digestive system, from the mouth to the anus

## What are the symptoms?

The most commonly reported symptoms include: abdominal pain, recurring or bloody diarrhoea, weight loss, and extreme tiredness. Typically, patients have recurrent attacks of these symptoms, with acute exacerbations interspersed with periods of remission or less active disease.

## What causes IBD?

The exact cause of IBD is unclear. It is thought that a combination of several factors triggers the inflammation. These include:

**Genetics** – You have a greater risk of getting the disease if one of your first-degree relatives suffers from it, suggesting a strong genetic component.

**Disruption to the immune system** – IBD may occur as a result of an auto-immune sensitivity with no obvious causal point or one that is triggered by a viral or bacterial infection.

**Environment** – Smoking is observed to be one of the most important risk factors for IBD, especially among CD patients.

## How is it diagnosed?

Diagnosing IBD is undertaken using a range of tools, including a detailed medical history, a series of blood tests and imaging modalities as well as histology.

Biopsies taken at endoscopy and imaging are used to monitor the symptoms throughout the disease process.

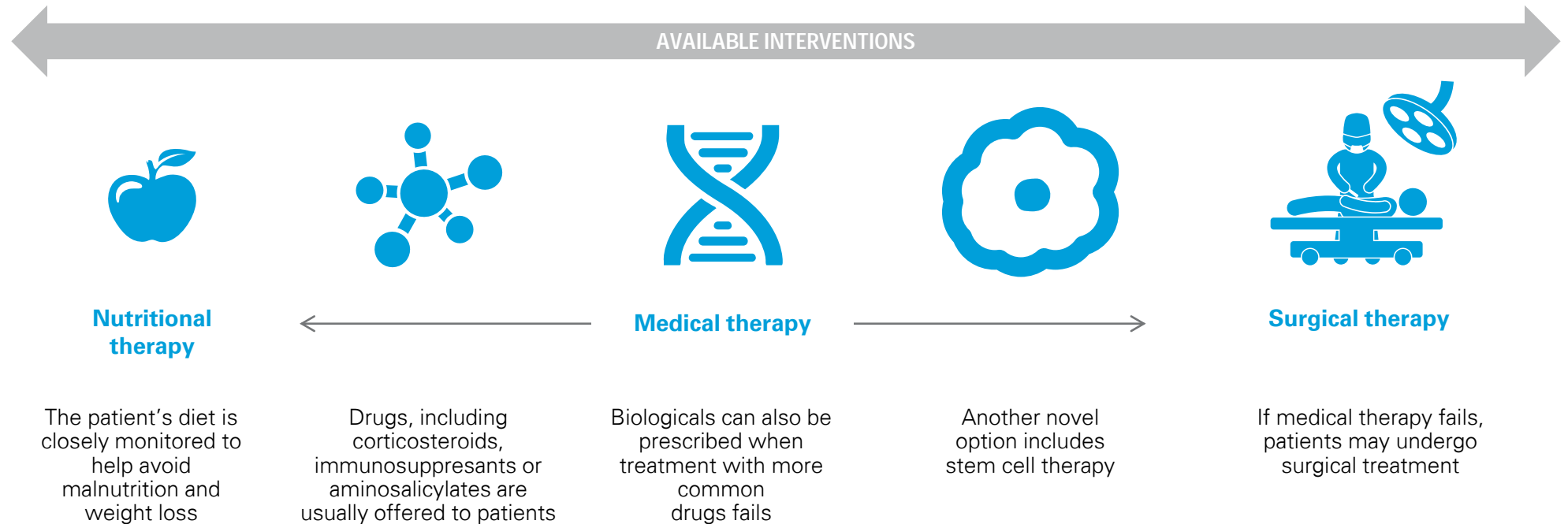


Sources: [IBD, NHS UK](#); [IBD, Mayo Clinic](#); [IBD, London Digestive Health](#); [eGuidelines UK](#), [The burden of inflammatory bowel disease in Europe, J Crohns Colitis 2013, 322-37](#); [An Evidence-Based Systematic Review on Medical Therapies for Inflammatory Bowel Disease, Am J Gastroenterol, 2011](#)

# THERE ARE A NUMBER OF TREATMENT OPTIONS CURRENTLY AVAILABLE

## How can IBD be treated?

There is currently no cure for IBD so treatments mainly focus on symptom relief. There are a number of options available for patients; the most appropriate interventions are selected on a case by case basis and are largely determined by the severity of the disease and its responsiveness to treatment.



Sources: Top Down vs. Step Up Therapy Biologics in IBD: Treatment Algorithms, GIHealthfounding.org, accessed 20 June 2014; [ECCO Guidelines on Crohn's disease, J Crohns Colitis, 2010, 28-62](#); [ECCO Guidelines on UC, J Crohns Colitis, 2012, 991-1030](#).

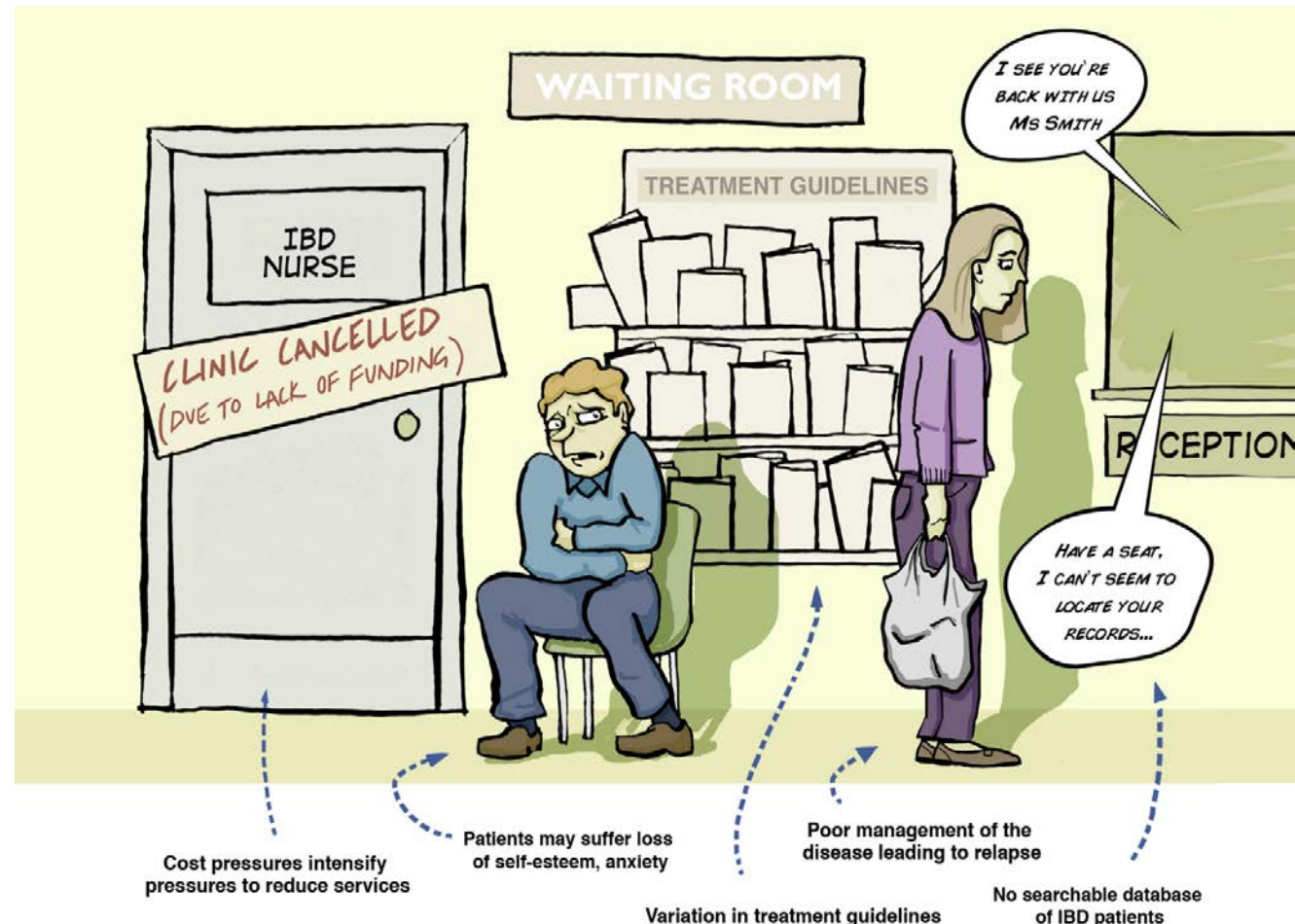
# PATIENTS, THEIR CARERS AND PHYSICIANS CURRENTLY FACE SIGNIFICANT CHALLENGES

## THE CHALLENGE

The current treatment of IBD can be **improved**.

Some frequently encountered challenges for IBD care are:

- Smaller centres found that reduced exposure to complex disease management limits the capability to provide a fully resourced holistic service
- Wide variations in the quality of care patients receive
- Ill-defined and fragmented pathways between primary and secondary care
- Treatment pathways that are 'physician centric' and not 'patient centric'
- Poor symptom control of active disease which increases the risk of relapse, morbidity and mortality
- Late diagnosis and referrals to specialist centres
- Lack of treatment of co-morbidities and exacerbating factors including disease associated depression, anxiety and stress
- Wide disparities in organisational structure from small centres with low patient volumes to large, well-coordinated and well-staffed clinics
- Opportunistic surgery, without co-ordination with medical care



Sources: UK IBD audit, Royal College of Physicians, 2012, [http://www.rcplondon.ac.uk/sites/default/files/1\\_page\\_summary\\_inpatient\\_experience.pdf](http://www.rcplondon.ac.uk/sites/default/files/1_page_summary_inpatient_experience.pdf); IBD care improvements needed, National Health Executive, April 2012, <http://www.nationalhealthexecutive.com/Health-Care-News/ibd-care-improvements-needed>; Do Inflammatory Bowel Disease patients with anxiety and depressive symptoms receive the care they need?, Journal of Crohn's and Colitis, 2012, [http://www.ecco-iccjournal.org/article/S1873-9946\(11\)00194-2/abstract](http://www.ecco-iccjournal.org/article/S1873-9946(11)00194-2/abstract);

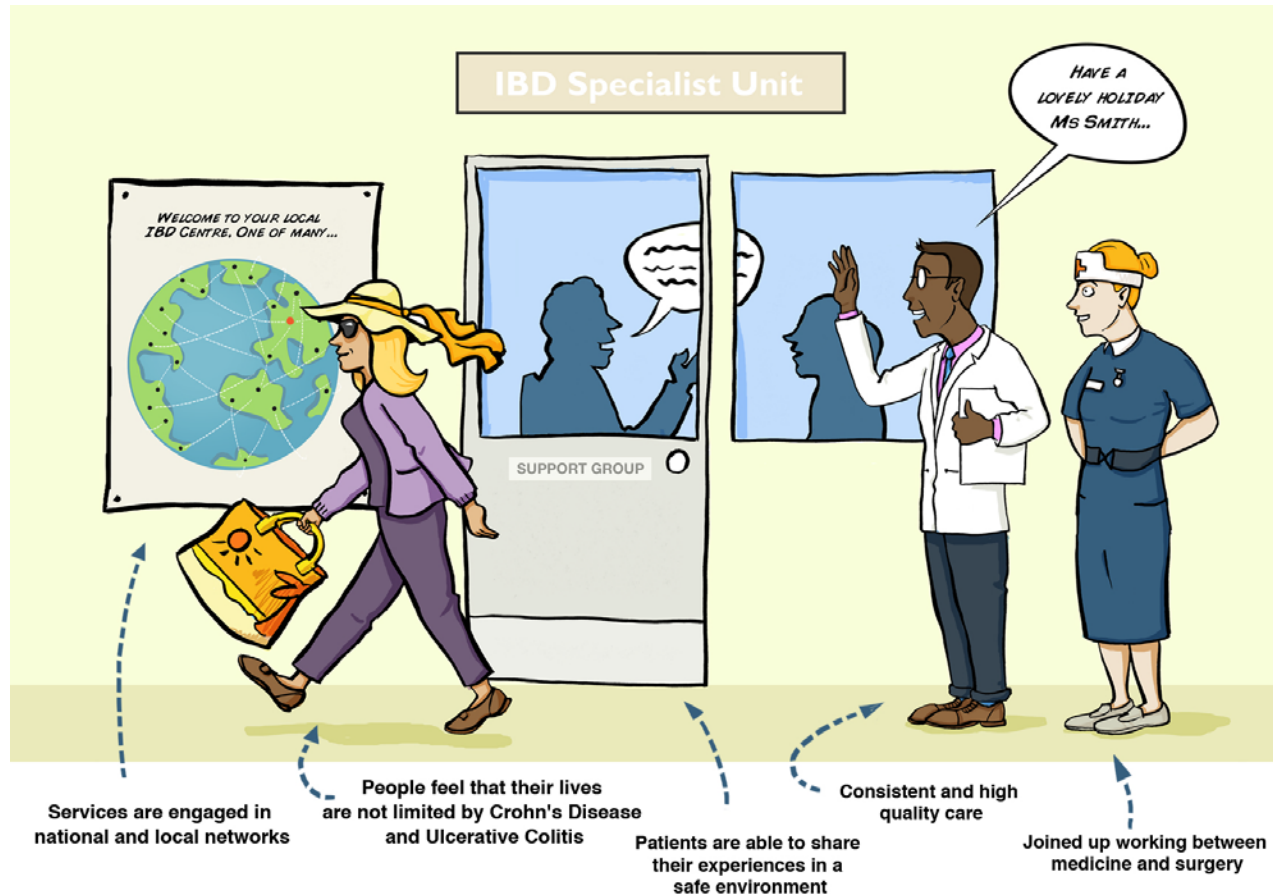
# THE AIM OF THIS STUDY IS TO DEFINE THE PRINCIPLES OF GOOD IBD CARE

## THE AIM

**Based on the best practices identified from eight reference centres our aim is to improve IBD care across Europe.**

**We want the next generation IBD care pathway to be characterised by:**

- A patient pathway that is designed around patient needs and drives consistent and high-quality IBD care
- Dedicated, patient-centric IBD centres displaying best-in-class characteristics such as:
  - Joined up working between medicine and surgery
  - Provision of dietetic services
  - IBD nurse specialists coordinating care
  - Treatment of associated psychological symptoms
- Care pathways and service specifications that are based on the best available bio-medical evidence and an integrated holistic approach
- An evidence base supporting hospital reconfiguration for IBD patient care
- A service model that engages national and local networks



# KPMG'S TEAM OF CLINICIANS AND RESEARCH SCIENTISTS LED THE WORK

## THE TEAM

### Who are we and why us?



#### PROF. HILARY THOMAS

Hilary is the most senior clinician within our Healthcare and Life Sciences practice and led this IBD-care initiative.

