More IBD Nurses - Better Care

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Tonight’s Webinar

Provide an overview of some of the work the Health Service Development team at Crohn’s & Colitis UK have been up to

2019 IBD Standards

Patient Survey

Increasing Access to IBD Nurses
The Road to Excellence

2005 - IBD Audit launched

2007 - IBD Standards Group formed

2008 - IBD Audit in the Annual Health check

2009 - IBD Standards launched

2010 - IBD Audit in the National Programme

2011 - IBDQIP - first round pilots

2012 - Audit results onto NHS Choices
- Funding extended to 2014
- IBD Registry pilot starts
- Peer support visits piloted

2013 - IBD Standards updated
- IBD Registry launched

2014 - Registry - Early adopters

2015 - IBD Audit Roadshows;
- NICE Quality Standard
- My Crohn's and Colitis Care

2016 - RCP IBD Audit ends

2017 - RCP Biologics audit passed to UK IBD Registry
- IBD UK launches

2019 - New IBD Standards, Benchmarking Tool and
- Patient Survey

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Aims of IBD UK

Sharing good practice & communication

Raising IBD on the political agenda

Defining quality - what does 'good' look like and how is it measured?

Embedding quality improvement in IBD services and care

Goal
To ensure that people with IBD have the best possible outcomes from their treatment and care

Monitoring and reporting on progress
THE IBD SERVICE
The IBD Multidisciplinary Team
Patient Engagement
Service Development
Electronic Management and Data/Registry
Provision of Information
Investigations and Treatment
Training, Education and Research

PRE-DIAGNOSIS
Pathways and Protocols
Faecal Calprotectin
Timelines for Referral
Appropriate Expertise
Information

NEWLY DIAGNOSED
Shared Decision Making
Holistic Assessment
Care Plan and Treatment
Information and Support

FLARE MANAGEMENT
Pathways and Protocols
Information to Patients
Rapid Access to Specialist
Advice and Treatment
Steroid Management

SURGERY
Multidisciplinary Working
Surgery by Specialists
Information & Psych Support
Laparoscopic Surgery
Post-operative Care
Waiting Times

INPATIENT CARE
Direct Admission to GI Ward
Access to Toilets
24 Hour Critical Care
Assessment
Access to IBD Nurse
Discharge Planning

ONGOING CARE
Access to IBD Team
Personalised Care Plan
Education/Self-Management
Pain and Fatigue
Shared Care
Ongoing Review
IBD Multi-Disciplinary Teams

Core members should all have a special interest in IBD or gastroenterology. For a catchment population of 250,000 people (the average for a district general hospital), the IBD multidisciplinary team should include:

- 2 whole time equivalent (WTE) consultant gastroenterologists
- 2 WTE colorectal surgeons
- 2.5 WTE clinical nurse specialists with a special interest and a competency in IBD
- 1.5 WTE clinical nurse specialist with a special interest and competency in stoma therapy and ileoanal pouch surgery
- 1 WTE dietitian allocated to gastroenterology
- 0.6 WTE expert pharmacist in IBD
- 0.5 WTE psychologist
- 0.5 WTE administrator to provide support for IBD meetings, IBD database recording and audit
- 1 named histopathologist with a special interest in gastroenterology
- 1 named radiologist with a special interest in gastroenterology
What is an IBD Nurse?

6.4  IBD specialist nurses

**Good Practice Recommendation 32.** Clinical nurse specialists are a vital part of the IBD team, where their role may include provision of cost-effective patient education, disease management and therapy monitoring, patient support, continuity of care, audit, and rapid access for advice and review during disease flares (Agreement: 100%)
Why are they so important?

The IBD nurse specialist role is central to managing patient pathways. Impact is often hidden, but evidence shows;

- The IBD nursing role reduces length of inpatient stay and attendances to A&E and outpatient clinics.
- Standards of IBD care are higher across the board in centres where the IBD team includes a nursing role.
- Across the UK IBD nurses have approximately 29,000 patient contacts per year (through advice lines, outpatient clinics or day case admissions).
- Nurses are central to the effective, cost effective pathways for high cost biological therapies.
- Supporters of Crohn’s and Colitis UK describe the nursing role as a lifeline.
What do Crohn’s & Colitis UK say?

