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Ymchwiliad i'r Adolygiad Blaenoriaethau ar gyfer y Pwyllgor Iechyd, Gofal
Cymdeithasol a Chwaraeon

Inquiry into the Priorities for the Health, Social Care and Sport Committee

Ymateb gan: Crohn's and Colitis UK

Response from: Crohn's and Colitis UK

Priorities for the Health, Social Care and Sport Committee

Consultation response from Crohn's and Colitis UK - September 2016

CONTACT:

xxxx, Social Policy and Public Affairs Officer

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Crohn's and Colitis UK

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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). **It is estimated that over 15,000 people are living with this chronic disease in Wales.** 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%.

Key facts about IBD:

- It's an invisible condition causing inflammation and ulceration of the bowel.
- It's a lifelong, incurable condition.
- It affects people of all ages, but commonly presents in the teens and twenties
- It fluctuates - people experience unpredictable flare-ups and remission during their life.
- It can have a devastating effect on quality of life, impacting work, education & social activity.
- Access to toilets is imperative due to urgent and frequent diarrhoea.
- **Prevalence is twice as high as for Parkinson's and Multiple Sclerosis with lifetime medical costs comparable to other major diseases such as diabetes and cancer (estimated at £900m per annum UK wide).**
- There is low awareness of IBD and it is both under-recognised and under-prioritised.

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. 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.

IBD IN WALES

People with Inflammatory Bowel Disease use and rely on gastroenterological services in Wales, with the condition primarily managed in secondary care. While standards of treatment and care for people with Crohn's Disease and Ulcerative Colitis in Wales have improved in recent years, they still fall behind the average for the rest of the UK.

Findings from the UK IBD Audit have found considerable variation between individual hospitals in the extent to which they meet the UK IBD Standards, which define what good care looks like. A number of these key findings echo the results of a patient survey of IBD services in Wales undertaken by Crohn's and Colitis UK between May and June 2015.

WHAT DO PATIENTS THINK ABOUT IBD SERVICES IN WALES?

Key survey findings

A survey of IBD patients in Wales by Crohn's and Colitis in April 2015 with 447 responses found:

- 20% of respondents were unsatisfied with their care;
- 42% did not have access to an specialist IBD Nurse;
- 26% were not having an annual review; and
- 38% were off work for more than 4 weeks.

A survey of IBD patients in Wales by Crohn's and Colitis in April 2016 found that:

- 38% of people said that they did not have access to an IBD Nurse specialist compared to 33% in Scotland and 30% in England.

WAITING TIMES - ENDOSCOPY

NHS Wales currently has a range of waiting time targets including patient access to inpatient, outpatient and day case treatment or appointments; diagnostic and therapy services; cancer treatment; and mental health services.

There are pressure areas where waiting times remain high, such as in diagnostic and therapy services and certain specialties such as orthopaedics. The Committee could examine the issue of waiting times and scrutinise the Welsh Government's plans to tackle areas of pressure in more detail.

Crohn's and Colitis UK would suggest that consideration is given within the scope of any waiting times scrutiny to include elective surgery waiting times for conditions such as IBD requiring colorectal surgical procedures currently lying outwith the current range of targets.

Our understanding is that this may be a particular issue in large Tertiary Centres offering specialist surgical procedures as priority is given to those with targets attached, resulting in often unacceptably lengthy waits for non cancer patients such as those living with IBD.

Crohn's and Colitis UK would be very supportive of an investigation into waiting times in the NHS as we are extremely concerned about the historical long waiting times for endoscopies in Wales.