[hilary.thomas@kpmg.co.uk](mailto:hilary.thomas@kpmg.co.uk)

I spent twenty three years in the NHS, from qualifying as a doctor in 1984 to becoming a Professor of Oncology.

Care system redesign is at the heart of my work at KPMG where we try to bring the entire healthcare community together to produce better outcomes, improve patient experience and reduce cost.



#### DR. ADRIENNE RIVLIN

Adrienne is one of our most experienced associate directors.

[adrienne.rivlin@kpmg.co.uk](mailto:adrienne.rivlin@kpmg.co.uk)

I have significant international experience leading large operational change programmes in both the public and private sector. I am passionate about redesigning services so that they are best able to meet patient and clinician demands and expectations.



#### DR. GUILLAUME FAVIER

Guillaume comes from a scientific background with a PhD in chemistry and works now as a Healthcare Strategy Advisor at KPMG. He specialises in the improvement of patient pathways.

[guillaume.favier@kpmg.co.uk](mailto:guillaume.favier@kpmg.co.uk)

Improving clinical pathways is what excites me the most in my day-to-day job as it has a direct impact on patients. For more than a year, I focused on stroke and helped British, Polish, French and Brazilian hospitals reduce delays from the onset of the symptoms to the delivery of treatment.



#### DR. LIZZIE TUCKEY

Lizzie trained as doctor in the NHS and is a senior advisor in our global life sciences team.

[lizzie.tuckey@kpmg.co.uk](mailto:lizzie.tuckey@kpmg.co.uk)

I am a qualified surgeon and have experience in developing clinical strategies for hospital services to ensure that they are patient centric and fully integrated. My goal is to improve patient outcomes as well as efficiency.



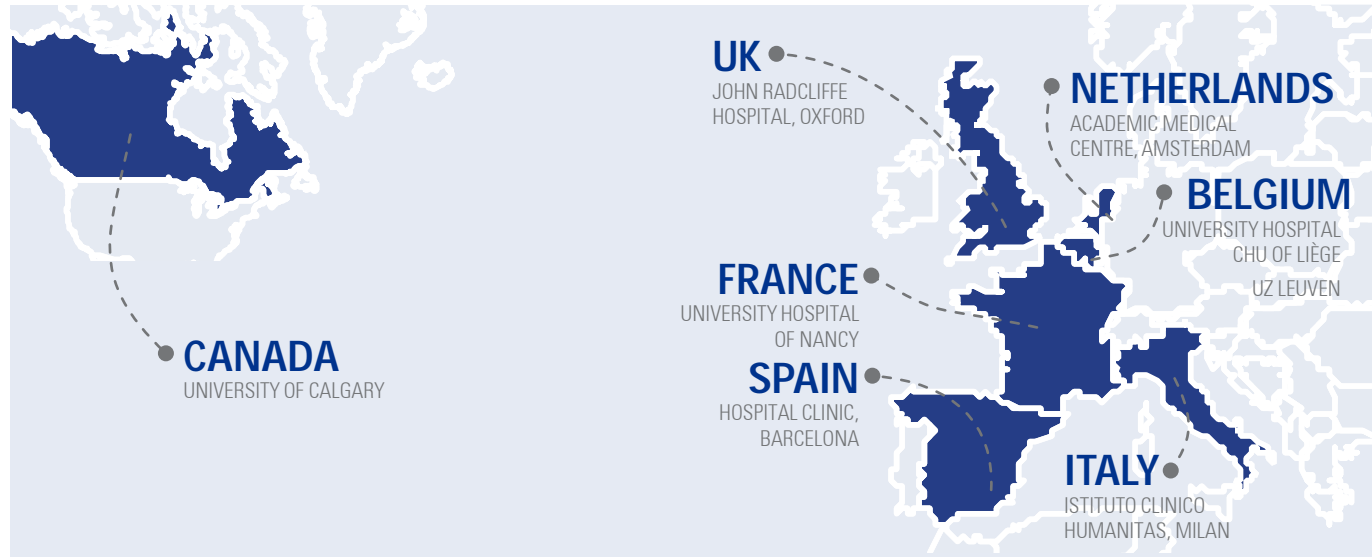
# KPMG VISITED EIGHT REFERENCE CENTRES WITH AN ACTIVE IBD TEAM

## Who did we target?

To understand current best practices, KPMG and ECCO selected renowned centres which had the resources to provide specialist IBD care to patients.



## Where did we go?

Between April and July 2014, the KPMG team visited eight reference centres across western Europe and Canada.





## 1/3 METHODOLOGY




APRIL

-  HOSPITAL CLINIC, BARCELONA
-  UNIVERSITY HOSPITAL CHU OF LIÈGE

MAY

-  UNIVERSITY HOSPITAL OF NANCY
-  JOHN RADCLIFFE HOSPITAL, OXFORD

JUNE

-  ISTITUTO CLINICO HUMANITAS, MILAN
-  ACADEMIC MEDICAL CENTRE, AMSTERDAM
-  UNIVERSITY OF CALGARY

JULY

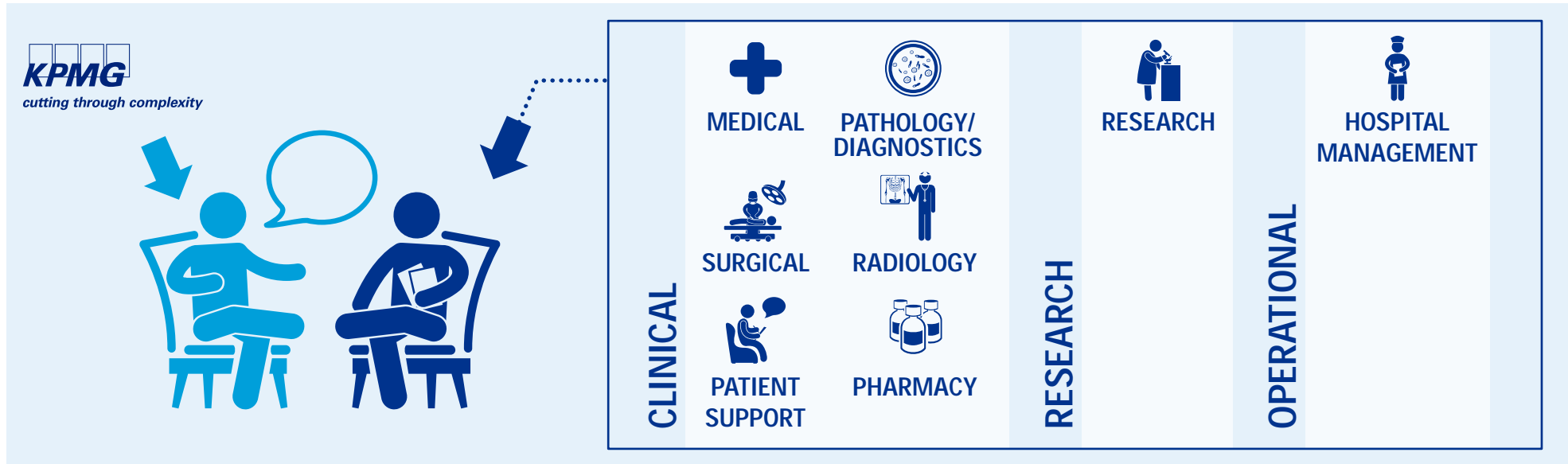
-  UZ LEUVEN

# KPMG INTERVIEWED STAFF INVOLVED IN THE MANAGEMENT OF IBD PATIENTS

2/3 METHODOLOGY

## Who did we interview?

During each visit, we conducted a series of one to one interviews. We met a range of people across the service and included clinical, research and operational staff.



## What did we ask?

We combined structured interview questions with open discussion in a private setting to get a complete picture of the care pathway, the service model, the best practices and the challenges that each organisation faced.

### We asked interviewees three core questions:

- 1) Please can you describe your involvement in the IBD team, and your role in supporting the management of IBD patients?
- 2) Please can you describe the practices and aspects of your organisation that, in your view, contribute to the quality of care that you deliver?
- 3) Please can you describe any ways in which you believe you could improve IBD care for patients? (This can relate to improvements you would make within your organisation or improvements that you would make to the way care is delivered across the disease pathway.)



# WE OBSERVED IBD CARE AND COLLECTED DATA TO UNDERSTAND HOW IBD TEAMS OPERATE

3/3 METHODOLOGY

## What did we want to observe?



### PROCESSES

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



### TEAM INTERACTION

To assess the level of interaction between the members of the IBD team, we attended multi-disciplinary group meetings



### PREMISES

We wanted to understand the patient experience and asked our hosts to walk us around the IBD services on a typical patient journey. One of our goals was to understand whether and, if so, how co-locations of services benefited a multidisciplinary approach

## What data did we want to collect?



### PROCEDURES

When centres described innovative pathways and medical procedures, we asked to be given hard copies to fully understand them



### EDUCATIONAL MATERIAL

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



### FORMS FROM IBD DATABASES

Some centres are currently setting up IBD databases to record data on their patient cohort. When available, we wanted to know what type of information they recorded



### PATIENT VOLUMES

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

# WE IDENTIFIED THREE KEY AREAS RELATING TO BEST PRACTICE IBD CARE

## FINDINGS

These principles were not ranked or prioritized. They all play a part in delivering high-quality patient care in different ways. In some contexts, it is the combination of several factors working together which contributes to high quality care.

### PATIENT-ORIENTED 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

# PATIENT-ORIENTED CARE

## PATIENT-ORIENTED CARE



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OF CARE



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AGE APPROPRIATE  
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## COLLABORATIVE APPROACH



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AND CULTURE

## FORWARD THINKING MINDSET



RESEARCH AND  
CLINICAL COLLABORATION



INNOVATIVE  
MODELS



TECHNOLOGY

# INTEGRATION OF CARE IMPROVES PATIENT EXPERIENCE AND RESULTS IN BETTER CLINICAL OUTCOMES

## Why is it important?

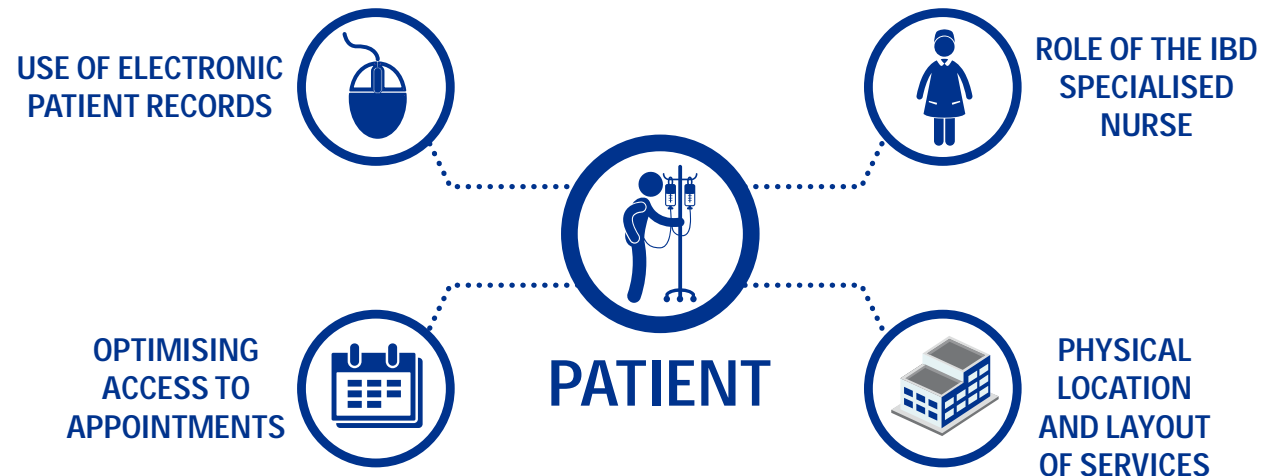
In some centres, the different elements of IBD care may be fragmented and there may be a lack of co-ordination between different aspects of care. This is especially relevant for IBD given that it is a complex chronic disease and patients may have a wide range of symptoms or associated conditions that need regular treatment.

## How is it done well?

A well integrated service joins up patient care across the disease pathway and achieves better patient outcomes.

A smooth and joined up approach provides a single point of contact allowing easy access into a service. It ensures that patient information is seamlessly shared across the care pathway via an electronic record which all healthcare workers have access to. The sharing of information in this manner allows staff to make informed decisions, and promptly direct patients to appropriate services or appointments. It also prevents patients from having to repeat themselves to each healthcare worker which is one of the most frequent aspects of care that patients complain about.

During our visits to the eight reference centres, we observed that there were a number of elements which helped to deliver an integrated service including the use of **electronic patient records**, **optimising access to appointments**, continuity of care through an **IBD nurse** and **physical location/layout of services**.





# USE OF ELETRONIC PATIENT RECORDS

**Relying on a single electronic patient record system allows the medical team to focus on patient care.**

Due to the large number of healthcare professionals who are part of the IBD team, it is important that they are able to access patient records. As a result, they can save time discussing issues already covered by their colleagues.

Many centres still rely on the transfer of paper records across the IBD service and between healthcare workers. Although this was often done very effectively, it ultimately does not provide real-time access to information.

