Crohn’s and Colitis UK welcomes the opportunity to contribute to the Committee’s inquiry into Technology and Innovation in the NHS. 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.

In 2016, in partnership with the Scottish Government Crohn’s and Colitis UK published “Scotland Leading the Way: A National Blueprint for Inflammatory Bowel Disease in Scotland”. Building on existing policy drivers including the Scottish Government’s 2020 Vision for Health and Social Care, the National Clinical Strategy for Scotland and the eHealth Strategy 2014-2017- the Blueprint provides a route map to achieving the following aims for people in Scotland living with IBD:

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

Crohn’s and Colitis UK supports 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 and we believe that these principles should be central to the development of technology and innovation in health and care services.

Rather than addressing the high level questions and the successes and failures of the existing eHealth strategy, this response will focus on the particular needs of the 26,000 people in Scotland living with IBD (where the prevalence of these conditions is the highest in the UK) and the particular role technology and innovation can play in supporting them to live well with these fluctuating and often life-limiting conditions.

We would highlight the fact that use of technology and innovation may be particularly pertinent to people with IBD. This cohort of patients tends to be younger than those affected by some other prevalent long term conditions. Many are in full time education or work and find traditional clinical models which involve travel to hospitals for outpatient appointments costly and inconvenient. Therefore, the introduction and dissemination of new technologies including telephone and video consultations, apps and patient portals, clearly fits with the Scottish Government’s policy ambitions set out in The Modern Outpatient: A Collaborative Approach 2017-2020.

We have provided answers to questions 3-7.
3. How well does the Scottish Government’s draft Digital Health and Social Care Vision 2017-2022 address the future requirements of the NHS and social care sector?

Crohn’s and Colitis UK supports the principles behind the new Digital Health and Social Care Vision 2017-2022 and the aspirations it describes.

We would particularly support the aspiration of “Moving from organisational-centred developments and architecture to placing the citizen at the centre” as this approach is necessary to create person-centred services and support successful self management. We would further suggest that technological development should always, where possible, explicitly embed co-production and co-design approaches.

These approaches were absolutely central to the Scottish IBD Service Development Project (2013-2016) which led to the development of the Scottish IBD Blueprint. Pilots in NHS Highland and NHS Greater Glasgow and Clyde used a co-design approach to map the patient journey and identify opportunities for improvement. This led to the development of workflows and innovations including telephone and email contact options, telephone helplines, video and telephone clinics and new IT solutions.

“Making better use of data - both health & social care and citizen-generated - for decision support, service delivery, planning and research” would also be key to supporting people with IBD to be as healthy as possible, managing the ups and downs of these fluctuating and often unpredictable conditions.

A frequently expressed view among specialist gastro consultants and IBD nurses is that data on IBD patients collected in the NHS is suboptimal. This hampers the quality of care and ability to provide a responsive service. This is often as basic as not knowing the number of people living with IBD in a particular Health Board. There is no diagnosis coding in outpatient services where most people with IBD receive their care. We have no idea how many people with IBD seek out of hours care in Scotland.

The IBD Registry is creating a UK-wide database of anonymised adult and paediatric data for prospective audit, quality improvement and research. The Registry aims to combine the IBD dataset with routinely collected NHS data to drive improvement, inform service design and increase understanding of outcomes.

The Registry has developed local and web-based IBD data collection systems but can receive data from any electronic patient management system. The Scottish IBD community is committed to the Registry project, but cannot currently transfer data from Scotland to the Registry as there is continuing work being done to ensure compliance with the relevant information governance issues.

As part of the DO IT (Delivering Outpatient Integration Together) programme, now continuing under the banner of the Modern Outpatient programme, an IBD working group has developed a minimum IBD dataset to be used with TrakCare, the nationally procured patient management system. TrakCare is an electronic patient record which includes outpatient and inpatient appointments, but does not offer patient access or support for self management. Work to develop the minimum dataset for IBD, including diagnosis codes for TrakCare continues under the Modern Outpatient Programme.

