SCOTLAND LEADING THE WAY
A NATIONAL BLUEPRINT FOR INFLAMMATORY BOWEL DISEASE IN SCOTLAND

CROHN'S & COLITIS UK

FIGHTING INFLAMMATORY BOWEL DISEASE TOGETHER

ALLIANCE
HEALTH AND SOCIAL CARE ALLIANCE SCOTLAND
people at the centre

SSPGHAN

With the support of

The Scottish Government
Riaghaltas na h-Alba

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FOREWORD

The Scottish Government is committed to ensuring that people in Scotland living with Inflammatory Bowel Disease (IBD), such as Crohn's Disease and Ulcerative Colitis, are able to access the best possible care and support.

We want to ensure that healthcare services for people with IBD are safe, effective and put people at the centre of their care, working towards delivery of our 2020 Vision - that people are able to live longer, healthier lives at home, or as close to home as possible. Our National Clinical Strategy sets out our vision on how NHSScotland will develop new approaches to ensure our health and social care services are fit for the future.

That is why it is important to us that we continue to work with key partners, including NHS Boards, third sector organisations and patient groups, to drive forward quality improvement in services and care in local areas. This Blueprint is an example of co-produced partnership working, being the result of a successful collaboration between Crohn's and Colitis UK, NHS health professionals and patients – with support and guidance provided by the Scottish Government – who have come together to produce sustainable best practice advice for the care and treatment of people with IBD in Scotland.

The Scottish Government considers the 2013 UK IBD Standards to provide the basis for good quality IBD care. We anticipate that this Blueprint will act as a valuable supplement to the 2013 Standards, assisting NHS Boards in facilitating their incorporation into healthcare delivery in Scotland, and thereby providing a route to delivering improved care for people living with IBD in Scotland.

Catherine A Calderwood

Dr Catherine Calderwood
Chief Medical Officer for Scotland

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EXECUTIVE SUMMARY

The UK IBD Audit of healthcare for people with Crohn's Disease and Ulcerative Colitis, confirmed that care is inconsistent and often fails to meet the IBD Standards. Only 30% of participating hospitals had adequate specialist nursing provision, while fewer than 25% had a defined pathway for access to psychological support.

Our vision is for people living with Inflammatory Bowel Disease (IBD) in Scotland to receive equitable, timely and appropriate care, thereby improving their health, and ability to participate in education, work, social and family life.

The IBD Audit[1] demonstrated a significant variation in care for patients living with IBD in Scotland. The aim of this Blueprint is to support improvement in the quality of clinical and person centred care, meeting the 2013 UK IBD Standards[2] by implementing new approaches to the management of IBD across all NHS Boards in Scotland.

Our belief is that this learning can be implemented across every NHS Board in Scotland to result in improved, equitable and more sustainable services aimed at:

- ✓ **Reducing outpatient appointments**
- ✓ **Reducing emergency hospital admissions**
- ✓ **Improving patient safety**
- ✓ **Enabling cost effective condition management**

Building on the Scottish Government's 2020 Vision[3] that we "achieve sustainable quality in Scotland's Healthcare", the National Clinical Strategy for Scotland[4] sets out the ideas on how NHSScotland needs to change to ensure health and social care services are fit for the future. This Blueprint provides a route to achieving these aims for patients in Scotland living with IBD.

Drawing on real life experience and examples from two diverse NHS Boards – NHS Highland and NHS Greater Glasgow and Clyde – we have identified the key components of an IBD service for Scotland that would lead to better care and a better quality of life for people living with IBD.

Through a planned "Once for Scotland" approach to re-shaping IBD care with NHS Board, patient and clinical engagement, it shows that there can be both improved patient centred/patient controlled services and better value for NHS Boards.

"Unpredictable symptoms mean immediate response needed. Better management of condition (Crohn's) required and advice needed to be able to do this."

Patient

1. National audit of inflammatory bowel disease, (IBD) service provision, UK IBD audit National report, September 2014 https://www.rcplondon.ac.uk/projects/ibd-inpatient-care-audit
2. http://www.ibdstandards.org.uk/
3. 2020 Vision http://www.gov.scot/Topics/Health/Policy/2020-Vision
4. A National Clinical Strategy for Scotland, Scottish Govt, Feb 2016 http://www.gov.scot/Resource/0049/00494144.pdf 'A National Clinical Strategy for Scotland