An Electronic Patient Record (EPR) system which links test results to the medical record and provides access to every member of the IBD team is the gold standard. It gives real-time access to information at any point of access (in A&E or at the outpatient clinic) and is an efficient way of communicating information across a pathway, especially where healthcare workers may be geographically separated.

Access to the EPR by a patient's community carer or family doctor is also essential and we expect to see IBD care linked across the healthcare system in the future.

Finally, the use of an EPR opens up the possibility of patients having access to their records. So called 'open record' systems give patients full access and ownership of their health record. This encourages self management and empowers patients to participate in their care. These innovations are only possible with EPRs.



## CHU NANCY, FRANCE

In Nancy, the IBD department recently volunteered to pilot a new electronic system. It is currently being implemented across the hospital. It allows HCPs to record consultation details and it links the patient record to their imaging and laboratory test results. It is accessible to all members of the IBD team.

The staff feel it has begun to change the way they interact with and treat patients. It provides up to date information and enables clinicians to make more informed decisions involving patients in their care in a different way.



If you asked me what the single most important aspect of delivering high quality IBD care was, I would say having an electronic patient record."

Gastroenterologist, Nancy



# OPTIMISING ACCESS TO APPOINTMENTS

**Giving patients well-planned appointments leads to engagement and an holistic treatment experience.**

Patients who suffer from IBD will often have a significant number of appointments and will interact with various members of the IBD team, across different locations.

Having easy access to appointment scheduling and being able to book multiple appointments at once keeps patients engaged with services and prevents them from making multiple visits at greater expense and impact on their quality of life. It also allows flexibility so the number of 'Do Not Attends' is reduced.

As IBD is often associated with other conditions such as Rheumatoid Arthritis and Cancer, we observed that some centres had allocated a particular doctor from these specialities to be the main contact for IBD patients. In some cases they offered joint clinics so that an IBD patient could see their Rheumatologist and their Gastroenterologist at the same time, this gives patients an holistic experience and provides a truly patient-centric service.



## HOSPITAL CLINIC BARCELONA, SPAIN

In Barcelona, patients have access to a hotline to book appointments as well as an online booking system. Patients can schedule multiple appointments in one day to minimise travel and expense. It also means that they can cancel and amend times, reducing the number of patients not showing up for their appointments.

The number of patients arriving at the emergency department is very low, perhaps indicating that patients are directed to the right initial treatment modality.



## HUMANITAS, MILAN, ITALY

In Milan, patients who are put forward for surgical treatment at the centre will be seen in clinic by the gastroenterologist and the surgeon at the same time.

Also, patients who suffer from RA (or other conditions associated with IBD) can see the relevant specialist at the same time as their gastroenterologist.



# ROLE OF THE IBD-SPECIALIST NURSE

**Where available, the IBD nurse provided continuity of care for patients educating them on their disease and giving support and advice across the disease cycle. Whether their title is official or not, the IBD nurse plays three key roles, amongst others, which are extremely helpful, even vital, to the IBD team. These are:**

## 1. Care co-ordinator

The IBD patient pathway is complex and typically involves interactions between multiple healthcare professionals which is often difficult for patients to keep track of. In some centres IBD nurses acted as the care co-ordinator for patients, helping them book appointments and triaging their care needs to the right specialist.

## 2. Treatment expert

Some centres used the IBD nurse to run nurse-led clinics managing different aspects of treatments including the administration and prescription of biologics, telephone consultations to triage patients' health needs in the community as well as running outpatient consultations on general IBD care. This provided centres with extra team capacity and acted as an efficient use of a healthcare resource.

## 3. Case manager

In some centres the IBD nurse acted as a case manager. Patients were allocated to a particular nurse who followed them on their treatment journey throughout their disease and acted as the main point of contact for that patient during care episodes. In this role the nurse became very close to patients and often provided support and advice for non medical, psycho-social symptoms as well.



A nurse who specialises in IBD care can spend time educating patients, which we doctors do not always have.”

Gastroenterologists from  
Barcelona and Leuven

# EXAMPLE RELATED TO THE ROLE OF IBD NURSE

## UNIVERSITY HOSPITAL OF LIEGE, BELGIUM

Until very recently there was no such thing as an 'IBD nurse' in Belgium. However, after visiting several IBD centres in the UK and USA, Prof. Louis who leads the IBD team from Liege, realised how valuable the role of an IBD nurse is.

As a result, he asked one of the nurses from his team to act as an IBD nurse, one of the first of her kind in Belgium.

To do so, the nurse shadowed Prof. Louis over several months, attending his consultations to understand his involvement with IBD patients and to identify areas in which she could support him.

She developed a specialist skill set and is now undertaking, amongst others, the following activities:

- **Acting on the gastroenterologist's behalf during consultations** - in 2000, the team in Liege started anti-TNF clinical trials. The nurse has since become an expert in these treatments and now consults patients without Prof. Louis. She can even manage patients under anti-TNF drugs and acts as the main point of contact for all these patients (planning appointments for infusions etc.)
- **Connecting the IBD team and the GPs** (general practitioner) - she writes a letter to the patient's GP after every appointment to make them aware of the treatments prescribed and decisions made.
- **Being an educator** - the nurse amplifies the educational structure that is already in place for patients. She dedicates several slots every week to answer any questions that patients may have. In addition, she has been asked by Prof. Louis to lead on an educational project to produce educative material. All team members are involved in this initiative.
- **Supporting patients with administration** - she helps patients to fill in their reimbursement papers.

The entire team recognises how important the role of an IBD nurse is. In addition, a similar role will be set up in other hospitals in Liege and in Brussels.

“



We need more IBD nurses. Ours do a great job but with an increasing volume of patients, it would be ideal to welcome someone else with the same skill set to the team.”

Gastroenterologist, Liege

“



Our IBD nurse has developed special skills and she is really good at what she is doing. We totally trust her.”

Gastroenterologist, Liege





# PHYSICAL LOCATION AND LAYOUT OF SERVICES

**There is an established body of evidence which shows that services that are designed around the patient and co-locate their research facilities close to clinical services provide a higher quality of care for patients.**

## Patient-centric design

The physical location as well as the layout of the different aspects of care can have a significant impact on how integrated the service feels for the patient.

If the different aspects are located close to one another, it makes it easier for patients to move from one service to another.

It also makes it easier for clinicians to interact with one another or get a second opinion while with the patient.

## Co-location of research facilities and laboratories

The location of research and laboratory faculties close to clinical facilities allows centres to drive research from a clinical perspective, giving better access to patients and their associated histopathologies.

Clinically driven research leads to quicker development of novel treatments and better understanding of resistance disease. It also promotes a culture of learning and drive towards excellence which is linked to achieving better patient outcomes.



## JOHN RADCLIFFE HOSPITAL, OXFORD

At the John Radcliffe Hospital in Oxford, all of the aspects of care are located in close proximity to one another. Patients can easily walk from one aspect of care to another.

Practically, this means that during clinics physicians can seek the advice of surgeons or other healthcare professionals while they are with a patient.



The laboratories are next to the ward, the ward is across the corridor from the day care unit, and the day care unit leads into the clinical trials facility."

Gastroenterologist, Oxford

# FOLLOWING A PATIENT-CENTRIC APPROACH LEADS TO BETTER OUTCOMES AND IMPROVES COMPLIANCE

## Why is it important?

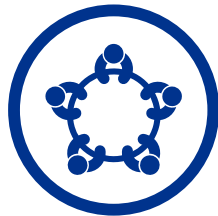
When centres place patients at the heart of the IBD team, they wrap service delivery around their needs and design services with the patient experience in mind. In this way, staff stay active in the patient's care across their journey, improving treatment outcomes and compliance.

## How is it done well?

We have observed a number of different ways in which a patient-centric approach was adopted across the centres including:



**PATIENT  
EDUCATION**



**LINK WITH  
PATIENT  
ASSOCIATIONS**



**RELATIONSHIP  
WITH PATIENTS**



**EVENTS**



**PATIENT  
EMPOWERMENT**



# PATIENT EDUCATION

**Educating patients with chronic disease about their pathology, the treatments they are taking and the progress they are making is essential to provide high-quality medical care which improves patient outcomes.**

We observed four features of excellent patient education on our visits:

## 1. It should be tailored to the individual

Some centres produced patient-specific information packs which are more engaging for patients and they are more likely to take them home and read them.

## 2. It should be linked to patient groups

Some centres were very well linked to patient groups and sent experts out to local events to help with the education process.

## 3. It should be continuous

Educating patients with IBD is not a one-off process and most centres had facilities to provide ongoing support and education to patients as needs arised.

## 4. It should use different channels of communication

Some centres were experimenting with different types of technology to communicate information to the patient. One centre was using Skype, another an iPhone app.



## HOSPITAL CLINIC BARCELONA, SPAIN

Educational material is tailored to the individual by the clinical / IBD nurse despite having an active pool of over 2,000 patients.

The patient is given multiple appointments and therefore the nurse can keep the information relatively high-level initially and use future appointments to explain more complex issues and focus on answering questions.

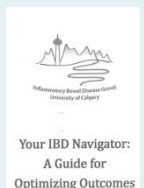
Family members and friends are allowed to attend the education sessions and separate sessions are offered to support close family if necessary.



## UNIVERSITY OF CALGARY, CANADA

Three to four times a year, the IBD team in Calgary organises educational seminars to update patients on the latest advancement in the treatment of IBD.

The group has also developed an “IBD Navigator”. This document is given to all IBD patients at the centre. It describes the disease, the types of treatments available and the opportunity to take part in clinical trials. Following patient feedback, the team also produced one page summaries on specific patient issues.



**CALGARY'S  
IBD NAVIGATOR**



# RELATIONSHIP WITH PATIENTS

**IBD is a challenging disease for patients to live with. Having a robust relationship with the IBD team is an important part of a patient's treatment and helps drive adherence and good disease management.**

We observed a number of ways that staff developed and maintained relationships with their patients:

- Regular contact via telephone and hotlines
- Allocating a patient to a single doctor
- Motivational interviewing
- Christmas cards updating patients of progress
- Patient engagement meetings to input into service design
- Events to socialise and interact with general practitioners or family doctors
- Seeking patient feedback
- Family appointments and education so that relatives can support patients

Evidence shows that good patient engagement improves treatment adherence and leads to better disease outcomes.

All the centres we visited highlight the importance of making time for patients and had many different strategies of developing relationships not just with the patients themselves but also the families and relatives as well.

These relationships form the basis of getting patients through flare ups and past the difficult medical decisions they may need to make along their disease trajectory.



You have to make sure that patients know you and that you know them. I try to provide the best care I can and in the way I would like to be cared for."

IBD Nurse, Amsterdam



One of my patients calls me 'mum kangaroo', we are quite close!"

Stoma nurse, Liege



We have dieticians in our hospital however we prefer to rely on someone from another centre who actually has Crohn's Disease herself and is also our own patient. She has developed a unique relationship with our patients!"

Gastroenterologist, Calgary



# PATIENT EMPOWERMENT

**Giving patients the right information and tools to encourage them to take part in the management of their disease leads to better outcomes. In all the centres we visited, IBD teams talked to their patients about the side effects, location and frequency of their treatment. In this sense, the physicians worked *with* the patients to choose the right treatment for them.**

We observed two main ways in which centres encouraged patient empowerment:

## 1. Patient are treated as part of the IBD team

Historically, doctors have acted paternalistically as the principal decision-maker, telling patients what treatment plan they should take. However today, patients tend to be more knowledgeable and want to be active in the management of their disease. Empowering patients by treating them as one of the team and enabling them to take control of their treatment themselves leads to better compliance.

## 2. Patient involvement

Most centres tried to involve patients in their service design and improvement. They did this via a number of innovative methods: patient feedback surveys, engagement meetings and suggestions boxes. Staff recounted that where patients can see they have been involved in changing a service their engagement is much stronger.



Every year we conduct a feedback survey which asks patient to comment on service improvement. When we act on a suggestion, patients feel part of improving the service and this is very engaging for them."

Gastroenterologist, Milan



It is important to involve patients. Quite often, they tell us 'you are the doctor, so you decide' however we always remind them that they are part of the team and should make decisions with us."

Gastroenterologist, Liege



## UNIVERSITY OF CALGARY, CANADA

In its "IBD Navigator", the team in Calgary has added an **IBD Clinic Visit Log** so patients can follow the evolution of their disease. In this section, the patient can read about findings, results, medication and future plans that have been discussed with the team.

This gives patients the opportunity to be more active in the management of their disease as they can discuss their treatment with their physician.

Sources: Patient Engagement, Health Policy Brief, [http://www.healthaffairs.org/healthpolicybriefs/brief.php?brief\\_id=86](http://www.healthaffairs.org/healthpolicybriefs/brief.php?brief_id=86), 14 February 2013; Effectiveness of strategies for informing, educating, and involving patients, BMJ. Jul 7, 2007, 335, <http://www.ncbi.nlm.nih.gov/pmc/articles/PMC1910640/>



# LINK WITH PATIENT ASSOCIATIONS

**Patient groups provide ongoing support and education for patients living with IBD. Evidence has shown that patients who have strong relationships with their relevant associations report better outcomes and develop better self management behaviours.**

Local patient groups can help centres provide continuous education to patients. They can focus on the burden of disease in everyday life. In addition, contact with other patients provides normalisation and psychological support for IBD patients.

An effective link between these groups and treatment centres can release the burden of the latter as well as increase the quality of care and outcomes for patients.



I attend the roundtables organised by our local IBD patient group. I learn a lot about my patients by engaging with them in a non clinical setting. It gives me the opportunity to share my knowledge and experience in different way. Often, I feel as if I learn more than the patients."

Nurse, Nancy



## CHU NANCY, FRANCE

In Nancy, the centre has strong links with local patient associations which helps to supplement the services offered by the centre (e.g. patient education and advice).



## JOHN RADCLIFFE HOSPITAL, OXFORD, UK

In Oxford, the IBD unit relies on brochures produced by UK patient group Crohn's and Colitis to inform patients on the treatment available for IBD, on how to transition from teenage to adult care etc.



## HUMANITAS, MILAN

The Milanese team is helping local and national patient groups with their educational programmes.