At the same time, whilst Crohn’s and Colitis UK would also fully support both the following aspirations: “Foster a fertile environment for innovation and economic growth” and; “Build on what we have, and spreading what works” we would also caution that these two aspirations can, to some extent contradict one another.
For example, the charity and the wider IBD community have experienced some difficulties (described in more detail later in the response) getting new IT solutions implemented in Health Boards and although we fully support the fertile environment for innovation fostered by the Open Innovation Collaboration approach we recognise that it can be a number of years before ‘winning’ innovations are fully developed and available to patients and clinicians whilst existing, tried and tested solutions remain ‘on the shelf’ rather than being built upon or spread.

4. Do you think there are any significant omissions in the Scottish Government’s draft Digital Health and Social Care vision 2017-2022?

As alluded to above, in line with the wider Digital Strategy and in line with the response to this inquiry provided by the Health and Social Care Alliance Scotland (the ALLIANCE), we feel that the draft vision requires more explicit commitment to co-production and co-design in order to foster real-world solutions that meet the needs of people living with IBD.

5. What key opportunities exist for the use of technology in health and social care over the next 10 years?

The IBD Patient Portal; “My IBD Portal” is an interactive website to support people with IBD to manage their condition and work in partnership with their IBD clinicians. The website provides secure access to blood tests, clinic letters and records direct from the hospital computer system. Individuals can keep up to date lists of current and previous medications and access trusted and reliable information about managing their condition. The portal also provides the opportunity for people to monitor and chart their symptoms.

This presentation give a quick and simple overview of My IBD Portal: https://prezi.com/owc1gjz_jeqj/a-guide-to-my-ibd-portal/

My IBD Portal is centrally hosted by PatientView and this platform is shared with the renal and heart failure versions of the product. The project is sponsored by Crohn’s and Colitis UK and is being trialled in England at Salford Royal Foundation Trust.

Remote Outpatient Care (ROC) is a proven solution for supporting patients with IBD (and other conditions) at home. It can provide information to carers, signpost to community support and provides multidisciplinary team meetings with up-to-date, accurate patient information.

ROC offers a patient-facing app which delivers accredited and vetted information and collects information about patients’ symptoms and holistic needs. It offers two-way, tracked communication with clinicians.

Clinicians can also benefit from a comprehensive dashboard, with alerts, graphs and tables. The system can also provide reports and statistics for management and quality indicators. ROC integrates with core systems in Scotland including SCI Store and TrakCare.

The patient application is hosted on Microsoft Azure; the dashboard is hosted on Azure or the NHS Board’s own infrastructure. It is currently only available to a number of patients in NHS Highland.
For more information about ROC, see the developer’s website: https://openbrollyroc.com/

Meetings of the Scottish IBD Service Development Steering Group and discussions with Scottish Government eHealth strategic leads in 2014 and 2015 resulted in the development of an IBD IT Strategy for the project. The decision was taken to implement both My IBD Portal and ROC in three Health Boards with a view to evaluating each. The Scottish Government made £20,000 available for this work.

With further support from the Scottish Government an IT Consultant was employed specifically to:

- Lead on the implementation of My IBD Portal and pilot it in three sites in Scotland: Glasgow, NHS Lothian, NHS Forth Valley, in collaboration with the team from Salford Royal Foundation Trust
- Identify and work collaboratively with the key personnel from other eHealth initiatives in Scotland to align the development and implementation of my IBD Portal within the overall Scottish eHealth strategy.
- Liaise with National IBD Registry and my IBD Portal team in Salford to facilitate the alignment of data sets within the portal to create synergy with the UK-wide IBD Registry.

Subsequently, it was discovered that my IBD Portal requires further technical development to make it functional across Scotland. This would cost in the region of £40,000 and the process for rolling out this platform has currently stalled. Subsequently, Crohn’s and Colitis UK would be willing to work together with NHS National Services Scotland to find this shortfall and to help deliver the required development to make the portal work across Scotland, but has been unable to secure buy-in for this approach.