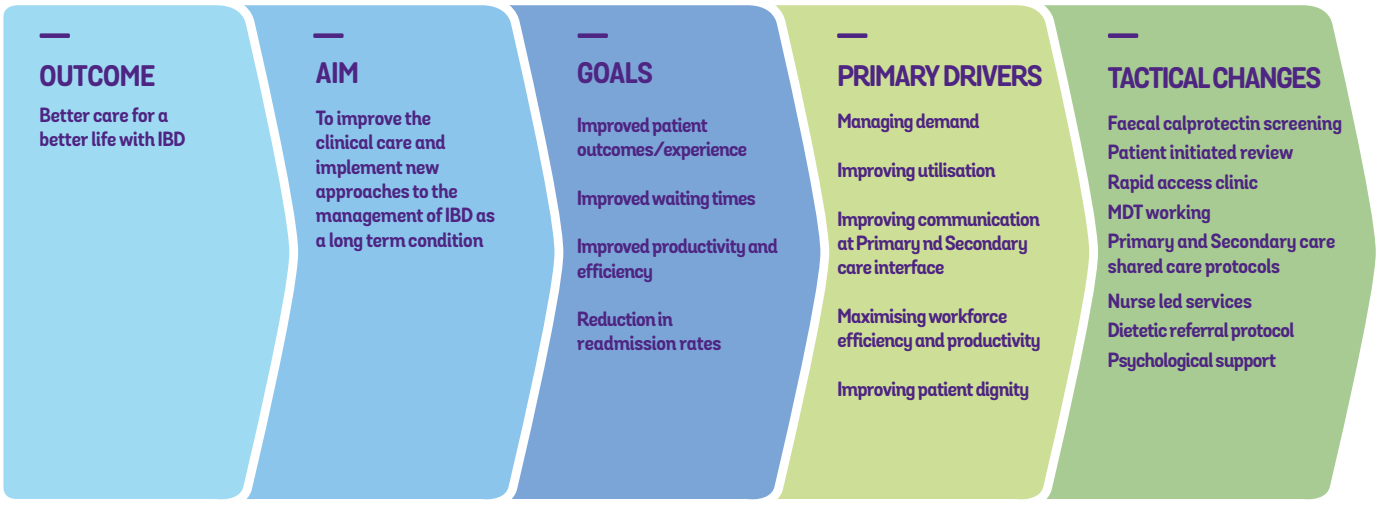
Key recommendations

Co-design and deliver now

- **A responsive IBD service, which provides:**
  - Patient advice via email and telephone
  - Expedited patient reviews within one week
  - Teleconsultation clinics and virtual clinics in addition to face to face appointments
  - Specialist IBD Nurse
  - Dedicated IBD Clinics
  - Access to specialist dietetic support
  - Access to pharmacy support
- **Multi-Disciplinary Team (MDT) working which is based on:**
  - Regular MDT meetings
  - A clearly defined MDT
  - Presence of an IBD Nurse
- **Appropriate IT support for the service, building on the IBD IT Strategy**
- **Access to specialist paediatric services for all patients under 16 with suspected IBD:**
  - Consistent care for under 16s i.e. equal access to paediatric IBD services
  - Standardised transition to adult services
  - Young adult clinic to bridge between paediatric and adult care
  - 24 hour support and advice
  - Uniform access to testing for Clostridium difficile in children of all ages with IBD
- **A Primary care faecal calprotectin programme to ensure timely referral for IBD diagnosis**

Co-design and develop

- **Access to dedicated Psychological Support for patients with IBD**
- **A Scotland-wide supported self management programme**
- **Fully integrated interface between Primary and Secondary care**



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BACKGROUND
WHY WE ARE DOING IT

In response to a Crohn's and Colitis UK survey of young people aged 16–25 years, 79% felt their condition had affected their confidence and self–esteem, while 69% felt it had prevented them from reaching their educational potential.

The IBD Audit identified an inconsistency in care provision for people living with IBD in Scotland. This led to the drive for the UK IBD Standards and a desire from the Scottish Government to develop a Blueprint for IBD in Scotland.

The aim of this Blueprint is to develop local IBD services where:

IBD patients in Scotland receive equitable, timely and appropriate care (including local delivery of care and supported self management where appropriate), in accordance with the 2013 UK IBD Standards, thereby improving their health and ability to participate in education, work, social and family life.

Health services and health professionals in Scotland deliver high quality, efficient care to IBD patients which is person centred, safe, effective and continually improving.

Collectively known as IBD, Crohn's Disease and Ulcerative Colitis are lifelong conditions that can develop at any age, but most commonly first present in the teens and early twenties (mean age of diagnosis is 29.5 years). At least 300,000, or 1 in 210, people across the UK have IBD, with approximately 18,000 new cases diagnosed every year.

With 26,000 sufferers, Scotland has the highest prevalence of IBD in the UK.

The conditions can affect an individual's ability to work, learn, socialise and form and maintain relationships, often resulting in increased absence from school and education and time away from work. Lifetime medical costs for IBD are comparable to other major diseases such as diabetes and cancer, with the annual cost to the NHS in Scotland estimated at more than £72m.

Research has shown that IBD nursing can be extremely cost–effective, reducing hospital visits by 38% and achieving a 19% reduction in in–patient length of stay.

Between 50 - 70% of people with Crohn's Disease will undergo surgery within five years of diagnosis, and with Ulcerative Colitis, lifetime surgery rates are approximately 20 - 30%. There can be an increased risk of bowel cancer for some people with IBD, especially those with longstanding and extensive Ulcerative Colitis or Crohn's Colitis (Crohn's Disease affecting all or most of the large colon). Research shows that the risk of developing cancer usually begins to increase approximately 8-10 years after the onset of IBD symptoms[6]. This would be addressed by the Cancer Surveillance Programme for IBD[7].

Research evidence consistently demonstrates that people with a long-term condition are also two to three times more likely to experience mental health problems than the general population[8].

This Blueprint has been produced by the Steering Group of the Scottish IBD Project[9]. It is based on the principles of co-design and co-production, adopting the Scottish Government's ambition to ensure that services are co-produced with the communities they serve, building on people's assets and supporting the health and well being of the whole person and their family.