Sources: Standards for the Healthcare of People who have Inflammatory Bowel Disease (IBD), IBD Standards Group, 2009, [www.ibdstandards.org.uk/uploaded\\_files/IBDstandards.pdf](http://www.ibdstandards.org.uk/uploaded_files/IBDstandards.pdf); Co-locating Health Services: A Way to Improve Coordination of Children's Health Care?, The Common Wealth Fund, [www.commonwealthfund.org/~media/files/publications/issue-brief/2008/jul/colocating-health-services--a-way-to-improve-coordination-of-childrens-health-care/qinsburg\\_colocation\\_issue\\_brief.pdf.pdf](http://www.commonwealthfund.org/~media/files/publications/issue-brief/2008/jul/colocating-health-services--a-way-to-improve-coordination-of-childrens-health-care/qinsburg_colocation_issue_brief.pdf.pdf)

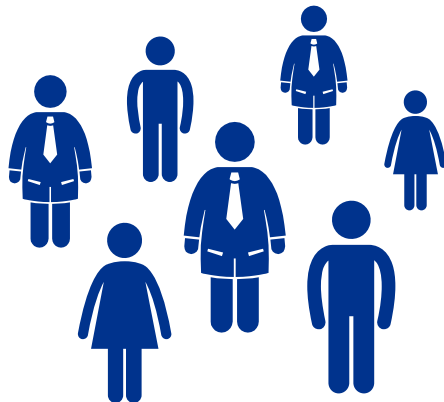


## EVENTS

**Many centres we visited ran regular patient events, these were designed to engage patients with the services at the centre but also allowed patients to meet other IBD sufferers.**

Some centres run regular patient events giving the opportunity for IBD patients to gather in the same place at the same time and interact with other sufferers of the disease.

This can help them to deal with the social and psychological effects of the disease outside of the treatment pathway itself, which in turn leads to increased awareness and engagement.



### HOSPITAL CLINIC, BARCELONA, SPAIN

In Barcelona, there is a patient day once a year which involves activities, workshops, medical updates and talks from clinicians.



### HUMANITAS, MILAN, ITALY

In Milan, yearly meetings are organised with the patients where discussion around their disease and symptoms take place. All patients of the centre are invited (~ 2,000 and usually around 300 attend. In 2014, patients who could not travel were still able to attend via webcast.

# AGE APPROPRIATE CARE SHOULD BE PROVIDED TO GIVE ALL PATIENTS ACCESS TO THE CARE THEY NEED

## Why is it important?

The traditional medical model separates the provision of child and adult services. The number of patients being diagnosed with IBD under the age of 18 is increasing. This means that there is a growing demand for paediatric IBD services. Centres committed to providing age appropriate services were trying to adapt their service model to deal with this changing demand.

## What are the current issues?

1. How should IBD centres provide access to specialist paediatric IBD care?
2. How can they provide a smooth transition from child to adult services?

## How are centres trying to address these issues?

Throughout our visits, we observed four features of an age appropriate service which address the two issues for delivering high quality care to children, teenagers and young adults. Some centres officially named this service a 'transition clinic'.



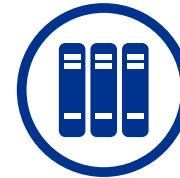
### TAILORED SERVICES

IBD care should be given in an age appropriate setting. That is, experts should collect around the child in a child friendly environment using appropriate information tools.



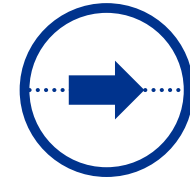
### TAILORED TEAMS

Some centres employed a special paediatric IBD team. This was a feasible option where the child population was large enough and if the incidence of childhood IBD continues to increase we predict this will become the model of the future. Where centres could not justify a specialist paediatric team, adult teams visited the paediatric faculties.



### KNOWLEDGE SHARING

The centres we visited all exchanged knowledge with paediatric centres and had a good relationship with them. A paediatric doctors' training programme existed in some hospitals where paediatricians would spend time learning about IBD care with the adult team.



### SMOOTH TRANSITION

Transitioning from child to adult care is a danger point in any chronic disease. Children often disengage with services as they find it hard to adjust to the way adult care is delivered. Services which provide a bridge between adult and child can give adolescents time to adapt to the differences in adult services and lead to better engagement and patient outcomes.

Source: The rising incidence of paediatric-onset inflammatory bowel disease, Arch Dis Child. 2012;97(7):585-586, [adc.bmj.com/content/97/7/585.extract](http://adc.bmj.com/content/97/7/585.extract)



## ACADEMIC MEDICAL CENTRE, AMSTERDAM, NETHERLANDS



For all paediatric patients of the AMC, an easily accessible website – KILK – has been developed by the psychological team for any outpatient treatment. This interface is systematically used by young IBD patients who have to answer a standardized questionnaire about their quality of life prior to their visit. The paediatric gastroenterologist can review the answers, pre-assessing the patient in advance, and can then directly target the problem the patient may be facing during the visit.

The questionnaires used in KLIK vary depending on the age of the patient. Very young patients will have their questionnaires answered by their parents and as they become older, they will become more involved to finally answer it by themselves.



KLIK VISUAL



I really try to let my patients get more responsibility early on. I usually start with 10 year old patients.

I also start to ask the patient more rather than the parents who can be over-dominating with a child suffering from a chronic disease.”

Paediatric gastroenterologist, Amsterdam

## UNIVERSITY OF CALGARY, CANADA



The team in Calgary does not have a dedicated transition clinic due to an insufficient volume.

However, the team has developed a **transition booklet** for teenagers aged 15 which they access along with an **educational transition symposium**.

- The booklet holds a series of modules that walks them through the disease in milestones.
- The symposium presents the differences between teenage and adult care, autonomy, what to expect etc.

When ready to transition, the young adults start to attend adult sessions.



## HOSPITAL CLINIC BARCELONA, SPAIN

In Barcelona, Hospital Clinic does not manage the care of children and teenagers. To prepare for the upcoming transition of young adult patients, one physician from the IBD team will travel to the paediatric centre, which is located in a different part of the city, on three different occasions. This has proved to be very helpful and reassured patients who will be welcomed by a familiar face in their new treatment centre.



PAEDIATRIC TEAM



ADULT TEAM

# PSYCHOLOGICAL SUPPORT CAN TAKE VARIOUS FORMS AND LEADS TO BETTER PATIENT EXPERIENCE

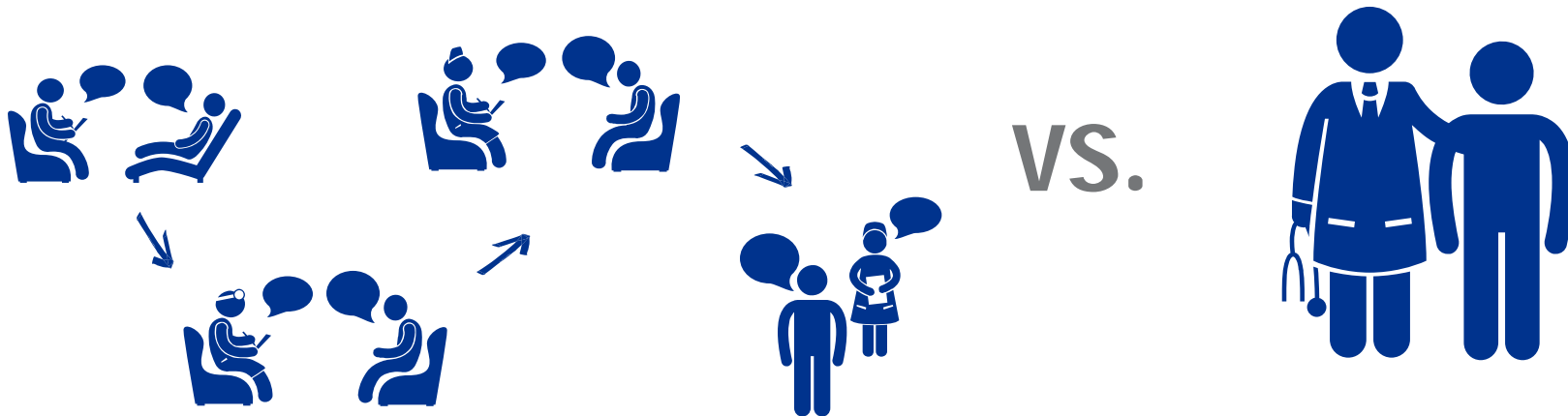
## Why is it important?

IBD has an impact on many aspects of a patient's quality of life. The disease can often impact on a patient's psychological state, for instance IBD patients have a higher prevalence of depression and anxiety. Some patients need psychological support to help them through difficult medical decisions and manage the impact of the disease on their social and working lives.

## How is it done well?

During our visits, we observed various ways in which the centres provided psychological support:

- One centre (Milan), has a team of psychologists dedicated to their IBD patients with a special programme
- In the other centres, the intervention of a psychologist is rare leading some of the team members (especially the nurses and the physicians) to provide any psychological support needed by patients



Source: Drossman DA et al. (1989) Health-related quality of life in inflammatory bowel disease: functional status and patient worries and concerns. Dig Dis Sci 34: 1379–1386

# EXAMPLES OF PSYCHOLOGICAL SUPPORT



## CHU NANCY, FRANCE

In Nancy, the IBD team does not include psychologists. As a result, the patient shares his/her feelings with the wider team. The team share this burden and support the patient to the best of their capability in terms of counselling.



“

Everybody on the patient pathway should do psychology. I do not believe that patients should be sent to a room to have their psychology isolated from the rest of the treatment.”

Gastroenterologist, Nancy



## HUMANITAS, MILAN, ITALY

At Humanitas, the IBD team includes two psychologists. Their involvement starts when patients suffer from stress due to the disease or when they refuse treatment.

Before becoming involved in the management of patients, psychologists first observed the IBD team for an entire year by attending clinics and consultations. During that time, they were able to observe patients and their interaction with the team to familiarise themselves with the disease.

During their first encounter with the patient, the psychologists discuss the disease, their medical history as well as the treatment currently followed. They also perform a series of tests to assess the mental health of the patient. The follow-ups will be used to remove any symptomatic symptoms the patient may have and also help them manage the anger/sadness they may feel towards their condition.



“

We wait for ‘good moments’ to intervene, that is to say when symptoms of the disease are less present and the patient is more prone to listen.”

Psychologist, Milan



“

We now have a better understanding of our patients with the help of our psychologists.”

Gastroenterologist, Milan

# COLLABORATIVE APPROACH

PATIENT-  
ORIENTED 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



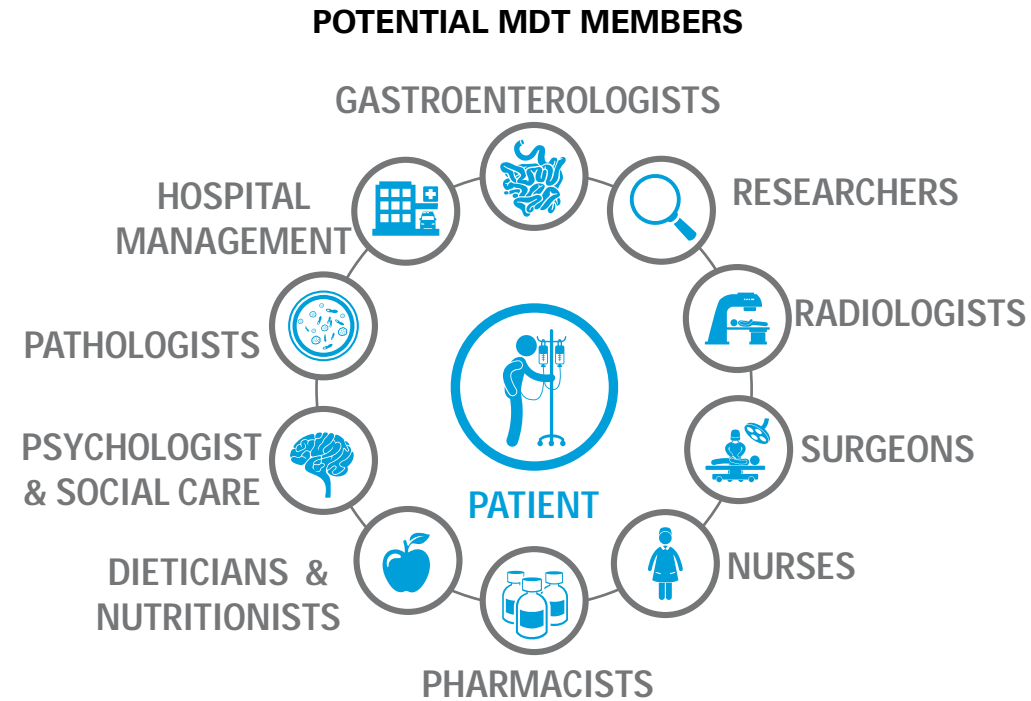
TECHNOLOGY

# A MULTIDISCIPLINARY APPROACH IS ESSENTIAL TO EFFECTIVELY MANAGE IBD PATIENTS

## Why is it important?

IBD is a complex disease and its symptoms affect multiple bodily systems. A multidisciplinary approach ensures that the treatment and care of patients are being considered by a healthcare professional with the specialist knowledge relevant to their particular disease manifestation.

The patient is the most important member of the multidisciplinary team (MDT) and collaboration between different members is essential to ensure the best recommendations are made, together with the patient, to improve clinical outcomes.



## How is it done well?

An effective multidisciplinary approach has an established team, which meets regularly to share information, collect data and discuss treatment options.

We observed a number of activities and a number of enabling and facilitating characteristics that supported a robust multidisciplinary approach.



**ACTIVITIES**



**ENABLERS AND FACILITATORS**



# ACTIVITIES

**During our visits, we observed several key activities that promoted a high-quality multidisciplinary approach.**



## MULTIDISCIPLINARY TEAM MEETINGS

MDT meetings are an opportunity for members of the IBD team to ask questions to their colleagues, especially with complex cases.

They are usually organised on a weekly or monthly basis and in some centres are in advance of clinics so that the team can discuss patients prior to seeing them on that same day.



