



Royal College
of Physicians

Setting higher standards

UK Inflammatory Bowel Disease Audit

A summary report on the quality
of healthcare provided to people
with inflammatory bowel disease

UK IBD Audit summary report 2014

This summary report has been prepared by the Clinical Effectiveness and Evaluation Unit at the Royal College of Physicians on behalf of the IBD programme steering group.

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Registered charity no 210508

The work was commissioned by:



In partnership with:



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About this booklet

This booklet is for anyone who is interested in the quality of healthcare provided for people with inflammatory bowel disease (IBD).

Each section outlines:

- an overview of some of the key findings of the IBD Audit reports 2014
- the standard of care being provided in the UK
- what should happen, based on the *IBD Standards* and national guidelines.

Further information and guidance are signposted at the end of the booklet. This includes how to access the full reports, which contain results for local services. Also highlighted is a new guide for people with IBD on how to get the best from their local health service, called: *My Crohn's and Colitis Care*, produced by Crohn's and Colitis UK.

Thank you to the Patient Focus Group and the team at Crohn's and Colitis UK who contributed to the development of this booklet.

What is inflammatory bowel disease (IBD)?

The two main forms of inflammatory bowel disease (IBD) are ulcerative colitis and Crohn's disease.

In both ulcerative colitis and Crohn's disease, parts of the digestive system, usually the intestines (or bowels), become swollen, inflamed and sore. People with IBD can experience pain, diarrhoea (sometimes with blood), weight loss and tiredness.

Some people develop anaemia or have problems with their joints, skin or eyes. Both Crohn's disease and ulcerative colitis are chronic (long-term) conditions that can flare up unpredictably, although people can also have periods of good health (remission). There is no cure at present.

The number of people living with IBD has been increasing in recent years and is now estimated to be around 300,000 people in the UK. In light of this, there is a need to ensure that services are able to meet the growing demand and provide quality of care for everyone with IBD.

What is the UK IBD Audit?

The UK IBD Audit collects information from doctors, nurses and patients about the services and care provided for people with inflammatory bowel disease (IBD) in the majority of hospitals across the UK. The audit uses this information to assess the quality of care that people with IBD receive against national standards, and across different hospitals. The information collected highlights what is working well and where improvements need to be made.

The fourth round of audit, in 2014, collected information on how local IBD services are organised and managed. It also assessed the care and experience of people with ulcerative colitis who were admitted to hospital. Although many services are still not fully meeting the *IBD Standards*, the results have highlighted many positive changes.

The UK-wide results are published and supported by a range of activities to promote quality improvements (see page 24 for further details).

The UK IBD Audit
2014 collected
information:



From 97%
of registered
UK IBD services



About the care
provided to
4,657 patients
admitted to
hospital with
ulcerative colitis



On experiences
of hospital care
from 1,550
of the 4,657
patients

Key findings I: IBD services

The IBD Audit assessed how inflammatory bowel disease (IBD) services across the UK are organised and managed, based on the *IBD Standards*, which set out what a good IBD service should look like.

Some key areas covered were:

- how IBD teams are organised, and how they work with other healthcare services
- how people with IBD are involved in decisions about their care
- what education and support is provided to help people manage their IBD
- what ongoing care is provided and how quickly people can access advice and assessment
- how people with IBD are asked to feed back about their experience of care.

Specialist care: the IBD team

The nature of inflammatory bowel disease (IBD) means that a number of different health professionals might need to be involved in providing specialist care. They should work together as part of a team to provide people with IBD with a joined-up service. The *IBD Standards* define who should be part of the IBD team and what it should look like.

The core IBD team should include:

- specialist IBD nurses (often called clinical nurse specialists)
- consultant gastroenterologists
- consultant colorectal (bowel) surgeons
- radiologists (who use imaging to diagnose and inform treatment)
- pharmacists
- dietitians
- histopathologists (who look at cells and tissue samples to diagnose and inform treatment).

Key findings

- **7 in 10 (70%)** services have an IBD team that includes at least a consultant gastroenterologist and IBD nurse specialist, a stoma nurse, a dietitian and a consultant colorectal surgeon.