6 AGA technical review on the diagnosis and management of colorectal neoplasia in inflammatory bowel disease. AU Farraye FA, Odze RD, Eaden J, Itzkowitz SH SO Gastroenterology.2010;138(2):746.
7. BSG Clinical Guidelines for the management of IBD in Adults
8 . (Naylor et al. 2012).
9. Acknowledgements P18

National Action to support local Implementation

The IBD Community will now develop and drive the overall implementation of this Blueprint, continuing to work collaboratively with the Scottish Government. It will further the development of the IBD Information Technology (IT) Strategy underpinned by the Scottish Government eHealth Strategy.

As part of this IBD Community, the Scottish Government, National Delivering Outpatient Integration Together (DO IT) Programme, has an established Scotland-wide Gastroenterology Collaboration and is the natural forum through which to implement elements of the Blueprint. The Collaboration will focus on the development of national patient pathways and new ways of managing these conditions across Primary and Secondary care on a "Once for Scotland" basis. The DO IT Programme Improvement Bundle, when implemented collectively, will improve outpatient flow, process and patient outcomes.
This Bundle ties the key change interventions together to improve, for example:

- Patient management in Primary care where appropriate, via "Advice Only" referral processes being in place.
- Person centred approaches to managing return patients, by establishing patient initiated review.
- Access to consultation closer to home by rolling out virtual (e.g. telephone, video) consultation review clinics, supported by the use of supported self management enabling technologies.
- The process and booking practices for return patients through establishment of planned patient return lists.

"As part of the Scottish Government's commitment to improving outpatient services, I'm delighted to support the implementation of the IBD National Plan via the Delivering Outpatient Integration Together Programme (DO IT) Gastroenterology Collaboration."

Pauline Fyfe
Programme Manager
Delivering Outpatient Integration Together (DO IT) Programme

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WHY IS IT IMPORTANT?

LINKING SCOTTISH GOVERNMENT POLICY TO IBD CARE

Table 1 below illustrates how improving the care of people living with IBD in Scotland is in keeping with a number of key Scottish Government policies for health and social care.

IBD AMBITION	POLICY	IMPACT
Implementing the 2013 UK IBD Standards **First national Blueprint for IBD in Scotland**	**Healthcare Quality Strategy for NHSScotland**[10]	**Aims** • To deliver the highest quality healthcare services to the people of Scotland. • For NHSScotland to be recognised as world leading in the quality of healthcare it provides. **Ambitions** • Safe • Person Centred/Person Controlled • Effective
Fully co-produced model **Building on implementing virtual clinics**	**2020 Vision** Everyone is able to live longer, healthier lives, at home, or in a homely setting.	• We will have a healthcare system where we have integrated health and social care, a focus on prevention, anticipation and supported self management. • When hospital treatment is required, and cannot be provided in a community setting, day case treatment will be the norm. • Whatever the setting, care will be provided to the highest standards of quality and safety, with the person at the centre of all decisions. • There will be a focus on ensuring that people get back into their home or community environment as soon as appropriate, with minimal risk of readmission.
Specialist IBD Nurse care **Developing supported self management**	**A National Clinical Strategy for Scotland**	**Sets out the case for:** • Planning and delivering integrated Primary care services, like GP practices and community hospitals, around the needs of local communities – integrated working with Social Care and the Third Sector. • Restructuring how our hospitals can best serve the people of Scotland. • Making sure the care provided in NHSScotland is the right care for an individual, that it works, and that it is sustainable. • Changing the way the NHS works through new technology.

10. http://www.gov.scot/Topics/Health/Policy/Quality-Strategy
11. Getting it Right for Every Child http://www.gov.scot/resource/0042/00423979.pdf.

IBD AMBITION	POLICY	IMPACT
Delivering person centred care to children and young people **Specialist services for paediatric IBD will fully embrace the principles of Getting it Right for Every Child (GIRFEC)[11]**	**Children and Young People's (Scotland) Act 2014[12]**	A key piece of legislation and all aspects of the Act may be relevant to children and young people with IBD; however of particular note are Parts 4, 5 and 18 (Provision of Named Persons, Child's Plan and Assessment of Wellbeing, respectively) these are related to the wider **Getting It Right for Every Child (GIRFEC) policy.** **Designed to ensure:** • that the right help is available at the right time and, • is delivered in a coordinated way working with children and families to, • achieve the outcomes they think are important. **Getting It Right for Every Child** is founded on 10 core components which can be applied in any setting and in any circumstance: • Ensures that services are brought together more effectively to provide help and support for children. • Recognises that services must be responsive to the needs of children - and how their needs change as they get older.
IBD IT Strategy founded on supporting self management, and clinical care, building data and informing research	**eHealth Strategy 2014–2017[13]**	**By 2020 eHealth in Scotland will:** • Enable information sharing and communications that facilitate integrated health and social care across all settings from the patient's home to the hospital. • Provide information processing, analysis and intelligence that supports and complements the work of health and social care professionals and improves the safety and quality of care. • Support people to manage their own health and wellbeing and live longer, healthier lives at home or in a community setting. • Contribute to a partnership between the Scottish Government, NHSScotland, the research sector and industry to enable Scotland to be a long-term leader in digitally enabled care.
Building "shared care" models between Primary and Secondary care provision	**Public Bodies (Joint Working) (Scotland) Act 2014[14]**	• Allows NHS Boards and Local Authorities to integrate health and social care services. • The overall aim is better and seamless health and care, more efficient use of resources and enabling change.