When the strategy for the treatment of a patient is changed, we all need to discuss and consider all options."

Surgeon, Leuven



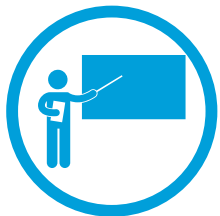
## SPECIALTY OUTREACH

Some centres had core and non-core members of the MDT. Non-core members were allocated professionals from a wide range of medical specialities that would liaise with IBD teams if required. For example, an allocated dermatologist would liaise with the IBD team if a patient had a skin manifestation of the disease.



Attending our weekly MDT meetings is the occasion to discuss complex cases and it is a great training opportunity!"

Gastroenterologist, Oxford



## UP-SKILLING

One way in which many of the centres we visited felt they improved their care significantly was by up-skilling their nursing staff.

We observed specialist IBD nurses who had a range of additional skills and expertise. For instance, in one centre nurses were 'prescribers' who had knowledge of biological treatments and were able to manage dosing regimens and monitoring for patients. Other centres had research nurses who had scientific backgrounds and were able to drive research agendas with patients and the rest of the IBD team.



I learned my "IBD nurse" role on the go, I attended consultations with the gastroenterologists and was showed how to practice."

IBD Nurse, Liege



# ENABLERS AND FACILITATORS

**During our visits, we observed several key enablers and facilitators that strengthened the multidisciplinary approach to patient care.**



**A COLLABORATIVE  
ENVIRONMENT**



**THE PHYSICAL  
PROXIMITY OF  
DIFFERENT  
MEMBERS**



**COORDINATION OR  
MANAGEMENT BY A MAIN  
POINT OF CONTACT**



**THE USE OF  
TECHNOLOGY**



**AN EMPHASIS ON  
THE IMPORTANCE OF  
ATTENDING MDT  
MEETINGS**

# STRONG REGIONAL NETWORKS ENABLE ACCESS TO SPECIALIST KNOWLEDGE

## Why is it important?

The majority of IBD patients are treated in care settings outside of specialist centres. One of the roles of a specialist centre is to share its specialist knowledge to enable high quality care to be delivered through the healthcare system.

An active and accessible network of care is essential to provide this support to healthcare professionals who may only have a small case load of patients with IBD. Examples of care providers that specialist centres were interacting with include:

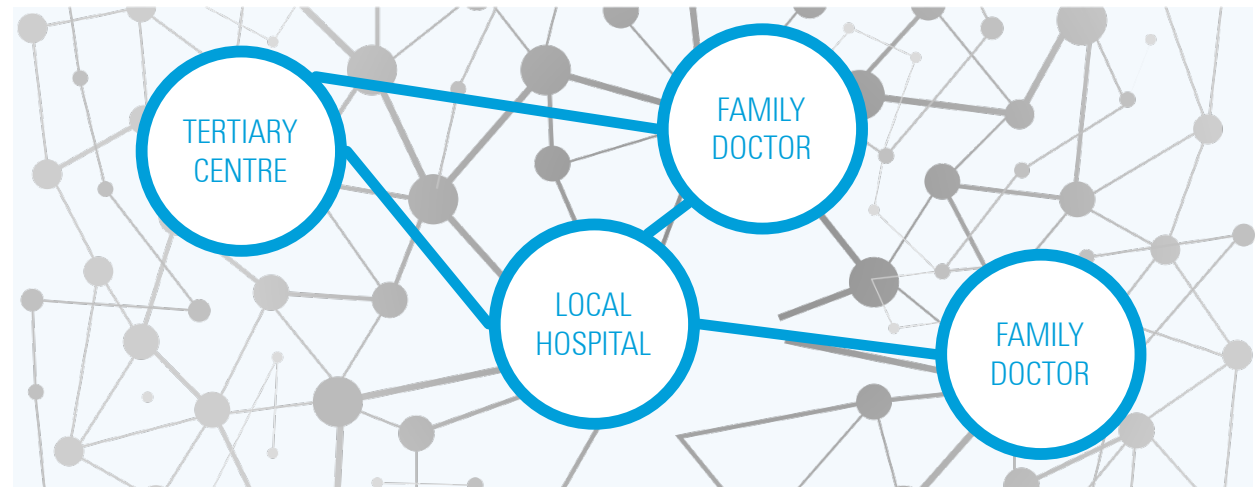
- Primary care doctors
- Smaller hospitals (secondary care)
- Private centres
- Community teams
- Patient groups

## How is it done well?

The information we collected across our site visits suggested that there were several aspects of good quality care provided outside of specialist centres:

- Timely referral to tertiary centres
- Good symptom monitoring
- Appropriate use of biological treatments
- Early and accurate diagnosis
- Accurate interpretation of surveillance imaging
- Accurate information about nutrition and diet

An effective network successfully supports all care settings in achieving these goals.





**A strong network empowers care providers to make better treatment decisions for patients by supporting judgements that can feel outside of day to day comfort zones. Facilitating access to specialist knowledge and disseminating across a healthcare systems enable high quality care to be provided at a lower cost.**



## FLEXIBLE MODEL OF CARE DELIVERY

Some centres had a flexible approach to care delivery where services were brought to the patient. In this way, they were able to ensure that different care settings were used to provide specialist services and enable community teams to learn from the specialists.



## VIRTUAL ACCESS TO SPECIALIST KNOWLEDGE

Such an access enables the delivery of higher quality of care to throughout the network. It provides clinical advice with the evidence needed to make treatment decisions outside of their traditional sphere of expertise and keeps patients out of hospital in the community.

In addition, informal contact is also given to peers via email and phone calls.



## CONNECTIVITY AND ENGAGEMENT

Beyond sharing knowledge with the regional IBD community, engaging it on a regular basis can only result in better outcomes for patients.



## JOHN RADCLIFFE HOSPITAL, OXFORD, UK

In Oxford, where a 'hub and spoke' model exists, one of the IBD consultants spends one day each week visiting IBD patients in Banbury Hospital, one of the 'spokes'.

While in Banbury, the consultant sees complex patients and helps disseminate knowledge with the staff.

Banbury will also have access to, and be part of, Oxford's IBD database.

On top of this, the team has set up an IBD telephone clinic to provide a limit the volumes the main hospital experiences.

Also, one of the KPIs the fellows answer to is about engaging with the community.



## UNIVERSITY HOSPITAL OF LIEGE, BELGIUM

In Liege, the centre is located out-of-town which can make it difficult for some patients to attend.

As a result, the team has decided to set up a 'spoke' in the town centre for half a day per week where some of the members of staff will visit patients in order to make it more convenient for them.



## ACADEMIC MEDICAL CENTRE, AMSTERDAM, NETHERLANDS

In 2013, the AMC and four other hospitals located in the vicinity of Amsterdam launched the 'IBD Network Amsterdam'.

Once a month, all members of the network meet at the AMC for 90 minutes and discuss their most difficult patients (45 min), the newest guidelines (20 min) and research protocols (30 min).

Altogether, the network encompasses 10,000 IBD patients. As a result, the five hospitals are now developing common and standardised processes to harmonise the care they provide to patients.

The idea behind this network is also to create 'academic patients' which can be included in studies. Another reason is also to 'get the patients to where they belong'. The AMC, being a tertiary centre, aims at focusing on more complex cases whereas other less specialised hospitals from the network have the capability and capacity to treat patients at a less severe stage of the disease.



## CHU NANCY, FRANCE

In Nancy, the IBD team relocates itself for half a day every week to the centre of town, acting as a community centre. It allows patients to be seen locally instead of travelling to the outskirts of the city where the hospital is located.

In addition, the team organises regional multidisciplinary meetings in their premises to share IBD knowledge with the wider community. Gastroenterologists from the region as well as other clinicians involved with IBD are invited.



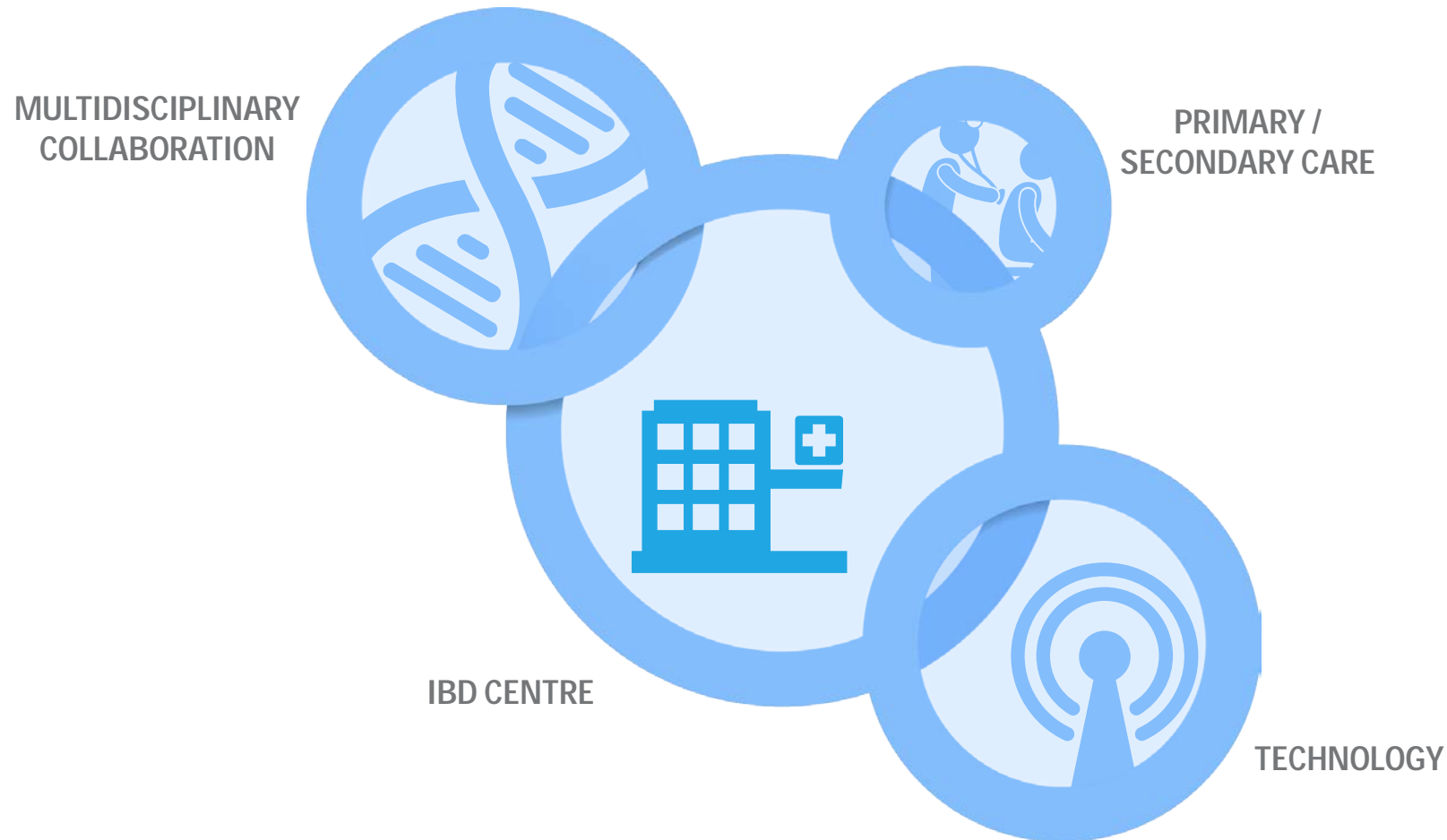
## HUMANITAS, MILAN, ITALY

Several times a year, the team in Milan at Humanitas organises dinner with the local general practitioners (GPs).

With time, the GPs came to trust the IBD team and consequently refer their patients suspected of IBD with more confidence.

In return, the GPs are more aware of IBD and can manage the easiest cases by themselves and pass on those that are more complicated to Humanitas.

**The future of the network for IBD centres we believe will see increasing amounts of 'reaching out' activities and more 'reaching in' activities from other care centres through the use of technology.**



## Why is it important?

There is likely to be a varied level of knowledge about IBD between different centres in a healthcare system and between junior and senior staff within a single centre. It is important that experts are given time to pass their knowledge on to colleagues across the healthcare system to raise levels of IBD understanding among peers ensuring that the highest possible quality of care can be delivered.

## How is it done well?

During our visits, we observed three innovative ways in which reference centres actively diffused their knowledge. Underpinning these features was a commitment of time - each healthcare professional had protected time for educational activities as part of their working day.

TIME ALLOCATED WITHIN THE WORKING DAY



### EDUCATIONAL MEETINGS / FORUMS

Regular academic or educational meetings were a core part of many of the centres that we visited.

These meetings allowed findings to be shared across the regional network as well as internally across specialities and to junior colleagues in the centre itself.



### EDUCATIONAL FELLOWSHIPS

Educational fellowships helped to support the IBD staff with their clinical and research responsibilities and therefore help to improve the quality of care that the centre provides. They also act as knowledge diffusers spending a short period of time within the centre and then are able to pass on that knowledge to future places of work when they leave.

Fellowships which blend clinical and research activities helped to drive convergence culture and produce more clinically driven research.



### INFORMAL ADVICE

The informal advice network was very strong in some centres. It manifested itself in two ways: Between colleagues at the centre – strong team work and good working relationships meant that colleagues would discuss cases and solve problems on an ad-hoc basis.

Between colleagues across the country – easy access to specialist advice through sharing personal contact details enabled advice to be given on difficult cases urgently.



## HUMANITAS, MILAN, ITALY

In Milan, the IBD team has set up different initiatives in the region/country:

- General practitioners are regularly invited to learn about the latest developments in the IBD field.
- A regional IBD Forum which takes place every six months brings together gastroenterologists as well as IBD specialists. During this event, participants are asked to share details of their most difficult IBD cases.
- The team has also launched a course programme for general practitioners and other healthcare professionals.



Example of course brochure



“

We educate general practitioners so they can enlarge their vision of the disease.”

Gastroenterologist, Milan



## JOHN RADCLIFFE HOSPITAL, OXFORD, UK

Through congresses, symposiums and publications, the Oxford IBD team has become well-known across the country.

