Cafodd yr ymateb hwn ei gyflwyno i ymgynghoriad y Pwyllgor Iechyd a Gofal Cymdeithasol ar Flaenoriaethau'r Chweched Senedd

This response was submitted to the Health and Social Care Committee consultation on Sixth Senedd Priorities

HSC PSS 34

Ymateb gan: | Response from: Crohn's & Colitis UK

Blaenoriaethau cychwynnol a nodwyd gan y Pwyllgor
Initial priorities identified by the Committee

Mae'r Pwyllgor wedi nodi nifer o flaenoriaethau posibl ar gyfer ei waith yn ystod y Chweched Senedd, gan gynnwys: iechyd y cyhoedd a gwaith ataliol; y gweithlu iechyd a gofal cymdeithasol, gan gynnwys diwylliant sefydliadol a lles staff; mynediad at wasanaethau iechyd meddwl; arloesi ar sail tystiolaeth ym maes iechyd a gofal cymdeithasol; cymorth a gwasanaethau i ofalwyr di-dâl; mynediad at wasanaethau adsefydlu i'r rhai sydd wedi cael COVID ac i eraill; a mynediad at wasanaethau ar gyfer cyflyrau cronig tymor hir, gan gynnwys cyflyrau cyhyrysgerbydol.

The Committee has identified several potential priorities for work during the Sixth Senedd, including: public health and prevention; the health and social care workforce, including organisational culture and staff wellbeing; access to mental health services; evidence-based innovation in health and social care; support and services for unpaid carers; access to COVID and non-COVID rehabilitation services; and access to services for long-term chronic conditions, including musculoskeletal conditions.

C1. Pa rai o'r materion uchod ydych chi'n credu y dylai'r Pwyllgor roi blaenoriaeth iddynt, a pham?
Q1. Which of the issues listed above do you think should be a priority, and why?

Crohn's & Colitis UK supports the recent Welsh NHS Confederation call for an increased focus on health inequalities in Wales. Examining such inequalities would provide a focussed overall framework for the work of the Committee during the next session.

Within the overarching framework of health inequalities, Crohn's & Colitis UK would recommend that the Committee consider receiving detailed evidence relating to two specific areas of interest highlighted in advance, that is *evidence-based innovation in health care* alongside *access to services for people with long-term conditions* as there are significant potential linkages between these two areas.

Crohn's & Colitis UK recommend that the Committee consider Inflammatory Bowel Disease (IBD) as one specific long term condition area which could be examined in detail.

There are increasing opportunities for harnessing technological developments for remote patient access and condition monitoring to assist the NHS cope with the increasing demand from people with a range of long-term conditions. Used correctly, such innovations have the potential to reduce demand on secondary care and provide a more personalised experience of care closer to home, all of which are identified priorities within current Governmental policy.

Increased exposure to both remote access and monitoring of health care during the continuing Covid pandemic has advanced patient and clinician experience and acceptance of this type of care. Whilst not suitable for all people, remote access and monitoring of people's Crohn's and Colitis would assist their ability to manage both the condition itself and, importantly, their wider personal lives, employment, education, etc.

Crohn's and Colitis – the two forms of Inflammatory Bowel Disease – are lifelong diseases of the gut. They are painful, debilitating and widely misunderstood. There is no known cure. When you have Crohn's or Colitis, your immune system doesn't work properly. Your body starts attacking itself, causing ulcers and inflammation in the gut leading to pain and urgent diarrhoea. Crohn's and Colitis don't just affect your gut. They can affect almost every part of your body and every aspect of your life: from your digestion and joints to your energy levels and mental health. People living with the conditions often face a lifetime of medication and, in many cases, major surgery. If left untreated, they can be fatal.

An analysis of Welsh Primary Care records by the SAIL Databank in 2020 revealed that there are over 50% more people in Wales with these conditions than previously thought with over 24,000 people with Inflammatory Bowel Disease known to GPs in Wales. That is approaching 1 in every 100 people or around 600 people in every Member's constituency - and the numbers are increasing.

Inflammatory Bowel Disease, like some other long-term conditions, fluctuates in severity over time, with periods when the person is feeling relatively well and other periods when they become acutely ill (referred to as a ''flare'') and rapid access to clinical services may be required.