12. http://www.legislation.gov.uk/asp/2014/8/contents/enacted
13. http://www.gov.scot/Publications/2015/03/5705
14. http://www.legislation.gov.uk/asp/2014/9/contents/enacted

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WHAT WE DID
WHAT THE PROJECT INVOLVED

The Project

The Scottish IBD Project was set up in 2013 with the aim to advance quality improvement in IBD care across Scotland and to demonstrate that, through a planned approach to re-shaping IBD care with Board, patient and clinical engagement, there can be both improved patient centred services and improved use of resources for NHS Boards. The Steering Group leading the Project developed a quality improvement approach based on the NHS Scotland Quality Improvement Hub model[15].

Pilot groups[16] were set up in two diverse NHS Boards where the patient journey was mapped against the 2013 UK IBD Standards, identifying the gaps and aspirations in service delivery[17]. These became the work streams and focus of the service redesign and the reconfigured services were tested for success.

Further work streams were developed by the Steering Group, involving Paediatrics and Information Technology. The Group shared good practice from across Scotland to develop the recommendations in this Blueprint.

"I've had Crohn's for 18 years for me it's pain, fatigue and always having to explain to people what's wrong with me and why I can't come to work or do things. Then they turn around and say but I don't look ill."

Patient

"Being a part of the Highland project has been great. I've learnt so much and knowing that I am helping change the shape of healthcare for IBD patients in the Highlands and in Scotland as a whole is hugely satisfying."

Susan Maniquiz

Who was involved?

The two year Project was led by Crohn's and Colitis UK and supported by the Strategic Planning and Clinical Priorities Team from the Healthcare Quality and Strategy Directorate of the Scottish Government. Funding was provided by both. The Project pulled expertise from across the whole IBD Community in Scotland, forming a Steering Group to guide and inform the work that included input from consultants, dietitians, GP's, nurses, pharmacists, psychologists, NHS Boards, the Scottish Government, patients and third sector partners.

How we did it

The approach used was based on a co-design and co-production model both at a national and local level.

15. http://www.qihub.scot.nhs.uk/default.aspx
16. Acknowledgements p.18
17. Appendix 1 Example of Patient Journey Mapping

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IMPROVEMENT IN PRACTICE
WHAT WE LEARNED FROM THE PROJECT

For each 2013 UK IBD Standard, this section identifies evidence from the pilot sites and work streams showing which interventions resulted in an improvement in care for people living with IBD.

Fundamental to each of these service improvements is the need to create room for innovation in healthcare workers plans and the importance of clinical leadership in championing the co-design and co-production process.

Standard A – High Quality Clinical Care

High quality, safe and integrated clinical care for IBD patients based on multi–disciplinary team working and effective collaboration across NHS organisational structures and boundaries.

What we did – Evidence of Improvement

Provide Specialist IBD Nurses
NHS Highland increased the role of specialist nurses in outpatients to enable them to support the introduction and delivery of teleconsultation clinics and virtual clinics to patients with IBD. The aim was to put the patient at the centre of their care and to improve their experience, as a patient, in an outpatients setting. This provided, where appropriate, a quality service closer to home for the patient and their family.

Provide Dedicated Psychological Support
Mapping patient care in a co-design approach in each of the pilots, highlighted that patients need support for the psychological aspects of their condition. The IBD Audit showed that access to psychological support for IBD patients remains low; only 12% (21/173) of services reported having access to clinical psychology via a defined referral pathway[18]. Crohn's and Colitis UK awarded a research grant to the University of Stirling and NHS Highland for a pilot randomised controlled trial (RCT) on the use of Mindfulness Based Cognitive Therapy (MBCT) for improving the quality of life for patients with IBD. See Appendix 2 . Patients reported finding the programme useful and beneficial, and said they would recommend it to other people with IBD.

Results from this small scale project cannot be generalised but suggest that MBCT offers the potential to improve depression, anxiety and the overall quality of life for patients with IBD.

As part of the NHS Greater Glasgow and Clyde pilot, a Clinical Psychologist from Liaison Psychiatry was released to train a group of Clinical Nurse Specialists in psychosocial skills, including the identification of psychological distress. This enabled them to provide level 2 psychosocial skills in the Stepped Care Model. See Appendix 2. While the training was well received, demand outweighs the capacity to deliver it and the associated practice support which is required as part of clinical governance. Additionally, due to an unfortunate gap in service provision, there is no dedicated psychological service for patients with IBD. Increased resources would be required to meet the psychological needs of patients with IBD.