As a result, the team often receives emails from gastroenterologists in the UK and elsewhere asking for advice with regard to particular cases.

The team is keen to share its experience with peers who may not have the same expertise in IBD and is willing to support them when the need arises.



“

I have the ability to talk with my senior colleagues who go abroad and learn about the development of medicines and how research evolves. All this information comes together and I can access it as I can always count on them to answer my questions”

Study coordinator, Leuven

# A PASSIONATE AND COLLABORATIVE TEAM WHO PUT THE PATIENT FIRST DELIVER GOOD CARE

## Why is it important?

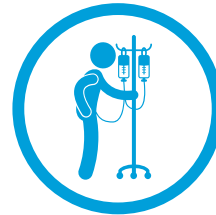
Team morale and culture is central to IBD care as it is a complex disease which requires dedication, teamwork and leadership in order to deliver effective treatment.

## How is it done well?

During our fieldwork, we observed that teams encouraged collaboration, team work, learning and development in order to ensure that the patient receives the best quality of care possible and that the patient comes first. In addition, they all felt their success was partly due to the motivation provided by an IBD champion (e.g. Head of Department, senior academic etc.) who was able to advocate for the importance of IBD within the hospital. These individuals not only engage the wider IBD community, they also remain close to their patients which is extremely well received by the rest of the team.



TEAM WORK



PATIENT FIRST



PRESENCE OF  
IBD CHAMPTION



## TEAM WORK

**In the centres we visited, it was clear that passionate colleagues form cohesive teams that enjoyed working together.**



We are colleagues but most importantly we are friends and working together is easy.”

Gastroenterologist, Barcelona



I’m not a radiologist outside of a team, I am a radiologist within a team and collaboration is a day-to-day phenomenon, this is crucially important.”

Radiologist, Liege



We have built a strong relationship over the years and it means that the thresholds and the language that we pathologists use are understood by the rest of the team.”

Pathologist, Oxford



It’s always nice to go for a drink with my colleagues from time to time. After all, I see them more than my own wife!”

Surgeon, Amsterdam





## PATIENT FIRST

**We observed strong dedication to patients and their relatives from the teams we followed.**



“

Patients come to our centre not only to receive treatment but also to contribute to our research. At Christmas every year, we feel that we should give something back. We send a bespoke card with a message for the patient updating them on their condition, their progress and thanking them for their contribution to our research.”

Gastroenterologist, Milan



“

I think we all dream IBD at night!”

Nurse, Amsterdam



“

The whole experience needs to be positive and it starts with the person who greets patients at the door.”

Gastroenterologist, Calgary



### UZ LEUVEN, BELGIUM

At Leuven, patients have been asking for more details on the latest development of IBD treatments, especially as the team is known to be involved in many trials.

As a result, every year the research team produces and sends out a newsletter to approximately 4,000 patients.

This initiative has been very well received and the newsletter, which started by being one-page long, now contains five pages.



“

We send a five-page long newsletter to our patients every year. It is a way to say ‘thank you’ for their contribution as they give us samples and participate in our research.”

Gastroenterologist, Leuven



## PRESENCE OF AN IBD CHAMPION

**One common feature we observed during our visits was the way members of the IBD team acknowledged the presence and contribution of their leader(s) to make their team focused, operational and motivated to provide the best care possible.**



We are good in Liege thanks to our leader who has a national and international aura."

Gastroenterologist, Liege



We have two great leaders and over the years they have built a team of experts. Everybody has a niche area so we can better address patient needs."

Gastroenterologist, Calgary



Since the arrival of our leader, things have positively changed and it is thanks to him that we have reached such a good level."

IBD nurse, Amsterdam



Our leader is very good with patients and has good relationships with the IBD community. They all know him."

Research nurse, Nancy

# FORWARD THINKING MINDSET

## PATIENT-ORIENTED 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

# COLLABORATION BETWEEN RESEARCHERS AND CLINICIANS HELPS IMPROVE THE QUALITY OF CARE

## Why is it important?

Strong research and clinical collaboration promotes a culture of learning and improvement. It helps teams to challenge existing care models and strive towards better management of the disease - whether this be through advancing their understanding of the disease process, introducing and testing new drugs or utilising new treatments.

## How is it done well?

Most of the centres we visited had close links with research teams. Many centres chose to co-locate their clinical and research facilities which they felt helped to promote a holistic approach to IBD care by encouraging clinicians to be more involved in the research and vice versa.

Clinically driven research questions are more patient-centred and trials tend to be more focused on unresponsive pathophysiology using real patient tissue samples and this helps to drive new treatments faster. The centres we visit felt this was particularly important for IBD where treatments are relatively new and rapidly developing.

Four themes emerged from the centres we visited that we believe characterise good research and clinical collaboration:



### PHYSICIANS INVOLVED IN RESEARCH

Most of the physicians we encountered during our visits spend time doing research, which allows them to understand the disease better.



### TRANSLATIONAL RESEARCH

With a dual research-clinical team, the IBD units we observed work on basic research which reaches patients through translational projects.

Both researchers and patient-facing staff collaborate and understand each other's needs and expectations.



### RANGE OF RESEARCH PROJECTS

It is important for centres to carry out a range of research projects in basic and translational science. Participation in clinical trials was an essential part of treatment development and attracts interesting cohorts of patient to centres. Good project governance needs to be balanced with results and return on investment.



### USE OF MIXED FUNDING MODEL

Government, industry and private funding to ensure a range of research questions are being asked in the centre.

# NEW AND INNOVATIVE CONCEPTS CAN BE PROMOTED TO ACHIEVE BETTER CARE

## Why is it important?

While it is important to rely on existing good practices and to provide good care to patients, innovation is key as patient needs constantly evolve.

## How is it done well?

During our visits to the different reference centres, we observed various ways in which the teams innovate by developing new models of clinics to achieve better outcomes and patient experience.



Innovation can be a risk, however our centre supports that risk. [...] Our culture is innovation driven.”

Gastroenterologist, Calgary



## UZ LEUVEN, BELGIUM



Every Thursday morning, the IBD team in Leuven welcomes general gastroenterologists from the region to their outpatient clinic.

On the one hand, it increases the task force of the team and allows it to see more patients.

On the other hand, it also gives the opportunity to the 'guest' gastroenterologists to see more complicated cases than what they would normally see in their practice and to learn from the experience of the IBD team.

In some cases, the visiting gastroenterologists bring with their own complicated cases.

Overall, patients from the region can benefit from a homogeneous and standardised care.

“



It is a win-win situation and what better way to learn than by practising it yourself?”

Gastroenterologist,  
Leuven

## UNIVERSITY OF CALGARY, CANADA



In Calgary, the IBD team has recently launched several clinics:

- Pregnancy clinic:

Recently pregnant or planning to conceive patients have been followed by the pregnancy IBD clinic with a series of appointments dedicated to them.

- High risk IBD clinic:

In order to reduce delays in the diagnosis of IBD, a high risk IBD clinic has been set up in Calgary in 2013. The Gastroenterology department receives approximately a thousand referrals per month and when triage identifies a patient as a high-risk IBD patient, they are seen immediately with a same day endoscopy.

After further tests and a follow-up of 28 days, the patient is either discharged or directed to the right service such as the IBD team.

This preventive approach is also used to collect data that may later be used to identify new biomarkers from these treatment-naïve patients.

“



We believe in a preventative approach.”

Gastroenterologist,  
Calgary

# NEW TECHNOLOGIES CAN BE USED TO BETTER UNDERSTAND IBD AND IMPROVE CLINICAL OUTCOMES

## Why is it important?

Adopting and embracing new technologies and processes can help to increase the quality of care provided to patients and give them more options if other methods of treatment have failed.

## How is it done well?

The use of IBD databases can help researchers and clinicians significantly increase their understanding of IBD, helping them to develop new treatments and processes. In addition, clinicians will be able to utilise these new methods and deliver better care to the patient.

In addition, relying on the latest technologies, such as mobile applications, can also provide more accurate treatment and monitoring of patients.



### DEVELOPMENT OF NEW TECHNOLOGIES

All the teams we met were keen to develop new technologies and protocols to improve care and patient outcomes.



### IBD DATABASES

Where technology and funding allowed it, teams built their own IBD database to identify patients eligible to take part in clinical trials quickly.



### M-HEALTH

Some of the teams we met are currently developing mobile applications to help patients and their physicians manage the disease outside of hospital premises.



# DEVELOPMENT OF NEW TECHNOLOGIES

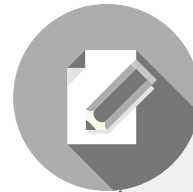
**During our visits, we observed a keen interest from many members of the centres to apply the latest technologies and develop new ones within their fields.**



## ACADEMIC MEDICAL CENTRE, AMSTERDAM, NETHERLANDS

The surgical team were the pioneers in the development of an endo-sponge treatment for anastomotic leakage after colorectal surgery.

Source: Surgical Endoscopy, June 2009, 23, 6, 1379-1383,  
[www.ncbi.nlm.nih.gov/pmc/articles/PMC2686802](http://www.ncbi.nlm.nih.gov/pmc/articles/PMC2686802)



## UZ LEUVEN, BELGIUM

The department of Abdominal Surgery has developed a novel technique of bowel sparing in Crohn's Disease.

Source: in press



## HUMANITAS, MILAN, ITALY & UNIVERSITY OF CALGARY, CANADA

Although, ultrasound is a relatively old diagnostic tool, it can now also be used to monitor the progress of IBD by detecting inflamed parts of the bowel wall and by showing abscesses and fistulas. During our visits, we observed the IBD teams in Milan and Calgary rely heavily on this technique. Calgary is one of the ultrasound leaders in North American and Milan has historically been a pioneer in the development of ultrasound techniques.

Sources: Alberta Health Services, Press Release, April 2013, <http://www.albertahealthservices.ca/8326.asp>; Modern imaging of Crohn's disease using bowel ultrasound, Giovanni Maconi, Inflammatory Bowel Diseases, Volume 10, 2004;





# IBD DATABASES

**Most of the centres which were part of our study have designed their own IBD databases. These databases are used to record their patients' medical history in such a way that when a new study is launched, eligible patients can be retrieved and contacted easily.**



## UZ LEUVEN, BELGIUM

In Leuven, the gastroenterology team is not the only one to manage an IBD database. Indeed, the surgical team is proactively maintaining an electronic database to record all the surgeries performed on IBD patients. The data can be used retrospectively to understand any infection rate issues etc.



## JOHN RADCLIFFE HOSPITAL, OXFORD, UK

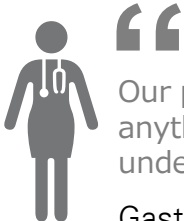
In Oxford, the team has developed a database which includes all their IBD patients (following their consent). The genotype and phenotype as well as the medical history of every patient is recorded, enabling the team to select certain groups when there is a need to recruit for a new study.



Patient registration form

The team is considering whether to link to the Electronic Patient Record System and also to integrate it within the entire service with a more streamlined process. The next step is to link it to pathology and blood test results.

In addition, a laptop will be available in the outpatient clinic so patients can complete their own profile while they wait to be seen by a physician.



“Our patients will try anything rather than go under the knife.”

Gastroenterologist, Calgary



## m-HEALTH

**Mobile phone applications can also be designed to help both patients and their physicians in the management of their disease. During our visit to the Academic Medical Centre in Amsterdam, we saw such an application being developed.**



### ACADEMIC MEDICAL CENTRE, AMSTERDAM, NETHERLANDS

Together with Maastricht University, the AMC is currently developing an application – IBD Coach – whose aim is three-fold:

1. Give an accurate picture of the **patient's medical history** – There is a need for physicians to understand very quickly the medical history of their patient. IBD being a complex and chronic condition, the patient file may include a large number of medical reports. The application provides a clear view of the different episodes of treatment and tests a patient has undertaken with a one-page visual.
2. Provide **educational material** to the patient – The application also allows patients to download and access information about their disease.
3. Act as a **coach** for patients taking biologicals medication – This provides information on the sides effects of the drugs and allows patients to communicate with their treatment centres. In the long term, the centre expects to create a standardised pathway for the use of biologicals.

Furthermore, the data processed by the application can be used directly by the centre's Electronic Patient Record system to avoid any duplication of efforts.

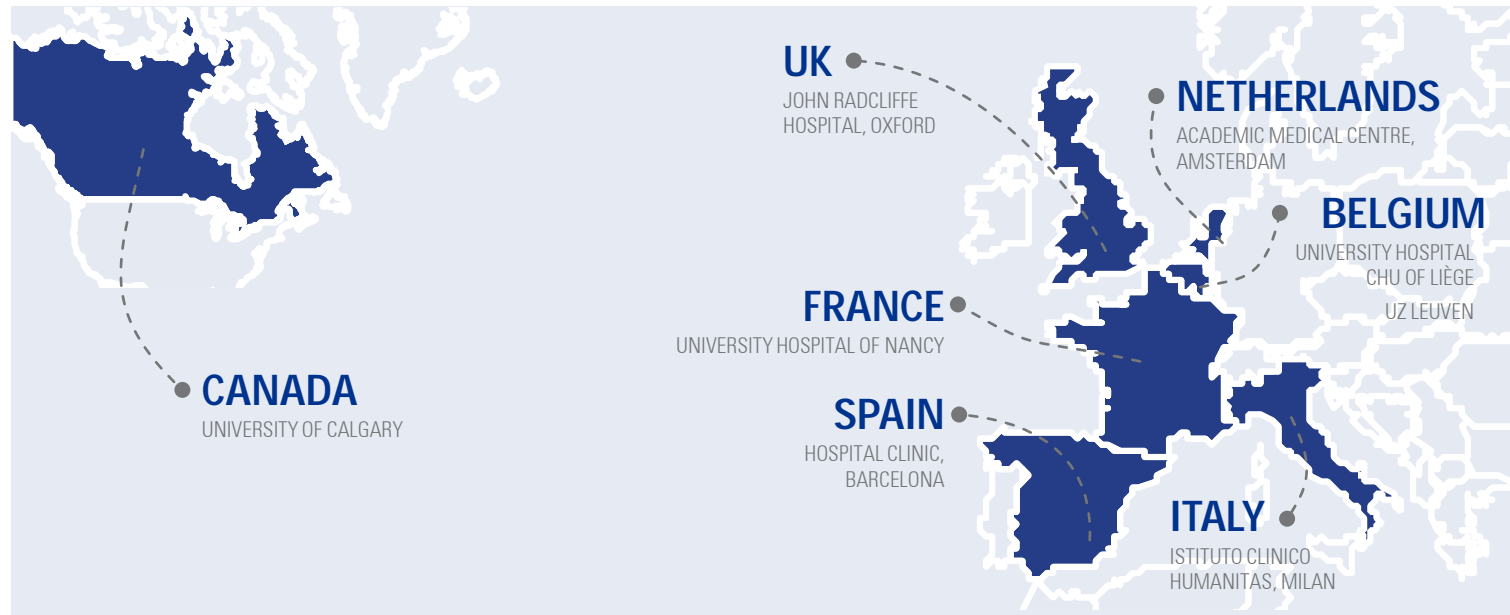
# APPENDIX

## What is in the appendix?

This appendix sets out the answers to the key questions we asked our interviewees during our visits to the 8 centres:

- What makes IBD care at your centre effective?
- How could IBD care be improved in your centre?
- How could IBD care be improved in general?
- How do you interact with the rest of the IBD team?

|           |    |
|-----------|----|
| BARCELONA | 55 |
| LIEGE     | 58 |
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| LEUVEN    | 76 |



# BARCELONA

Clinic Barcelona  
University Hospital, Spain



The Barcelona team is led by Prof. Julian Panes.