There are currently over 200 users of ROC-IBD in NHS Highland and the team behind its development are pursuing further development via by entering the IBD Small Business Research Initiative (SBRI) Challenge. The Scottish Government, Highlands and Islands Enterprise and NHS Scotland have recently launched this new open innovation competition to support the development of innovative ideas from industry that can be used to improve the delivery of IBD services across Scotland. The aim is to identify ways to enable personalised care, better education and remote monitoring for people living with IBD.

6. What actions are needed to improve the accessibility and sharing of the electronic patient record?

Crohn’s and Colitis UK fully supports the current strategy’s commitment to providing people with online access to their patient record and the continuation of this aim under the new Digital Health and Care Strategy. In order for people with IBD to have access to their IBD record we believe that the key opportunities outlined above and/or other tested and evaluated solutions to make this possible must be explored, further developed and rolled out by the Scottish Government, NHS National Services Scotland and individual Health Boards as a priority.
7. What are the barriers to innovation in health and social care?

There are a number of challenges and barriers to innovation in health and social care, particularly in relation to supporting people with IBD. For example:

- The innovation support landscape can be confusing for innovators (both for third sector organisations and private sector developers). Innovators do not always know where and how to apply for funding and support.

- Processes such as the Small Business Research Initiative (SBRI) stimulate competition and allow companies to tender on the basis of offering promising solutions to a specific problem, but they also mean the applicants are on a steep learning curve to understand the particular problem and the complexities of a particular condition or health professionals’ job roles within a short timeframe. It can be difficult for them to make contact with end users to instigate and continue with an effective co-design process within the boundaries of such a competition.

Applicants can invest a great deal of time and money into developing solutions that are not taken up whilst other previously developed solutions are not taken up because they are not seen as innovative. At the same time there is no scope within such a process for these existing technical solutions that could potentially be built upon, to be ‘seen’ by innovators and decision makers. Companies that have already developed products have to do further work and invest in making new applications to such competitions with no guarantee of success at the end of the process.

- There are challenges to introducing innovations and rolling them out across Health boards and services as outlined above. The confusing landscape means that third sector organisations such as Crohn’s and Colitis UK and clinicians may struggle to make contact with the ‘right’ people in Government and the NHS in order to progress IT solutions or to fully understand some of the technical barriers to introducing an innovation. There is sometimes a lack of awareness or understanding of strategic eHealth policy at service level and a lack of capacity to prioritise technical innovation within an already overstretched NHS.

The specific issue of trying to implement My IBD Portal in Scotland is an example of where blocks in communication, issues with leadership and lack of continuity or technical support have hindered the progress of an innovation that is essentially ready and waiting to be trialled and to benefit people living with IBD in Scotland.

- A cultural shift may be required in secondary care to expect gastro consultants and specialist IBD nurses to get to grips with and begin to enter data to patient management systems during consultations. Time with each patient is already limited and equal importance must be placed on the quality of the interaction and relationship between patient and professional as well as on the effective use of data to support people to manage their IBD and live well in the community.
ABOUT 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).

Established in 1979, the charity’s services include four helplines, a wide range of accredited information sheets and booklets and a nationwide network of locally-based volunteer groups, including one in Northern Ireland. The charity raises awareness of these little known and understood conditions, campaigns for improved services and care for people with IBD, funds vital research and seeks to influence policy to ensure that it reflects and meets the needs of people living with IBD.

ABOUT INFLAMMATORY BOWEL DISEASE

At least 300,000 people or 1 in 210 people in the UK have Crohn’s Disease or Ulcerative Colitis, collectively known as Inflammatory Bowel Disease (IBD). IBD is a lifelong condition that most commonly first presents in the teens and early twenties (mean age of diagnosis is 29.5 years).

In IBD the intestines become swollen, ulcerated and inflamed. Symptoms include acute abdominal pain, weight loss, diarrhoea (sometimes with blood and mucus), tenesmus (constant urge to have a bowel movement), and severe fatigue.

Symptoms vary in severity from person to person and from time to time and relapses often occur suddenly and unpredictably throughout a person’s lifetime. Between 50% and 70% of patients with Crohn’s Disease will undergo surgery within five years of diagnosis. In Ulcerative Colitis, lifetime surgery rates are approximately 20-30%.

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.