> "More IBD nurses need to be available to those suffering with IBD. It seems it's a bit hit and miss depending on where you live but when you are suffering with a chronic illness it is essential that you have support and understanding from a professional who specialises in this disease. ."
>
> **Patient**

18. National audit of inflammatory bowel disease, (IBD) service provision, UK IBD audit National report, September 2014

> Access to psychological therapy to help manage emotions and transition of illness

> IBD has left me feeling a complete waste of a man

> I would like to have access to a counsellor, someone to talk to

Patients

> The MDT has been a very successful route for discussing the change in practice of the use of biologics. The potential possible underspends as a result of these changes have been agreed to be moved to alternative aspects of the patient pathway. This will also be positively impacted by the potential to introduce the use of bio similars for patients.
> NHS Highland pilot

IBD Multi Disciplinary Team (MDT)
NHS Highland identified the key people for an IBD MDT, comprising specialist IBD Nurses, gastroenterologists, surgeons, dietitians, and when needed, a paediatric IBD nurse, which met once a week to discuss complex patients and make joint decisions about appropriate care for the individual. This led to better monitoring of patients, shared decision making and an increase in holistic care for the patient. NHS Tayside[19] highlighted the need for good, robust administration support for this to be effective.

Increase access to dietetic services
NHS Highland put in place a joint clinic with the dietitian and the clinician. The aim of this was to ensure a "fast track" dietetic referral process that enabled patients to be seen at the time of their clinic consultation. This reduced patient waiting times and the subsequent associated administrative processes of providing return outpatient appointments. Dietetic input continued to be provided to assess and support new and relapsing cases, to advise and provide appropriate dietary information to empower supported self management and enable the patient to exercise treatment choice.

Faecal calprotectin testing is recommended as an option to support clinicians with the differential diagnosis of IBD and Irritable Bowel Syndrome (IBS). It is widely used in Scotland in hospitals to monitor disease activity and it is a useful screening test that can help avoid costly treatments and hospital admissions. The use of modern diagnostic tools in Primary care, such as faecal calprotectin testing, help ensure timely referrals of patients with suspected IBD to specialist services.

The effective use of faecal calprotectin testing should enable the quicker identification of suspected IBD patients and their subsequent referral to a specialist. Testing may also reduce the number of unnecessary endoscopies carried out on people who have IBS and could save a significant amount of money for NHSScotland.

Care of Children and Young People
Discussion and feedback from patients, families and clinicians during the Project highlighted the gap in service provision in the care of children and young people living with IBD.

The Blueprint recommends:

- Access to specialist paediatric services for all patients under 16 with suspected IBD
- Consistent care for under 16s i.e. equal access to paediatric IBD services
- Standardised transition to adult services
- Young adult clinic to bridge between paediatric and adult care
- 24 hour support and advice
- Equal and timely access to diagnostic services most notably small bowel MRI
- Uniform access to testing for Clostridium difficile in children of all ages with IBD

19. Do It funded programme

> The specialist nurses & consultants are amazing! .... they get down to the child's level & make things seem less scary

Parent

Support from Pharmacy Team
The pilots found that Pharmacists and pharmacy technicians have a crucial role to play in improving the care of patients with IBD. Patients with IBD often receive complex regimens of drugs, with a range of potential adverse effects, toxicities, monitoring requirements and interactions. Pharmacists, working in a variety of roles, may be involved in the education of patients starting on new therapies, monitoring compliance with medications, identifying adverse or toxic effects of medications and preventing potentially serious drug interactions. Pharmacists aim to improve the safe and effective pharmacological management of patients with IBD, and encourage evidence based, clinically and cost effective use of medicines. Pharmacist Independent Prescribers also have a role to play in prescribing for patients with IBD, and this role is likely to expand as more pharmacists are supported to undertake this qualification. Furthermore, the Medicines Information service within pharmacy is frequently utilised by gastroenterologists for complex enquiries, to ensure the safe use of medicines for their IBD patients.

Standard B – Local Delivery of Care

Care for IBD patients that is delivered as locally as possible, but with rapid access to more specialised services when needed.

What we did –Evidence of Improvement

Virtual and Telephone Clinics
NHS Highland, using a co-designed approach built on the patient journey mapping, showed the need to provide clinics for patients "at the right time by the right person in the right way". They set up and introduced video and teleconference clinics, trialling them with patients. This service has been hugely popular with patients, who can now avoid long journeys to a physical outpatient clinic; this simple addition to care puts patients at the centre and is designed for their convenience.

As a direct consequence of reshaping the outpatient service, virtual clinics enabled the development of a "rapid access" clinic for patients, ensuring the necessary care could be provided in the appropriate timescale to support patient care. Both NHS Highland and NHS Tayside again highlighted the need for good, robust administrative support for this service model to be effective.

Shared Care Protocol for Medicine Management
The Project highlighted that NHS Lothian has developed and put in place a medicine monitoring service, based on an agreement between Primary and Secondary care for the prescription and administration of azathioprine/6 mercaptopurine and methotrexate locally, for example. This service means that patients receive their medication from their local surgery instead of having to go into Secondary care. Similarly, NHS Greater Glasgow and Clyde has shared care Enhanced Service protocols for azathioprine/6 mercaptopurine, methotrexate, sulphasalazine, aminosalicylates to enable monitoring and prescribing in Primary care under the direction of the Secondary care consultant.

NHS Tayside – IBD Service Redesign. DO IT Programme

1

THE PROBLEM

Unresponsive

Clinics overbooked

Helpline not resourced

Staff under pressure

2

WHAT DID WE WANT TO ACHIEVE?