## MEDICAL / SURGICAL TEAM



**3** FULL TIME  
GASTROENTEROLOGISTS



**3** SURGEONS



**2** RADIOLOGISTS



**1** DIETICIAN



**1** CLINICAL NURSE



**2** GASTROENTEROLOGIST  
FELLOWS



**1** HOSPITALISED PATIENT  
PHYSICIAN



**1** PATHOLOGISTS

PATIENT POOL: ~2,000

CATCHMENT AREA: CATALUNYA MAINLY + SPAIN

## RESEARCH

NUMBER OF STAFF IN RESEARCH TEAM 15

NUMBER OF PUBLICATIONS\*

0 50 100 150+

A TEAM OF  
**13**  
SCIENTISTS

WITH

**2**  
RESEARCH  
NURSES

\* Number of publications for the entire team



## WHAT MAKES IBD CARE AT YOUR CENTRE EFFECTIVE?

### Multi-disciplinary approach

Fellows indicated that there is a real multi-disciplinary approach at the centre but also a sense that decisions are made as a team not just by the most senior consultant

The connection that we have between radiology and surgery is vital but does not exist everywhere in Spain

### New processes and treatments

A significant element of the team's research focuses on transplants for IBD patients which is then used in the centre

Being pioneers in the development of new treatments and processes including haematology transplant, transplant therapy options, dendritic cells etc.

Imaging is used to detect complications, inflammations, lesions. The radiologist says the quality of images is high compared to other centres which makes a big difference for surgery

Laparoscopy is technically more difficult but has quicker recovery times than other types of surgery

### Nutritional support

There is a nutritionist who is specialised in IBD, a role normally performed by nurses. She sees both in-patients and out-patients. There is also a stoma nurse who spends 20% of her time on IBD patients

### Patient centrality – relationships & assistance, empowerment, education

The patients' main point of contact is the IBD nurse, whom they can call Monday to Friday from 9am to 2pm with any issues or questions.

There is a patient day once a year where all clinicians give talks on IBD

Colonoscopy, MRI and blood tests are all performed on the same day to make sure that patients minimise time travelling and days of preparation.

Initially, not much information is given to the patient but then after a week, there is an extended meeting where the disease is discussed in detail with the patient and their family

When a patient is pregnant, the IBD nurse coordinates her transfer to the maternity ward



## HOW COULD IBD CARE BE IMPROVED IN YOUR CENTRE?

Our waiting list for MRIs is increasing so it would be good to address this  
We also experience long waiting list for surgeries and this can be a problem for patients  
I would like to have more surgical room  
We are not enough surgeons to meet the demand  
Our outpatient unit is running at full capacity

## HOW COULD IBD CARE BE IMPROVED IN GENERAL?

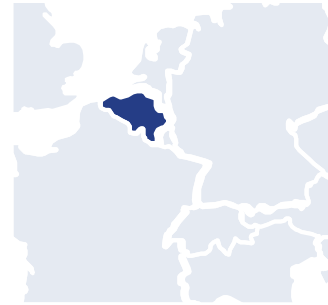
Quality of imaging could be improved in other hospitals  
A dedicated nutritional support for IBD patients is not common in other hospitals, so this could be set up everywhere to give patients a better support

## HOW DO YOU INTERACT WITH THE REST OF THE IBD TEAM?

We hold multi-disciplinary meetings every two weeks  
The key interactions are between the consultants and the surgeons, and between the radiologists and surgeons

# LIEGE

CHU de Liege,  
Belgium



The Liege team is led by Prof. Edouard Louis.

## MEDICAL / SURGICAL TEAM



**PATIENT POOL:** ~800 ACTIVE PATIENTS  
**CATCHMENT AREA:** WALLONIA

## RESEARCH

NUMBER OF STAFF IN RESEARCH TEAM

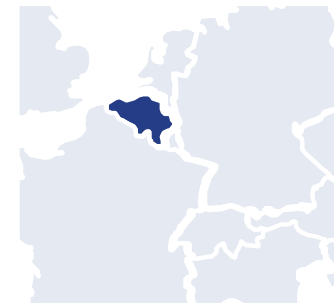
7

NUMBER OF PUBLICATIONS\*

0 50 100 150+



\* Number of publications for the entire team



## WHAT MAKES IBD CARE AT YOUR CENTRE EFFECTIVE?

### IBD focus and specialism

Our leader has a national and international reputation

The role of our IMID (Immune Mediated Inflammatory Disorders) nurses is uncommon in Western Europe

Everybody in the team undertakes both clinical and research work

We have a patient pool large enough to justify the role of stoma nurse at the hospital

We have a separate ambulatory unit

Our dermatologist is specialised in anti-TNF treatment

Our nutritionist sees outpatients when they experience weight loss

### Multi-disciplinary approach

There is an excellent collaboration within the entire IBD team

### Patient centrality

Our patients are generally always seen by the same doctor

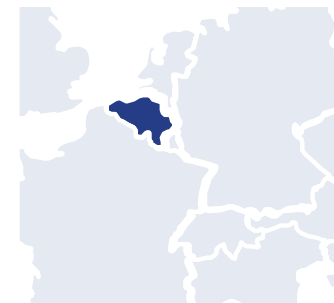
Some members of staff will visit patients in the town centre for half a day per week

There is an emphasis on patient education and empowerment , e.g. patients are taught to do injections themselves and are kept well-informed at all times

The IMID nurse helps with all aspects of patient life including pregnancies, flying issues, insurance papers, booking appointments etc.

We have an electronic file which shows the history of the patient so that whoever answers the phone can quickly be aware of the patient's condition and advise them





## HOW COULD IBD CARE BE IMPROVED IN YOUR CENTRE?

There is always a way to improve things. On the nutritional side, we could involve our dietician even more as it is the case in oncology

If things could change, I would involve more IBD nurses to support us the clinicians

At the moment, we do not have any guideline ruling our protocols at our centre. Most of them are based on oral communication and they need to be documented. Writhing up these guidelines for the care of IBD patients is one of our priorities for the next year

## HOW COULD IBD CARE BE IMPROVED IN GENERAL?

I believe in personalised care for IBD patients

Patients need to become more active in the management of their own care

## HOW DO YOU INTERACT WITH THE REST OF THE IBD TEAM?

We all collaborate, being a small team, we need this

We also have a good wider team including radiologists and surgeons, our multidisciplinary status is very important as when a case becomes complex, we all have to discuss

Team work is very important, it's a day by day collaboration

# NANCY



The Nancy team is led by Prof. Laurent Peyrin-Biroulet.

## MEDICAL/SURGICAL TEAM

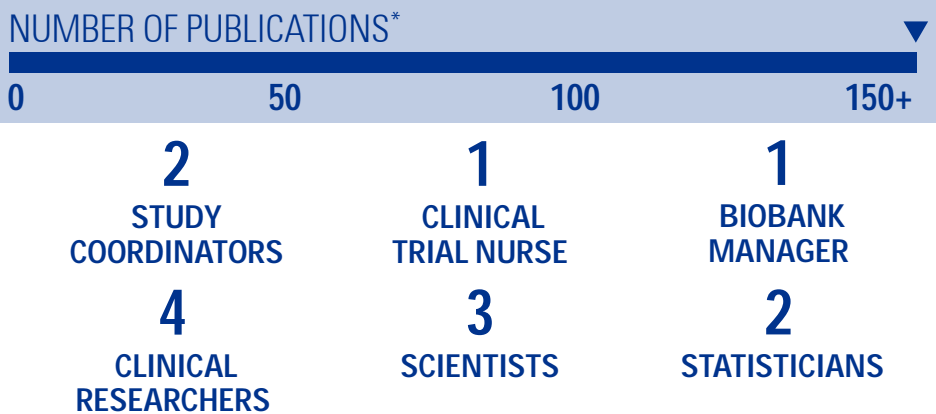


**PATIENT POOL:** ~2,500 active patients

**CATCHMENT AREA:** NORTH EAST OF FRANCE

## RESEARCH

NUMBER OF STAFF IN RESEARCH TEAM **13**



\* Number of publications for the entire team



## WHAT MAKES IBD CARE AT YOUR CENTRE EFFECTIVE?

### **New processes and treatments**

We try to use innovative treatments

We are one of a few centres in France which run clinical trials so patients who have an untreatable disease are sent here for newer experimental drugs

### **IBD focus and specialism**

Our patient pool is of the right size

All physicians have to perform endoscopies half day per week

Our pathologist is an expert in IBD and a renowned academic

Operation for peri-anal fistula abscess is performed by the gastroenterologists

### **Multi-disciplinary approach**

MDT working the mode of working the communication the listening

We have a permanent discussion with radiology

Our staff, no matter their “rank” within the hierarchy can talk to each other directly

### **Regional network**

We are building a regional network with private practice and we also rely on telemedicine. That way, patients are treated the same around the region

Our leader has a good relationship with the IBD community within our region, everybody knows him well



## HOW COULD IBD CARE BE IMPROVED IN YOUR CENTRE?

The nurse appointments are limited to patient education and administrative bits of the clinic, they could take on more responsibilities  
We lack in outreach care although our patients are given leaflets and are sent to patient associations

## HOW COULD IBD CARE BE IMPROVED IN GENERAL?

We should improve the quality of referrals, in particular from smaller centres  
It would be ideal to diagnose and treat with first line treatments in primary/secondary care and then refer to a tertiary centre if not successful  
Doses and treatments guidelines are often out of date in primary or private centres  
Patient associations are very active and could be one of the keys to connecting large and small centres within a region

## HOW DO YOU INTERACT WITH THE REST OF THE IBD TEAM?

We hold continuous conversations between the radiologists, surgeons and gastroenterologists  
Share communication video conference (all university hospitals all gastroenterologist) Once a month, we hold a meeting to discuss a radiology case



The Oxford team is led by Dr. Simon Travis.

## MEDICAL/SURGICAL TEAM

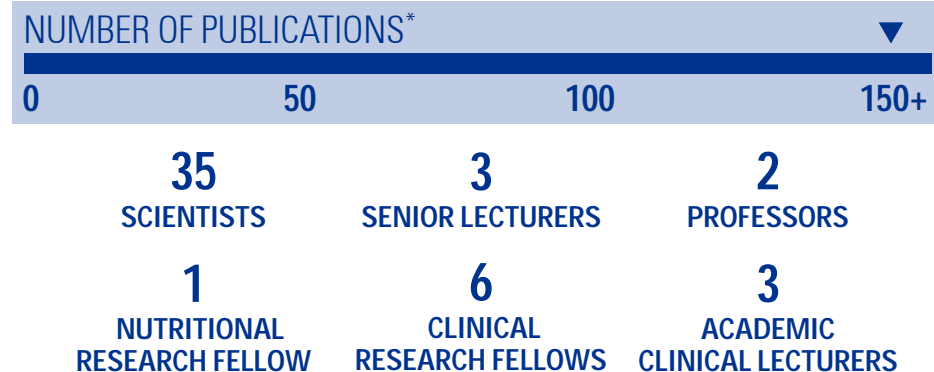


**PATIENT POOL:** ~3,500 active patients

**CATCHMENT AREA:** OXFORDSHIRE + UK

## RESEARCH

NUMBER OF STAFF IN RESEARCH TEAM 50



\* Number of publications for the entire team



## WHAT MAKES IBD CARE AT YOUR CENTRE EFFECTIVE?

### **IBD focus and specialism**

Our service is based on the local community, with 80% of our patients from the local area and 20% being tertiary referrals

Our IBD specialists are internationally recognised

We have a large amount of specialist support in our centre

Our specialised IBD nurses do an excellent job and run an advice line for urgent access by patients or GPs as well as telephone clinics

We have designated clinics for special groups - paediatric, young persons and urgent cases, as well as our general IBD clinic

Our physicians and surgeons jointly see acute and complex cases

### **Truly multi-disciplinary approach**

There is a collaborative spirit and an excellent communication between all the members of the IBD team

We hold overlapping physician and surgeon clinics so that each can consult the other if a patient has an issue they need advice on

Our clinics and multi-disciplinary meetings are on the same day

All parts of our service are in one complex which enables improved communication and collaboration between the members of the IBD team

### **Continuity of care and patient access**

There is a smooth transition between paediatric and adult care with dedicated team including consultants, surgeons, IBD nurses and dieticians

We have an emergency advice line for patients

We also hold a telephone clinic, which is cheaper than a physical clinic and more convenient for patients

### **Outreach programme in Banbury 1 day per week**

### **Established IBD cohort– used for both clinical care and research**



## HOW COULD IBD CARE BE IMPROVED IN YOUR CENTRE?

IBD patients need more psychological support than they are currently getting – in particular outpatients – there is a business case for a dedicated IBD psychologist  
 Video-linked multidisciplinary meetings would enable regions to be included but may also lead to decreased engagement  
 Integration of the IBD database with the ePR would improve care and research  
 We need to integrate cellular and molecular capabilities

## HOW COULD IBD CARE BE IMPROVED IN GENERAL?

The current guidelines benefit the majority of patients but are less effective for smaller sub-groups  
 Waiting times, budgets and targets result in conflicting motives  
 We still see too many people who should have been referred earlier  
 If you could track when patients are likely to flare up then you could organise care more effectively  
 It would be ideal to set up a red flag system to identify patients which are high risk to discuss early their long term treatment strategy  
 We want to give the opportunity for consultants from other hospitals to join our IBD clinic and discuss complex cases  
 I would like to see a better communication between GPs and hospitals including access to letters, notes etc.  
 Small centres could engage in a small level of research to make them think about IBD more

## HOW DO YOU INTERACT WITH THE REST OF THE IBD TEAM?

We hold multi-disciplinary meetings every Friday which include the whole team – although the proximity of all parts of the service to one another means that ad-hoc discussions are very easy and quick (especially relevant for emergencies)  
 Multi-disciplinary meetings are a chance to discuss complex cases and is a great opportunity for all involved to develop and learn

# MILAN

Humanitas Research Hospital,  
Milan, Italy



The Milan team is led by Prof. Silvio Danese.