‘The availability of IBD nurse specialists across the UK is vital for people living with IBD to be able to access responsive health services and improved clinical outcome.’

‘Specialist IBD nurses play a fundamental role in delivering high quality patient care and experience, lead patient centred service redesign, improve the quality of care and represent excellent value for money.’
MORE IBD NURSES – BETTER CARE

2 IN 3 UK IBD PATIENTS WOULD CHOOSE PATIENTS HAVE CONTACT WITH A SPECIALIST IBD NURSE

80% OF PATIENTS WITH ACCESS TO AN IBD NURSE SAY THEY ARE SATISFIED WITH THEIR CARE

95% OF PATIENTS WITH ACCESS TO AN IBD NURSE SAID BEING ABLE TO SPEAK TO THEM QUICKLY IS IMPORTANT

9 OUT OF 10 PATIENTS WITH ACCESS TO AN IBD NURSE SAID SUPPORT WITH THEIR MEDICATION IS IMPORTANT

7 OUT OF 10 PATIENTS WITH ACCESS TO AN IBD NURSE SAID THE EMOTIONAL SUPPORT THEY PROVIDE IS IMPORTANT

65% OF PATIENTS WITH ACCESS TO AN IBD NURSE-SAID NUTRITIONAL SUPPORT IS IMPORTANT

1 IN 3 IBD PATIENTS DO NOT HAVE ACCESS TO AN IBD NURSE

63% OF IBD SERVICES DO NOT HAVE THE RECOMMENDED NUMBER OF NURSES

14% OF HOSPITALS HAVE NO IBD NURSE AT ALL

65% OF IBD NURSING SERVICES ARE SUSPENDED WHEN THE NURSE IS ON LEAVE

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• Everyone living with IBD in the UK should have access to an IBD Nurse Specialist.

• Across all four UK countries, we should work towards meeting the recommended minimum number of 2.5 full-time IBD Nurse Specialists nurses per 250,000 population, with a maximum of 500 patients per full-time nurse, as defined by the ‘Modelling Caseload Standards for IBD Specialist Nurses’ report 2017.

• A clearly defined career pathway for all grades of nurses working within IBD care, with sufficient resourcing for all IBD Nurse Specialists to hold, or work towards, Masters level nursing qualifications, is needed to retain high calibre nurses and encourage more into IBD Nursing.
And HSJ, for Healthcare Leaders, agree!

If you can get expert nurses to assess patients and either keep them at home or move them along quicker, it frees up the front door for those emergencies that need support from other areas.

They’re an encyclopaedia of knowledge. If ever I had any questions, they would either give me the answer or point me in the direction to find the answer.

Where nurses are running effective advice lines, patients with complex Crohn’s or complex ulcerative colitis - or a flare of a straightforward condition - don’t pitch up at A&E.

IBD nurses were important in providing information to patients, both over the telephone and within clinic visits, and also speaking to staff at the day unit where the infliximab infusions are administered.

Just by doing this clinic, I’ve brought in five patients rather than them going through accident and emergency, so that was a £9,000 saving.
“You can just pick up the phone to a specialist nurse and say ‘You know what I think I might be having a flare.’ And the treatment can be in place within days. When you look at the long term cost savings - the price per head of an admission per night compared to an IBD nurse’s salary - it just makes perfect sense to have these specialist nurses.”

Anon patient
IBD nurses in 2016

Percentage of IBD Patients who have contact with a Specialist IBD Nurse

- No: 30%
- Don’t Know: 68%
- Yes: 2%

Over the last 3 years, has the establishment (number of funded posts) in your IBD specialist nursing service changed?

- No change (47%)
- Increased (52%)
- Decreased (1%)

Number of IBD Nurse Specialists in each UK country:

- England: 250
- Scotland: 50
- Wales: 10
- N. Ireland: 5

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How are we improving things?