Responsive service

Give appropriate time to patients

Be more proactive

3

THE SOLUTION

Telephone clinic for those with stable disease

Planned helpline service

4

RESULTS – PHYSICAL CLINIC

Reduced overbooking

Longer appointment times

Protected space for urgent review

Reduced number of patients coming to clinic by 30%

5

RESULTS – TELEPHONE CLINIC

Four telephone clinics per week

Resource available for sustainability

Urgent or return appointments available at medical clinic

Selection criteria and pathways are workings

6

RESULTS – IBD HELPLINE

Planned organised work

Administration support

Appointments for patients

Work captured on shared drive – audit data

7

RESULTS –PATIENT EXPERIENCE

Alternative pathway for stable patients to be reviewed

Responsive service

Less waiting time at clinic

Longer with consultant at clinic

8

RESULTS –STAFF EXPERIENCE

Dedicated sessions for IBD advice calls

Full time IBD nurse to lead the service

Administration support

Time out to reassess service provision

Less pressure

Standard C – Maintaining a Patient – Centred Service

Patient centred care should be responsive to individual needs and offer a choice of care strategies where possible and appropriate.

> "As I live on an island I had to fly to Aberdeen for scans and treatment. In 1 week I had an MRI scan and a bone scan. Both on a different day, so I had to take 2 days off work and the NHS had to pay for 2 sets of return flights. Neither department would change the date of my scan to prevent this from happening."
>
> **Patient**

What we did – Evidence of Improvement

Patient Centred Care
NHS Highland and NHS Greater Glasgow and Clyde using the co-design approach for mapping the patient journey identified the care strategies available for patients and the opportunities for improvement. These included dedicated IBD clinics and Nurse led clinics including telephone and email contact options, and follow up options ranging from a telephone helpline, to video, telephone, and face to face clinics.

The rollout of these and future innovative IT solutions will provide a model to support patient initiated review and supported self management and lead to a more comprehensive and patient centred IBD service.

Standard D states– Patient Education and Support

IBD care should empower patients to understand their condition and its management. This will allow them to achieve the best quality of life possible within the constraints of their IBD.

> "For people with IBD, even a trip to the shops can be a challenging experience; so to be able to remove that stress altogether will, I believe, have a positive impact on the lives of so many of our patients."
>
> **Clinician**

What we did – Evidence of Improvement

Providing Patient Information
The pilots identified the stages during a patient's diagnosis and care where information and support and knowing the services which are available to them, was fundamental to understanding the condition and it's management e.g. patients provided with a Crohn's and Colitis UK Newly Diagnosed Information pack on diagnosis.

Both NHS Highland and NHS Greater Glasgow and Clyde alongside Crohn's and Colitis UK, supported IBD Service Open Days for patients in their area. This enabled patients to get a greater understanding of their condition and an opportunity for the clinical team to reflect on their service model and gain feedback from patients. Patients and their families, really valued meeting their IBD teams in these meetings.

Local Crohn's and Colitis UK group meetings and the organisation's website, Facebook pages and accredited publications help patients to build and develop an understanding of their condition and how to support themselves. Patients in the pilots acknowledged the role of Crohn's and Colitis UK as a key partner in this process.

> "As someone who lives with IBD, having easy access to reliable information makes a huge difference. Not just to my physical health, but to my career, my family and my overall wellbeing."
>
> **Patient**

Supported Self Management
Through a process of co-design with patients, clinicians and Crohn's and Colitis UK, NHS Highland utilised the patient mapping process to identify the tools required to support patients to self manage their condition. This led to the development of a Toolkit for future development and use.

Standard E – Data, Information Technology and Audit

An IBD service that uses data, IT and audit to support patient care effectively and to optimise clinical management.

What we did – Evidence of Improvement

Use of IT

During the course of the Project the use of e-health initiatives has emerged as a valuable and innovative tool to transform care, with a Scotland-wide IBD IT Strategy emerging that meets the Scottish Governments eHealth strategic direction. Examples from the pilots include the following:

Remote Outpatient Care (ROC)[20] created by NHS Highland with support from Crohn's and Colitis UK, is a proven solution for supporting patients with IBD (and other chronic conditions) at home. In addition, it can provide information to carers, sign post to community support and provides hospital MDT meetings with up-to-date, accurate patient information. The service is provided for patients in NHS Highland and NHS Tayside.

- This IT development offers a patient facing app which delivers accredited and vetted information and collects symptoms and holistic needs from patients. It also offers optional two-way online, tracked communication with clinicians.
- For clinicians there is a comprehensive dashboard with rule-based alerts, patient information graphs and tables and treatment summary completion. The system can also provide reports and statistics for management and quality indicators. ROC integrates with core systems in Scotland, including Docman, SCI Store and TrakCare.

"It helps me keep track of flares, symptoms and to see what causes them."

IBD App

The IBD Patient Portal is an interactive website to help support people with IBD. The website provides secure access to blood tests, clinic letters and IBD records direct from the hospital computer system.

"I have been very impressed with the entire site, it has been invaluable to me, I have used it often to help resolve minor flare–ups which I would normally have had to go to the GP for medical advice. This site has given me confidence in being able to deal with minor problems and being able to access all my test results at a glance. It has often allayed any worries I may have had."