## MEDICAL / SURGICAL TEAM



3

IBD PHYSICIANS



1

IBD SURGEON



2

RADIOLOGISTS



1

DIETICIAN/NUTRITIONIST



1

IBD NURSE



2

PSYCHOLOGISTS



1

ENDOSCOPIST

PATIENT POOL: 2,000 ACTIVE PATIENTS  
CATCHMENT AREA: ITALY

## RESEARCH

NUMBER OF STAFF IN RESEARCH TEAM

10

NUMBER OF PUBLICATIONS\*

0

50

100

150+

5

STUDY  
COORDINATORS

5

PhD  
STUDENTS

\* Number of publications for the entire team





## WHAT MAKES IBD CARE AT YOUR CENTRE EFFECTIVE?

### **Patient centricity**

We focus on the patient and the disease in general, we have a preventative approach  
We communicate with our IBD community with a newsletter, twice a year

### **Regional network**

We have a network in place with approximately 80 General Practitioners of the region  
Every six months, we organise a regional IBD Forum which focuses on gastroenterology. We ask for the country's most difficult IBD cases to be presented and we discuss the cases for new and innovative treatments

### **Multidisciplinary approach**

We do combined visits with the gastroenterologists and the surgeons for our patients who need a double approach. The surgeon and the gastroenterologist will be in the same room for the consultation. This is the case for all patients who we are considering for surgery.  
We have good links with our dermatology, rheumatology and ophthalmology colleagues

### **Psychological support**

We need to help patients manage the stress of the disease and life which are shown to impact on recurrence and severity of the symptoms  
We have developed a standardised approach to consultation using a number of protocols for mental health disorders screening tools

### **Research as part of job description**

All of the members from the team have to do research and we all embrace this policy. This is one of the reasons I joined the team



## HOW COULD IBD CARE BE IMPROVED IN YOUR CENTRE?

We need to make the hospital's senior management more aware about the importance and relevance of IBD and the burden of the disease. This might help us to obtain more resources, as these are usually directed towards major diseases such as cardiovascular or cancer

I also wish we could optimize the clinical pathways for IBD patients in order to make life for our patients easier and smoother (i.e. had an anaesthetist in our team)

We are investing more and more in clinical research and we are trying to set up a clinical trial unit to support us more efficiently

## HOW COULD IBD CARE BE IMPROVED IN GENERAL?

The personal aspects needed to follow patients with IBD are unique. Members of IBD teams need to have great empathy, patience and dedication. It would be good to see this in any centre across the world

I would like the whole region to treat all patients in the same way

Our field is slow because there are too few patients and not enough money. Most of the advances in the IBD field are related to industry funding as it doesn't attract public funding. This needs to change

## HOW DO YOU INTERACT WITH THE REST OF THE IBD TEAM?

I have an easy access to all my colleagues and can collaborate with them at all times

It is very easy to work all together, we are all friends and can reach out to whoever at anytime

# AMSTERDAM

Academic Medical Centre,  
Amsterdam, Netherlands



The Amsterdam team is led by Prof. Geert D'Haens.

## MEDICAL / SURGICAL TEAM



4

IBD PHYSICIANS



3

SURGEONS



3

RADIOLOGISTS



1

DIETICIAN



3

IBD NURSES



3

PATHOLOGISTS



16

ENDOSCOPISTS

PATIENT POOL: 3,500 ACTIVE PATIENTS

CATCHMENT AREA: NETHERLANDS

## RESEARCH

NUMBER OF STAFF IN RESEARCH TEAM

27

NUMBER OF PUBLICATIONS\*

0

50

100

150+

1

RESEARCH  
COORDINATOR

6

CLINICAL  
TRIAL NURSES

1

PROJECT  
MANAGER

18

RESEARCH  
FELLOWS

1

BIOBANK  
COORDINATOR

\* Number of publications for the entire team



## WHAT MAKES IBD CARE AT YOUR CENTRE EFFECTIVE?

### Education focus

We provide lots of educational activities, not only for patients, but also for our staff and gastroenterologists from over the whole world

Teaching is on-going

We hold masters classes a few times a year (topics range from fistula to quality of care etc.)

### Case mix

We have exposure to many difficult cases which teaches us a lot. When you want to be an expert you need to see complicated and rare cases

### Network

The idea of our INA-network (BD network Amsterdam) is to bring the patients where they belong: in regional hospitals for mild and moderate disease and at the academic centre for complicated and refractory cases

### Patient feedback

We have recently appointed a quality manager who will track patient feedback, this is very important to us

We invite patients to give feedback

We have developed a survey pole in the infusion room

### Multidisciplinary approach

For a year, we (the gastroenterologists) have been running a fistula clinic together with the surgeons

Our team includes team members from radiology, paediatrics, surgery, psychology and nutrition. We also have the help of a social worker

We work with basic scientists

### Research

We have many options for patients who do not respond to the commonly available treatments, we have two to three times more alternatives compared other centres in the country



## HOW COULD IBD CARE BE IMPROVED IN YOUR CENTRE?

I would like to have more interactions with the GPs, they are key in the management of our patients

General care is good however waiting times are too long, this could be improved

Patient-reported outcomes is a hot topic and I feel that we are not well advance in this field, we need to do more on this

We are sometimes under-staffed, we need more people

## HOW COULD IBD CARE BE IMPROVED IN GENERAL?

We need IBD care to be harmonised throughout the region, the country and beyond, which is why we are developing new tools to score endoscopy and other procedures

It would be good to track patients remotely

## HOW DO YOU INTERACT WITH THE REST OF THE IBD TEAM?

We all have a very good interaction with each other, I can access to medical expertise outside of my field very easily thanks to our multidisciplinary meetings and catch-ups

There is no barriere between the different members of the team, we look outside our own fences beyond



The Calgary team is led by Dr. Remo Panaccione and Dr. Subrata Ghosh.

## MEDICAL / SURGICAL TEAM



8

GASTROENTEROLOGISTS



7

SURGEONS



2

RADIOLOGIST



1

DIETICIAN



1

IBD NURSE



2

BIOLOGICAL COORDINATORS



1

IBD FELLOW



1

ENDOSCOPIST



2

PATHOLOGISTS

PATIENT POOL: ~5,500 ACTIVE PATIENTS

CATCHMENT AREA: ALBERTA

## RESEARCH

NUMBER OF STAFF IN RESEARCH TEAM

24

NUMBER OF PUBLICATIONS\*

0 50 100 150+

3  
RESEARCH  
COORDINATORS

1  
CLINICAL  
TRIAL NURSE

1  
BIOBANK  
MANAGER

8  
CLINICAL  
RESEARCHERS

11  
SCIENTISTS

\* Number of publications for the entire team



## WHAT MAKES IBD CARE AT YOUR CENTRE EFFECTIVE?

### Complementary and young team

All of us have been trained in big IBD centres (e.g. Mass. Gen., Uni. Chicago, Mayo Clinic etc.) and everybody has a niche area of their own. There is some overlapping but we are still distinct:

- Remo focuses on clinical trials
- Gil is the epidemiology lead
- Kerri has imaging
- Yvette focuses on tracking patient outcomes

Also our patients are happily surprised how young and relaxed the team is

### Preventive approach to care

We have developed a high risk to IBD clinic

We also have protocolised into urgent and same day endoscopy with pick up rates of circa 20%

### IBD network

We have set up an outreach clinic in Medicine Hat which has a high incidence of IBD and no gastroenterologists. We then spend an entire day every month to dismantle the urban- rural divide.

We also run telephone consultations on a regular basis

Soon, a Canadian IBD network will be launched. It will include our centre with 8 others across Canada

### Education

We regularly organise education seminars for patients

We also give our patients an "IBD passport" which allows them to track symptoms, visits etc

### Patient feedback

We have mechanisms in place for collecting patient feedback in a systematic basis. We distribute questionnaires randomly in endoscopy and clinics



## HOW COULD IBD CARE BE IMPROVED IN YOUR CENTRE?

We could improve on three main things:

- there is no joint clinics, for now they just sit alongside each other
- we do not have a dedicated Electronic Medical Record System, however we should be moving to on very soon
- we do not reliably have MDT 'rounds', they are too sporadic and need to be feasible once a week. We are in the process of organising those.

## HOW COULD IBD CARE BE IMPROVED IN GENERAL?

In general, patient centricity should be improved. A simple way would be with providing patients with better websites so they can access information easily.

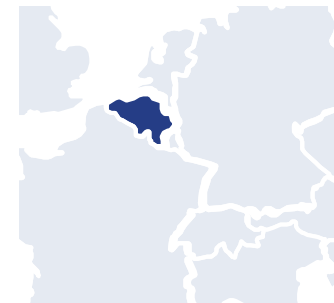
It would be good to track patient specific outputs:

- satisfaction
- productivity
- quality of life, etc.

## HOW DO YOU INTERACT WITH THE REST OF THE IBD TEAM?

We all know each other and all have our own areas of interest. We can easily interact on an ad-hoc basis to discuss specific cases and new protocols.





The Leuven team is led by Dr. Severine Vermeire and Dr. Gert Van Assche.

## MEDICAL / SURGICAL TEAM



3

GASTROENTEROLOGISTS



3

IBD SURGEONS



2

RADIOLOGISTS



2

PATHOLOGISTS



2

IBD NURSES



2

PHARMACISTS

PATIENT POOL: ~ 4,000 ACTIVE PATIENTS

CATCHMENT AREA: BELGIUM

## RESEARCH

NUMBER OF STAFF IN RESEARCH TEAM

25

NUMBER OF PUBLICATIONS\*

0

50

100

150+

8

STUDY  
COORDINATORS

1

BIOBANK  
MANAGER

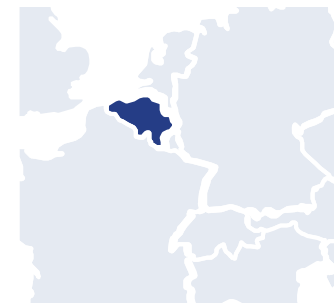
6

TECHNICIANS

10

RESEARCHERS

\* Number of publications for the entire team



## WHAT MAKES IBD CARE AT YOUR CENTRE EFFECTIVE?

### Team work

We work as a group and we can step in when one of our colleagues is on leave or away on a conference, there is trust  
I know how my colleagues deliver care and I can easily let them see my patients when I am away

### Harmonisation of care

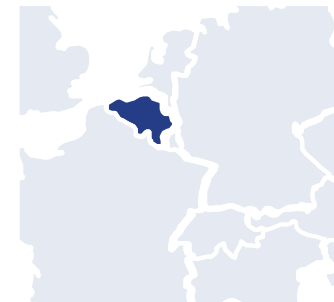
Patients discuss between themselves so it is important they realise they all benefit from the same type of care. As a result, we have protocolised our procedures and the way we manage patients

### Patient centricity

We have our own patients and we try to see them on their own by ourselves  
The only time someone else sees them is when I am on leave or sick  
We send out a yearly newsletter to all our patients and they really appreciate it  
We asked gastroenterologist from the region to bring us their most difficult cases so we can help them give the best care to these patients  
Patients like to be managed by a small number of people, and this is what we do here at Leuven

### Therapeutic studies

We focus on clinical trials and translational research.  
Many patients are sent to us because we can provide them with the largest number of clinical trials.



## HOW COULD IBD CARE BE IMPROVED IN YOUR CENTRE?

It would be good to increase the availability of the MRI machines, this is our next battle

We feel that clinical trials are still not well understood and appreciated, we have to fight for room and convince the hospital management of the value those studies can add to patients and to the hospital

The ideal would be to have a paediatrician and a gastroenterologist see the patient at the same time during the transition to adult care

I wish I had more time to spend with patients during consultations

## HOW COULD IBD CARE BE IMPROVED IN GENERAL?

Waiting lists are always too long, they need to be shortened everywhere

The role of the IBD nurse is not official in Belgium but we all believe this role is necessary

It would be great if patients could come with their medical history so we would know exactly what we are dealing with

Improving the link between local hospitals and university hospital would make things much smoother

## HOW DO YOU INTERACT WITH THE REST OF THE IBD TEAM?

We, the radiologists, talk everyday with our colleagues from surgery and gastroenterology

I have the ability to talk with my senior colleagues who go abroad and learn about the development of medicines and how research evolves. All this information comes together and I can access it as I can always count on them to answer my questions

We all know each other, we have a close contact, so it is easy to go straight to the point when we discuss a patient



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