Working locally with individual services business planning and service development

Web resource for supporters and other health care professionals

Developing education and training about IBD nursing & developing services:
  • Crohn’s & Colitis IBD Nursing Programme
  • Advice Line Service Delivery Training

Celebrating and advertising success

Raising awareness with supporters, managers and health care leaders
Thinking of becoming an IBD Nurse Specialist?

Find out if you have what it takes for a career as an IBD Nurse Specialist.

The effective management and treatment of *Crohn’s Disease* and *Ulcerative Colitis* requires an expert level of knowledge from a dedicated IBD Nurse Specialist.

As well as providing clinical care for patients, an IBD Nurse Specialist is a mentor, emotional supporter and an advocate for an end to stigma and better care.

**YOUR RESPONSIBILITIES**

As an IBD Nurse Specialist, you’ll provide expert clinical care and management of your patients’ conditions. You’ll also need to help educate others and conduct research to make sure you’re informed of the latest developments in IBD care.

Typical IBD Nurse Specialist duties include:

> Working as an IBD specialist nurse is an incredibly rewarding job. You really get to know your patients, you get to watch them through their journey and when you manage to make a difference to people’s lives you just can’t really put that into words."

*Lisa Younge*

Lead IBD Nurse Specialist
If you think that your IBD service needs improving, read our step-by-step guide on how to build a business case.

To improve your service, you will usually need to build a strong case for training or recruiting new staff. The key here is in showing value and there are lots of different factors that play into it – service efficiency, A&E avoidance and drug management to name a few.

This page offers examples, guidance and resources for building and presenting your business case – but remember that each individual case will vary depending on your needs.

**STARTING OUT**

The first task is to gather as much information as you can.

**BUILDING YOUR CASE**

Once the foundations are laid, you can start making a plan.

**GATHERING YOUR EVIDENCE**

Make sure that you have strong evidence, data and patient feedback to support your case.

**PRESENTING YOUR CASE**

Getting your case in front of the right people is key.
10,038 hits
6,746 post code searches
In 9 months!!!!
394 individual WTE IBD Nurse Specialist posts were identified across the UK in total, an increase in overall workforce since 2012 of 98%.

39.6% (59/149) services reported an increase in nursing establishment since 2016

59% (88/149) reported provided nursing services over more than one site, with 10% (16/149) providing services over more than three sites.

Evidence of more complex working

45% (122/274) of nurses have a non-medical prescribing qualification

13% (35/274) educated to MSc level

98% (269/274) provide advice line access for patients as part of their service

10% (28/269) have had any formal training to provide this service
Crohn’s & Colitis UK nurse specialist programme

• A unique opportunity to fund and support nurse education and development as long as they are working in their current post.

• A chance to join with other nurses in the programme, building a community of support for nurses working in the role.

• Access all the skills, knowledge and resourcing that the charity has, including senior nursing leadership, information and support services, communications and IT skills, research development and so much more.
Annually fund 10 MSc’s in advanced nursing practice,

Annually recruit 10 MSc qualified nurse specialists to complete RCN Advanced Practice Credentialing

Both become Crohn’s & Colitis UK nurse specialists
Crohn’s & Colitis UK members have previously referred to the provision of advice lines as a ‘lifeline’ to them.

There is a need to provide skills-based training for IBD nurses so that they are able to run their advice lines in the most productive way possible.

We have developed an advice-line training programme specifically for specialist IBD nurses.

Co-designed and developed with IBD nurse specialists and the Crohn’s & Colitis UK support team, it will deliver practical training sessions that can be replicated to support all IBD nurse specialists across the UK.

Our first courses will roll out in January & March 2020.
Member Support

100 IBD Nurses Appeal
What can you do?

Complete the IBD Patient Survey
Promote the IBD Patient Survey
Encourage your local IBD services to register for the Benchmarking Tool
Look out for the results in early 2020 and use these to find out more about IBD Nurses!
Involving IBD nurses as Medical Advisors
Thank you.