Patient – My IBD Portal

The IBD Registry is creating a UK-wide database of anonymised IBD adult and paediatric patient data for prospective audit, quality improvement and research purposes. The Registry aims to combine the IBD dataset with routinely collected NHS data to drive continuous improvement in patient care, to inform service design, and to increase understanding of real-world outcomes. The Registry has developed local and web-based IBD data collection systems for hospitals, but can receive IBD data from any Electronic Patient Record system. The Scottish IBD clinical community is wholly committed to participation in the project, and the Registry team is coordinating with eDRIS and the various IBD developments in Scotland to ensure interoperability.

20. Recipient of the Scottish Enterprise Innovation Award

Standard F – Evidence–Based Practice and Research

A service that is knowledge–based and actively supports service improvement and clinical research

What we did – Evidence of Improvement

The Project highlighted that Scotland has a strong background in producing high quality research into IBD with healthcare teams across the region working collegiately to recruit patients into a variety of clinical trials. This research is valued by people with IBD who are both seeking answers about the cause of the disease and hoping for new treatments. People with IBD welcome innovations in care. For Scotland to continue to contribute to high value research and innovation for the benefit of patients, adequate time and resources need to be built into healthcare workers' job plans.

> "Scotland has an enviable record in producing high quality research in Inflammatory Bowel Disease. I fully support the continued drive to understand the disease and to find new ways in treating it. The Scottish Government will continue to support research structures to help recruit patients with IBD into clinical trials to meet these aims"

Professor Andrew Morris
FRSE FMedSci
Professor of Medicine
Director of the Usher Institute of Population Health Sciences and Informatics

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IMPLEMENTING THE BLUEPRINT

Continuing to work collaboratively the IBD Community will:

TASK

- Look at national provision of IBD Nurse Specialist Care (level of specialist nurse resource and the role of IBD nurses currently). Develop consensus recommendations for the role and job structure of IBD nurses in IBD services.
- Develop shared care protocol between Secondary and Primary care.
- Develop national IBD clinical guidelines and decision tools for use in Primary care which improve referral and investigation practice.
- Testing and feasibility of delivering national community based faecal calprotectin testing. (DO IT Gastro Collaboration- IBS Pathway Working Group).
- Improve inter-consultant referrals process to ensure timely advice and treatment from other specialties.
- Develop protocols for access to dietitians throughout a patient's journey.
- Age appropriate paediatric care.
- Uniform access to testing for Clostridium difficile in children of all ages with IBD.
- National development of shared care protocols with Primary care in relation to review of patients with particular reference to Annual Review, on-going prescribing and monitoring.
- Development of Scotland wide supported self management tools for patients.
- Develop and implement IBD IT Strategy.
- Explore opportunities to support a national approach to IT development in IBD care, building a "Once for Scotland" approach.
- Reach a consensus around a minimum data set for Scottish IBD patients.
- The continued planned National and Regional events will ensure sharing, learning, adoption and spread of best practice in IBD care across Scotland.

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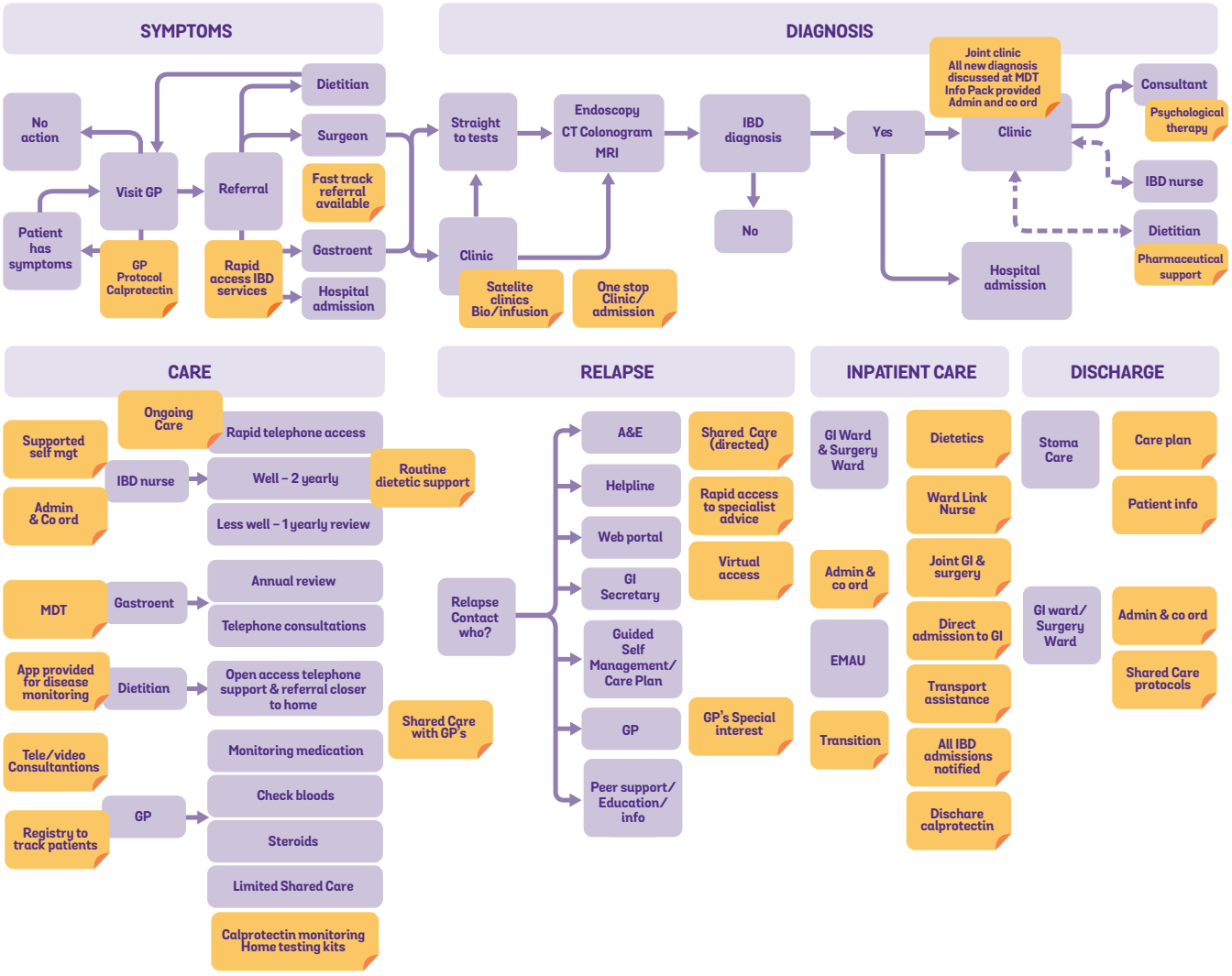
APPENDICES