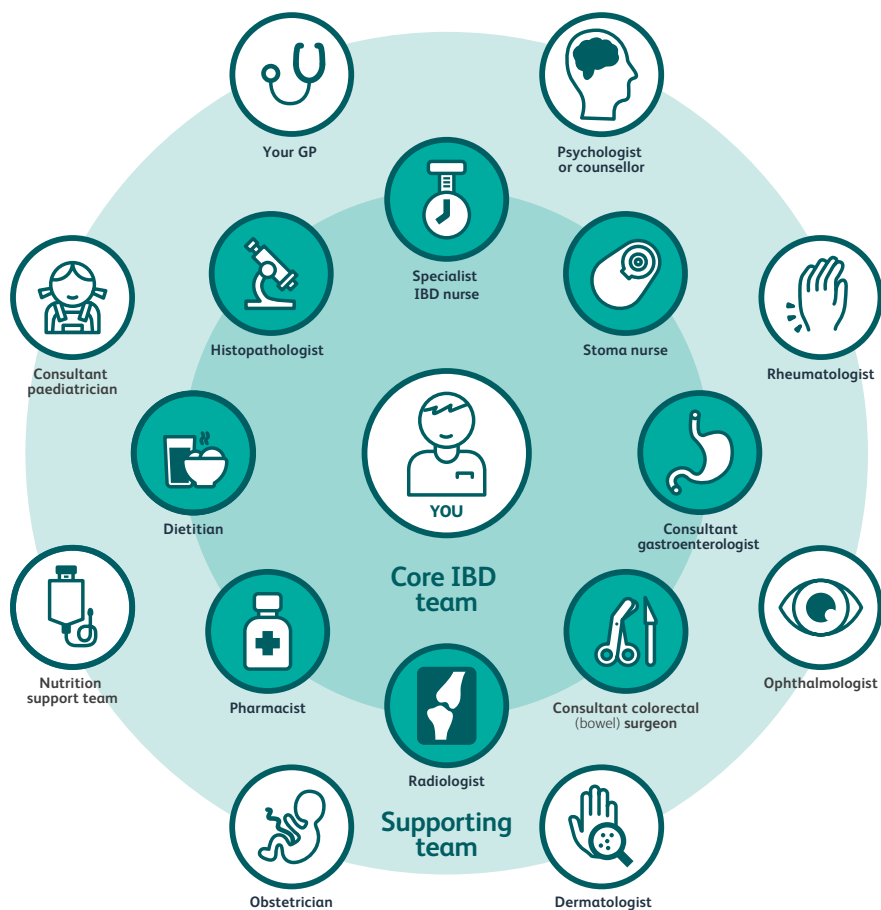
However:

- **only 3 in 10 (30%)** meet the full definition set out in the *IBD Standards*.



3 in 10 services
have an IBD team
that meets the
ideal standard

Your IBD team





Specialist care: IBD nurses

Specialist nurses have received specific education and training to provide expert support to people with inflammatory bowel disease (IBD). They are able to provide tailored care and play a vital role in supporting people with IBD to manage their lives with the condition.

The number of services with IBD specialist nurses has been increasing since the audit began in 2006.

Key findings

- **Over 8 in 10 (86%)** services reported that they have some IBD nursing provision.

However:

- **more than 6 in 10 (63%)** services do not meet the standard for the number of IBD nurses that are considered necessary to deliver the right level of service and support.
- **just over 1 in 10 (14%)** services have no IBD nursing provision.

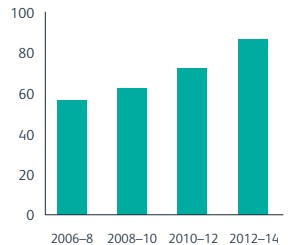
What should happen?

The *IBD Standards* state how many IBD specialist nurses are required in each IBD team depending on how many people it needs to support. For larger services, this will be two or more nurses. For smaller services, it will be fewer.

86%

Over 8 in 10 services have IBD nurses

% of services with an IBD nurse





Specialist care: dietitians

Nutrition is a very important part of treatment, both in times of a flare-up and during remission. Dietitians can give advice on how to eat a healthy, balanced diet and can provide nutritional support if people have difficulty eating during a flare-up.

When inflammatory bowel disease (IBD) flares up, it can be harder for the gut to digest and absorb nutrients from food. There may also be a decrease in food intake due to symptoms such as pain and discomfort. This can lead to weight loss, tiredness and lethargy.