The cost of managing IBD is 6x higher when a patient's condition is flaring than when it is stable and in remission. In addition, a 2019 UK-wide study revealed that 72% of all hospital admissions for people with IBD were unplanned emergencies.

Given the life-long nature of Crohn's and colitis and the relatively early mean age of diagnosis, 28 years of age, people with these conditions will have prolonged contact with NHS services in Wales with the associated cumulative costs of such extended periods of treatment.

Currently the care of people with Crohn's and colitis is focussed largely within hospital-based secondary care settings and is often co-ordinated through the traditional 6 monthly outpatient review system. This traditional service model can mean that busy outpatient clinics may consist of many patients who are well at the time of the appointment and do not need to be at the clinic,

whilst people who need to be seen due to a flare-up of their condition find it difficult to access space appointments at the clinic.

Whilst all Health Boards operate IBD services, the structure and staffing of these services vary noticeably across Wales. The 2021 IBD UK Report "Crohn's and Colitis Care in the UK: The Hidden Cost and a Vision for Change" highlighted considerable variation in patient outcomes between services here in Wales and those elsewhere in the UK even prior to the additional difficulties Covid has brought.

68% of patients in Wales waited more than the recommended 4 weeks for their appropriate investigative tests compared to 29% in Scotland, with 11% waiting over 6 months

Only 46% of patients in Wales reported their elective (non-emergency) IBD surgery as having occurred within the recommended 18 weeks – the figure was 86% in Northern Ireland

Services in Wales were the least likely across the UK to report their being an established referral pathway between Primary and Secondary care. Only marginally above half of services (54%) said that such a pathway existed here, compared to approaching three quarters (71%) of services in Scotland

Potential Outcomes

There are a number of issues which the Committee could investigate which could have practical and positive outcomes for the above situation:

1) The Committee could examine whether differences in existing service structure and service levels in Health Boards across Wales lead to service inequalities.

IBD UK National Report – "Crohn's and Colitis Care in the UK:
The Hidden Cost and a Vision for Change" report published in 2021 indicated clearly, that the provision of care through a multi-disciplinary team approach delivered the optimal care from both a patient and clinical perspective.

No service in Wales currently meets the agreed IBD Standard for multi-disciplinary teams with, for example, no IBD service in Wales having dedicated dietetic support; no service having psychological support; no service meeting recommended IBD nurse numbers; etc

The newly appointed IBD Wales Clinical Lead, Dr Barney Hawthorne, has recently completed a baseline audit, including staffing levels, of all IBD services across Wales which would be available to the Committee

2) The Committee could examine whether the establishment of a national "service innovation fund" or similar could provide a method whereby new working practices could be funded whilst being trialled. Such innovative programmes will need to be run alongside existing services during their pilot

phase and hence Health Boards face the issue of ''double funding'' for a period.

Stakeholders

There is a considerable range of data, evidence, and Stakeholders already available to the Committee to help any such enquiry. These include:

IBD UK National Report – Crohn's and Colitis Care in the UK: The Hidden Cost and a Vision for Change
IBD Service Benchmarking Reports from 11 of the 16 Welsh Hospitals 2020 illustrating significant service differentials
IBD UK Patient Survey IBD UK 2020
Dr Barney Hawthorne, NHS Clinical Lead for IBD in Wales – recently completed a service baseline audit of all IBD services in Wales
Inflammatory Bowel Disease in Numbers: Understanding the Scale of Crohn's and Colitis in Wales. Feb 2020. SAIL databank.
IBD Wales: Multi stakeholder group made up of gastroenterologists, IBD Nurses, Surgeons, GPs, people with Crohn's and colitis, etc
The Association of Coloproctology of Great Britain and Northern Ireland
IBD UK. Multi-stakeholder group representing BDA, BSG, RCN, RCGP, etc
People with Crohn's and colitis

Methods of Addressing Issues

The Committee might undertake a time limited Enquiry or similar into agreed issues, with the NHS IBD Clinical Lead and other clinicians being asked to provide evidence of current services and related issues.

Evidence of 'Lived Experience' is readily available from people with long-term conditions such as IBD which can be presented to the Committee in person.