Appendix 1

Example of Patient Journey Mapping



Appendix 2

Psychological Models NHS Highland:
The purpose of this project was to examine if Mindfulness-Based Cognitive Therapy (MBCT) can help improve depression, anxiety and overall quality of life for patients with IBD.

A high percentage of patients with IBD report depression and anxiety and require psychological support. MBCT is an evidence-based eight week psychological therapy designed to help manage depression and anxiety symptoms. MBCT is a recommended therapy by the National Institute for Health and Care excellence (NICE) guidelines for patients with re-current depression and chronic worry. Although patients with other chronic conditions such as cardiac, fatigue or Parkinson's disease found MBCT useful, its usefulness in IBD has remained untested until this project.

A total of 44 participants were recruited and allocated to two groups: MBCT group and control (22 each). The preliminary analysis showed improvement of all measured outcomes: depression, anxiety, disease activity, quality of life and mindful attention in the MBCT group. When asked about their experience of the MBCT program, participants reported they found the MBCT program useful and beneficial and they would recommend it to other patients with IBD.

Because this was a small scale project, a larger scale study is needed to be able to verify and generalise the findings. Therefore, the recommendation of this project is for a further larger study testing the effectiveness of MBCT in IBD to be conducted.

NHS Greater Glasgow and Clyde

Personal Outcomes Approach in IBD Care
Original Model of Care:
Patients with IBD were seen in clinic and referred by the IBD Nurses to Clinical Psychologists for care as necessary.

Personal Outcomes Approach:
NHS Education for Scotland (NES) supported the programme for the Clinical Psychologist to receive Train the Trainer training to enable her to provide a Developing Practice course to a cohort of nursing staff from mixed clinical areas. This included IBD nurses.

The Developing Practice course (Level 2 on the Stepped Care Model) is of a six month duration for specialist nurses and doctors. It provides training to Level Two Psychosocial Skills which includes:

- Assessment skills and basic psychological intervention.
- Development of skills including communication, listening and systems i.e. who is important to the patient and what is the impact on them.
- Adjustment, depression, suicide.
- Range of social/psychological tools available.
- Concerns Checklist.

The course is run on a combined workshop, homework and reflective practice model and is multidisciplinary. This latter point was felt to be particularly helpful.

This approach has produced the following recognised benefits in providing care to IBD patients:

- Increased the capacity of the IBD nurses to provide greater psychosocial intervention and support to patients at nurse led clinics which has delivered positive patient outcomes.
- Enabled the clinical psychologist to provide an increased input for patients for those with a higher level of need.
- Encouraged and enabled a greater amount of joint working between clinical teams.

Additional factors in the delivery of the model include:

- Ensuring that patients understand the boundaries of the service being offered by the IBD nurses.
- Practice support for the nurses is currently provided (unfunded) by the clinical psychologist. This is on an ad hoc basis currently and is key to the model by providing continuity and support from the initial training period.

APPENDICES – CONT.

Appendix 3

Resources and Tools Available

- Examples of psychological intervention options e.g. NHS Greater Glasgow and Clyde and NHS Highland examples. **Appendix 2**
- Telephone Clinics - **www.fons.org/**
- Medicine Management – Lothian Joint Formulary – Shared Care Protocols **www.ljf.scot.nhs.uk/SharedCareofMedicines/Pages/default.aspx**
- Crohn's and Colitis UK **www.crohnsandcolitis.org.uk/support**
- Scottish Society of Gastroenterology (SSG) **www.thessg.org/**
- IBD Scotland **www.ibdscotland.org/**

Appendix 4

References

A. CMO Annual Report 2014-2015. **www.gov.scot/Resource/0049/00492520.pdf**

B. Better Health Better Care, Hospital Services for Young People in Scotland which sets out the guidance on age appropriate care for young people and transition. **www.gov.scot/Publications/2009/05/07130749/0**

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