Dietitians can also provide guidance and support in the use of liquid diets for treatment of Crohn's disease.

Key findings

- **1 in 4 (23%)** IBD services have no access to a specialist dietitian.
- **Just over 3 in 4 (78%)** services provide nutritional information to new IBD patients.
- **Just over 3 in 4 (76%)** services record the weight and BMI of all new IBD patients at their first appointment.

What should happen?

Access to a dietitian should be available to all IBD patients.



78%

Three-quarters of services provide nutritional information



23%

1 in 4 services have no access to a specialist dietitian



Specialist care: psychological support

Having inflammatory bowel disease (IBD) can affect people's lives and emotional wellbeing. This can be due to unpredictable symptoms, loss of sleep and/or anxiety about the condition and its treatment. Access to a psychologist or counsellor can help people to cope with living with these aspects of IBD.

Key findings

- **Just over half (53%)** of services can refer people with IBD for psychological support as and when it is needed.
- **Just over 1 in 10 (12%)** services reported having a clear process to enable people with IBD to see a psychologist or counsellor with a particular knowledge of IBD.
- **Under 4 in 10 (37%)** services provide information to people with IBD about how they can access counselling support.

What should happen?

Every IBD service should have access to a named psychologist or counsellor with knowledge of IBD.



53%

Just over half of services can refer people for psychological support



37%

Under 4 in 10 provide information about accessing counselling support



Involvement in decisions about care and treatment

People with inflammatory bowel disease (IBD) should have the opportunity to discuss their treatment with their IBD team, and be as actively involved in their care as they wish to be. This can help people to feel more confident and able to manage their condition.

Key findings

- **Just over three-quarters (77%)** of services report that people with IBD are able to actively participate in decisions about their care.
- **Almost half (49%)** of services routinely provide people with IBD with information on how they can obtain a second opinion about their treatment and care.

77%

Just over three-quarters of services enable people with IBD to participate in decisions about their care

What should happen?

People with IBD should:

- receive information and support so that they are able to make choices about their treatment. For example, this might include choice between drug treatments and dietary therapy for Crohn's disease, or between medical therapy and surgery during a severe flare-up of ulcerative colitis.
- be supported in their choice of follow-up care, which might include attending hospital as an outpatient, supported self-management or care from their GP, with links to the IBD team.
- be advised how they can discuss their care with their IBD team and/or obtain a second opinion.



Education and support

People with inflammatory bowel disease (IBD), their families and carers, should have the opportunity to learn about IBD. If they are more informed, they may feel more confident to manage their condition. Patient organisations can provide valuable information and access to support networks for people with IBD.

Key findings

- **Just over half (52%)** of services offer all those who are newly diagnosed with IBD a patient education session to help them understand their condition. This can be either one-to-one, in clinic or as part of a group education programme.
- **Under half (48%)** of services offer regular educational opportunities to people with IBD and their families, either as individuals or in groups.
- **6 in 10 (60%)** services provide people with IBD and carers with information about patient support groups.

What should happen?

The IBD service should provide education for people with IBD and their families, including information about their condition, ways they can manage it and options for treatment. Everyone with IBD should be provided with contact information for the relevant patient organisations.

52%

Just over half of services offer patient education sessions

48%

Under half of services offer regular educational opportunities



Access to specialist advice

Inflammatory bowel disease (IBD) is a fluctuating condition and can be very unpredictable. People with IBD should have access to specialist advice when they need it, be seen quickly when they have a flare-up, and have regular reviews.

Key findings

- **9 in 10 (91%)** services have a specialist IBD telephone line for patients.
- **Roughly two-thirds (67%)** of services offer a specialist email service.
- **More than 8 in 10 (84%)** services report that calls and emails are responded to within 48 hours by an IBD specialist.
- **Just over half (56%)** of services are able to see people with IBD who are experiencing a flare-up within 5 working days.
- **More than 8 in 10 (86%)** services review their IBD patients who are not under immediate or ongoing care annually.

What should happen?

- People with IBD should have access to a dedicated telephone service that provides a response to any queries or concerns by the end of the next working day.
- Services should offer people who are experiencing possible flare-ups a specialist face-to-face review within 5 working days.
- Everyone with IBD who is not receiving immediate or ongoing care, including those whose condition is stable, should have an annual review.