Evidence from across the UK of other service structures and methods would be available through the IBD UK Network and Crohn's & Colitis UK.
Clinicians with an interest in IBD who work in other parts of the UK could be invited to provide evidence to the Committee. Mutual support within the IBD clinical community is very strong and a positive level of engagement could be expected
Existing reports can be analysed (see above)

Timing

The IBD Clinical Lead, Dr Barney Hawthorne, is finalising his report into baseline service data of all IBD services across Wales. This should be completed by October 2021

All other data and evidence mentioned above is currently available and hence this work could commence as soon as the Committee was ready

Blaenoriaethau allweddol ar gyfer y Chweched Senedd
Key priorities for the Sixth Senedd

C2. Yn eich barn chi, pa flaenoriaethau allweddol eraill y dylai'r Pwyllgor eu hystyried yn ystod y Chweched Senedd mewn perthynas â:

a) gwasanaethau iechyd;

b) gofal cymdeithasol a gofalwyr;

c) adfer yn dilyn COVID?

Q2. In your view, what other key priorities should the Committee consider during the Sixth Senedd in relation to:

a) health services;

b) social care and carers;

c) COVID recovery?

Gwasanaethau iechyd
Health services

Viewing this question from the patient's perspective, additional priorities which the Committee could examine would include;

1) The Committee could examine how improved surgical coding and data collection which would benefit Quality Improvement exercises in the field of surgery within the NHS, particularly in relation to Inflammatory Bowel Disease.

1.1) The issue of coding within secondary care is an issue which hinders attempts at quality improvement due to the inaccuracy of significant portions of current data. For example, when surgical colleagues were shown data obtained from NWIS in 2019 indicating the officially recorded 'Top 15 procedures carried out on patients with Crohn's and Colitis', this was regarded as significantly inaccurate and of no use for planning or QI. One surgeon stated that he alone was likely to have carried out more of a particular surgical procedure than had been recorded for the whole of Wales in the PEDW data set.

1.2) The Committee could look at centrally recorded data for IBD-related surgery and examine the processes, including the current administrative process, through which procedures are recorded within a Health Board, assisted by surgeons and clinicians who carry out those procedures.

1.3) This aspect of any enquiry would mirror the aims of 'Prudent Health Care' and subsequent Welsh Government priorities for the NHS in Wales.

2) The Committee could consider the IT systems within secondary care in NHS Wales. Few, if any, Health Boards currently operate an IT system which allows

their clinicians even to generate a current and accurate register of all patients with Inflammatory Bowel Disease, a situation which will significantly hamper effective planning and service provision both at a service and strategic, Health Board level.

2.1) In advance of the first ever IBD-specific meeting of all Health Boards in 2019, no Health Board was able to provide details of the number of patients with IBD who lived in their area. All numbers provided were estimates based on the existing supposed prevalence rate of 1:250. The more recent primary care data cited elsewhere in this submission gives a prevalence rate of around 1:117. This suggests that whatever planning of IBD services that was taking place within Health Boards, was likely to seriously underestimate the number of people who would potentially be accessing IBD services in any given area.

3) Given the increasing demands on the NHS in Wales, the Committee could consider the further development of the 'self-management' ethos and resources within selected long-term conditions, including IBD. Increased focus on, and provision for, self-management would enable patients to assume greater control over their conditions and, importantly from a patient perspective, the effect that condition has on their wider life – relationships, work, education, social activity, travel etc

Adfer yn dilyn COVID
COVID recovery

Crohn's & Colitis UK offer no extensive comment on this issue as the Committee will, no doubt, be fully aware of many of the issues related to Covid recovery within the NHS which are often common across condition areas.

However, we would draw the Committee's attention to the issues mentioned earlier in this submission concerning diagnostic tests and surgery. These delays will have inevitably lengthened and will likely result in even further reduced health outcomes in the long term unless these matters are addressed and with some urgency.

68% of patients in Wales waited more than the recommended 4 weeks for their appropriate investigative tests compared to 29% in Scotland, with 11% waiting over 6 months

Only 46% of patients in Wales reported their elective (non-emergency) IBD surgery as having occurred within the recommended 18 weeks – the figure was 86% in Northern Ireland

Finally, we would draw the Committee's attention to the positive effect which increased focus on, and resources directed towards, patient self-management, including very practical issues such as remote access and condition monitoring, might play in dealing with demand levels within the NHS by enabling patients to play a greater role in managing their condition and hence their wider social, employment, educational and family lives.