91%

9 in 10 services
have a specialist
IBD telephone
line for patients



86%

More than 8 in 10
services review their
IBD patients annually



Feedback and involvement in service improvement

Learning from patients' experience and feedback is fundamental to improving patient care.

Key findings

- **Nearly three-quarters (72%)** of services give people with inflammatory bowel disease (IBD) the opportunity to provide feedback on their care.
- **Fewer than 1 in 3 (28%)** services involve people with IBD in service planning and improvement.

What should happen?

People with IBD should be directly involved in, and have a say in the development of, the IBD service. The service should be able to demonstrate that processes are in place to obtain patient feedback and respond to it.

72%

Nearly three-quarters of services provide opportunities for patients to provide feedback on care

28%

Fewer than 1 in 3 services involve people with IBD in service planning

Key findings II: hospital care

The IBD Audit looked at treatment and care in hospital. Patients with ulcerative colitis, and the staff caring for them, provided information for this part of the audit separately.

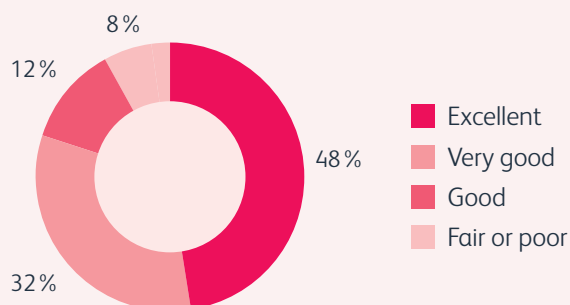
This included:

- care on a specialist ward
- tests and assessment
- treatment for associated conditions
- communication and understanding.

Overall, just under half (48 %) of adults with ulcerative colitis rated their care in hospital as 'excellent'. Fewer than 1 in 10 (8 %) rated their care as either 'fair' (6 %) or 'poor' (2 %).



How patients rated their care in hospital





Care on a specialist ward

A gastroenterology ward is managed by a specialist team with detailed knowledge of inflammatory bowel disease (IBD). It should be equipped with facilities to meet the needs of people with IBD, for example, by providing more toilets than a standard ward.

Key findings

- **Around 3 in 10 (31%)** patients were not transferred to a bed on a gastroenterology ward during their stay in hospital.
- **Two-thirds (66%)** of adults with ulcerative colitis were visited by an IBD nurse during their stay.
- **Fewer than 3 in 10 (27%)** services had one toilet per three beds on their gastroenterology ward.
- **Over half (54%)** had one toilet per four beds and **nearly 9 in 10 (88%)** had one toilet per six beds.

What should happen?

- People with IBD should, wherever possible, be cared for on a designated specialist ward.
- The IBD specialist nurses should be notified when people with IBD are admitted.
- Wards for IBD patients should have a minimum of one easily accessible toilet per three beds.

66%

Two-thirds of adults were visited by an IBD nurse

Patients' views and experiences

'The nurses were all polite but poorly trained to deal with patients with IBD.'

'I felt more comfortable being on a dedicated gastroenterology ward with a coordinated medical and surgical team.'

'My IBD specialist nurse was a godsend – but she was only told about my admission after 3 days.'



Tests and assessments

Inflammatory bowel disease (IBD) can be unpredictable. This makes rapid access to the relevant tests and appropriate assessment particularly important as it should ensure that the right treatment and care is provided when it needs to be.

Key findings

For new patients, it was found that:

- **over a quarter (27%)** of adult IBD services are unable to see all people with suspected IBD who have been referred urgently within 4 weeks or more rapidly if necessary.

For inpatients, it was shown that:

- **almost all services (99%)** have a process in place to ensure patients have access to an endoscopy within 72 hours if a flare-up is suspected.
- **more than 8 in 10 (82%)** patients had a nutritional assessment during their stay in hospital.
- **7 in 10 (70%)** services reported that dietitians reviewed new patients identified as needing dietetic support.

27%

Over a quarter of IBD services are unable to see referred patients within 4 weeks

Patients' views and experiences

'I asked for a dietitian but never saw one.'

What should happen?

- People with suspected IBD should be referred to the IBD service within 4 weeks, or sooner if necessary.
- Urgent assessment by endoscopy for those experiencing a flare-up should be possible within 72 hours.
- People with IBD should receive a nutritional assessment during their stay in hospital and be seen by a dietitian or nutritional support team where necessary.



Treatment for associated conditions

Associated conditions, such as anaemia and osteoporosis, can occur for people with inflammatory bowel disease (IBD).

Anaemia is when blood does not have enough red blood cells. This can be due to a lack of iron in the diet or poor absorption of iron from food, but can be made worse by ongoing blood loss. Anaemia can make people feel very tired, but this can also be due to the side effects of some of the drugs used for IBD.

Osteoporosis is the thinning and weakening of bones. This can also be caused by some of the drugs used for IBD, for example steroids, the inflammatory process itself and/or poor absorption of nutrients in inflamed intestines.

Key findings

- **Almost half (48%)** of those admitted with ulcerative colitis were anaemic. Of those with anaemia, over half did not receive any treatment for iron deficiency.
- **Over a quarter (26%)** of those prescribed steroids were not given treatment to protect and strengthen their bones and to help prevent osteoporosis.

What should happen?

- Anaemia should be investigated and the causes identified and appropriately treated.
- People with IBD who are prescribed steroids should receive treatment to protect and strengthen their bones.

48%

Almost half of patients admitted with ulcerative colitis were anaemic

26%

Over a quarter of those prescribed steroids were not offered treatment to protect against osteoporosis



Communication and understanding

Good communication is vital to ensuring that people with inflammatory bowel disease (IBD) are knowledgeable and confident about managing their condition. This includes understanding what to do if side effects or reactions to drugs are experienced.

Key findings

- **Three-quarters (76%)** of adults said they had full confidence and trust in the doctors treating them.
- **Just over half (53%)** of patients reported that they were involved as much as they wanted to be in decisions about their care and treatment.
- **One in three (31%)** adults did not feel that they were completely able to discuss worries or fears about their condition or treatment with a doctor.
- **Over one-third (35%)** of patients said that before they were discharged, they were not told about the sorts of changes that should prompt them to get in touch, for example, side effects or potential reactions to drugs.
- **Just under a quarter (22%)** of adults reported they were not given enough information about their conditions or treatment.



22%

Just under a quarter of adults were not given enough information about their condition

Patients' views and experiences

'I was disappointed how I was seen by a number of different doctors who told me conflicting information about what was wrong with me and what I might expect to happen.'

What should happen?

- Everyone with inflammatory bowel disease (IBD) should be offered appropriate information relevant to their age, understanding and the communication needs of the individual and carers.
- Information should be provided about their care and treatment options at all stages of their condition.
- For people admitted to hospital, information should be given about their follow-up care prior to discharge from the ward.



53%

Just over half were involved in decisions about their care and treatment

Patients' views and experiences

'The gastroenterologist explained everything very clearly, always listened to my concerns, spent the time to speak to my partner and explain the condition and was very understanding.'

'It would have been helpful to have more information about drug side effects, what symptoms to look out for and how to medicate myself better.'



Key findings III: children and young people

Inflammatory bowel disease (IBD) is often diagnosed in those who are in their teens and twenties. There are an increasing number of children being diagnosed with IBD. Treatment and care should meet their specific needs.

Key findings

- **Just over 4 in 10 (43%)** paediatric IBD services have access to an IBD nurse specialist with suitable paediatric experience.
- **Under half (45%)** of paediatric IBD services provide each young person with an individual transition plan for moving to adult services.
- **Nearly three-quarters (73%)** of young people treated in a paediatric service rated their overall care as 'excellent'.
- **By contrast, around a quarter (26%)** of young people treated in an adult IBD service rated their care as 'excellent'.
- **2 in 10 (20%)** young people reported that they wanted advice about how to manage their IBD either at work or at school, but this was not given.

26%

A quarter of young people treated in an adult IBD service rated their care 'excellent'

Patients' views and experiences

'I could have been placed in a better ward, all the other patients were over 60 and I was a teenager.'

What should happen?

Children and young people with IBD should have the choice of being cared for in an age-appropriate environment by specialists with paediatric experience. There should be a clear process for transition between paediatric and adult services.



How are the data used to make improvements?

Since the first IBD Audit in 2006, there have been significant improvements in the quality of care provided to people with inflammatory bowel disease (IBD). Although key findings from the 2014 IBD Audit show that there are aspects of care that remain below the agreed standards, a number of approaches are used to help bring about improvements.

- **UK-wide reports** are publicly available to view and download from the Royal College of Physicians' website: www.rcplondon.ac.uk/ibd.
- **Local results** are provided to all hospitals who have participated in the audit so that hospital teams can see how they compare with the national results. Detailed local service results are not published, although some key aspects are included in tables within the national reports. Hospitals may be prepared to share results if asked.
- **Action plans** are included within the reports to help hospital teams consider how to introduce improvements in care.

- **Action planning workshops**

A series of workshops were held across the UK in March 2015. These brought together local IBD teams to focus on developing action plans to implement improvements to their local services.

- **Letters to chief executives** to

highlight the key findings of the audit and encourage them to think about how they can assist hospital teams to make improvements in how they provide care to people with IBD.

How to get involved in improving care

Your views and experiences of care could help to improve your local service. You can share these by:

- speaking to your IBD nurse or the lead IBD doctor for your local service.
- finding out if there is a local IBD patient panel. Ask your IBD team or visit the Crohn's and Colitis UK website for further details or email: patientpanels@crohnsandcolitis.org.uk
- visiting the hospital website to identify other ways to register your feedback and get involved.



Crohn's and Colitis UK

Crohn's and Colitis UK is a national charity leading the battle against Crohn's disease and ulcerative colitis. We provide high-quality information and services, support life-changing research, and campaign to raise awareness and improve care and support for anyone affected by inflammatory bowel disease (IBD).

Our Information Service provides callers with clear and balanced information on a wide range of issues relating to IBD. Call **0845 130 2233** or **01727 734 470**, or email **info@crohnsandcolitis.org.uk**.

We produce over 40 information sheets, booklets and guides about all aspects of IBD which are available to download for free on our website: **www.crohnsandcolitis.org.uk**.

My Crohn's and Colitis Care has been produced by Crohn's and Colitis UK. It aims to help people with IBD to get the best from their local health service. It is available at: **www.crohnsandcolitis.org.uk/MyCare**.



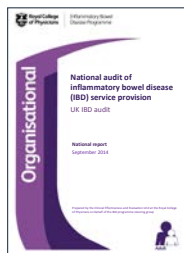
IBD Standards

The *IBD Standards* define what is required to provide safe, effective, patient-centred, high-quality and joined-up IBD services for the people who need them.

The *IBD Standards* were developed in 2009 by patient associations and a wide range of professional organisations working together and set out what a good quality IBD service should look like. The aim of the *IBD Standards* is to ensure that people with IBD receive consistent, high-quality care wherever they live in the UK.

The *IBD Standards* were updated in 2013 and continue to provide a benchmark for healthcare services. They have recently been used to inform the development of a new NICE quality standard for IBD.

The *IBD Standards* can be accessed online at: **www.ibdstandards.org.uk**.



IBD Audit

The UK IBD Audit is managed by the Clinical Effectiveness and Evaluation Unit at the Royal College of Physicians, who have worked together with Crohn's and Colitis UK to produce this summary of key findings from the 2014 IBD Audit. The full audit reports, including information about individual hospital services, can be accessed and downloaded at: www.rcplondon.ac.uk/ibd.

Healthcare Quality Improvement Partnership

The UK IBD Audit is commissioned by the Healthcare Quality Improvement Partnership (HQIP) as part of the National Clinical Audit and Patient Outcomes Programme (NCAPOP).

To find out more about other national audits and patient involvement, visit the HQIP website at: www.hqip.org.uk/patient-and-public-involvement.

National Institute for Health and Care Excellence

The National Institute for Health and Care Excellence (NICE) produces guidelines for the management of Crohn's disease and ulcerative colitis. NICE also produces quality standards that are designed to improve the quality of care in a particular disease area.

A NICE quality standard for inflammatory bowel disease (IBD) has been developed for England, identifying four 'quality statements' that service providers should achieve. The quality standard reflects many of the expectations outlined in the *IBD Standards* and can be viewed online at: www.nice.org.uk/guidance/qs81.

In association with:



The Association of
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The Association
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FIGHTING
INFLAMMATORY
BOWEL DISEASE
TOGETHER



Healthcare Quality
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