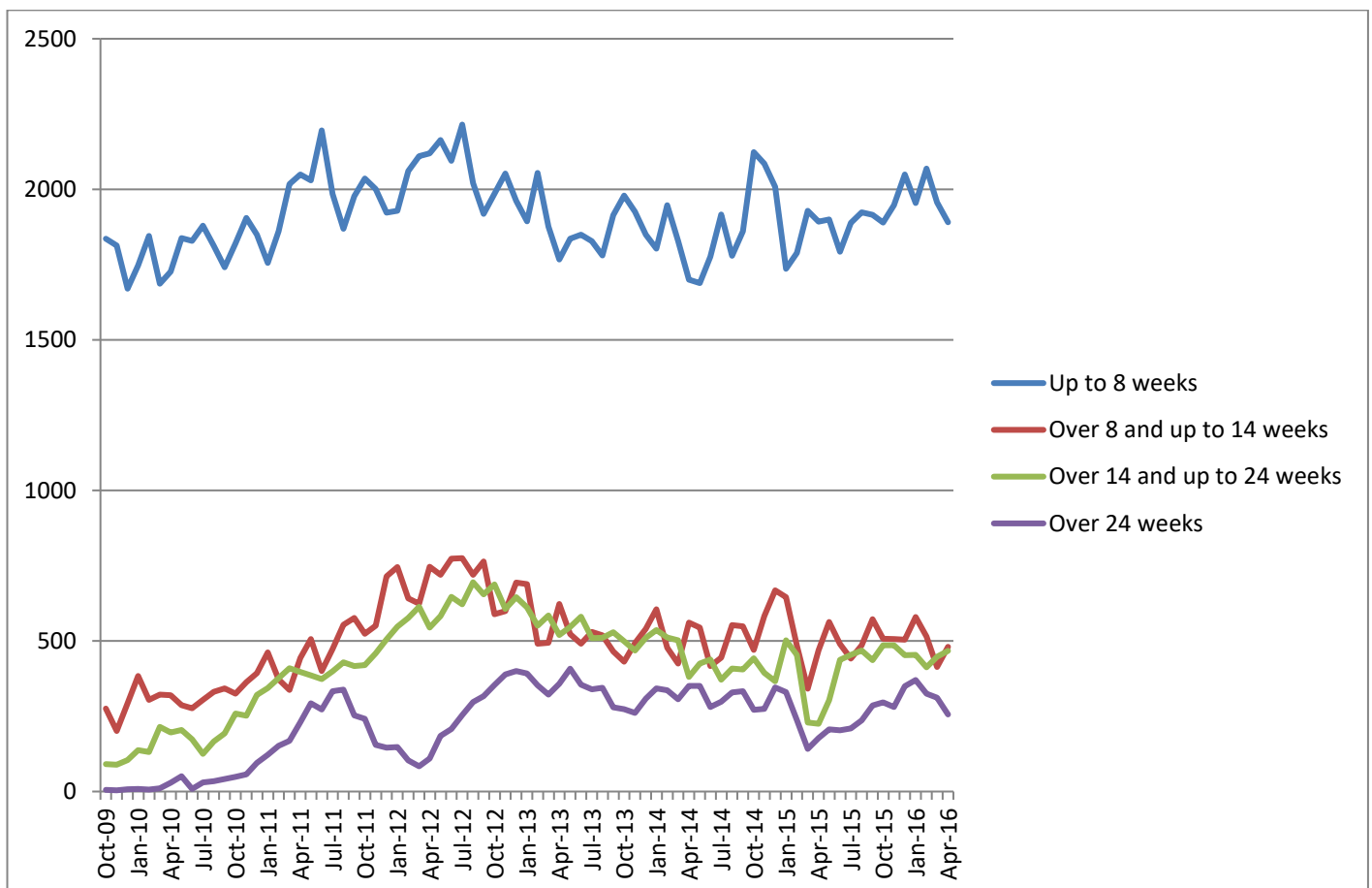
In the majority of cases, IBD can't be diagnosed until a colonoscopy has taken place, therefore receiving a timely colonoscopy ensures that patients can be diagnosed promptly and receive the correct treatment and healthcare that they need. Colonoscopies are also critical in surveillance monitoring of bowel cancer and dysplasia as those with IBD, are at a higher risk as there is an established link between IBD and an increased risk of developing colorectal cancer.

From the Government's own figures, it shows that waiting times for endoscopies has significantly increased across Wales particularly for those waiting beyond 14 weeks:

- Number of patients waiting between **8-14 weeks** has increased from 276 in October 2009 to 481 in April 2016. **This is an increase of 74%.**
- Number of patients waiting between **14-24 weeks** has increased from 91 in October 2009 to 467 in April 2016. **This is an increase of 510%.**
- **Number of patients waiting over 24 weeks has increased from just 5 in October 2009 to 256 in April 2016. This is an increase of 5000%.**

Despite investment in diagnostic services by the Welsh Government, endoscopy waiting times are still far too high and Crohn's and Colitis UK would recommend that the Committee deem this area a priority area for further investigation when looking at waiting times.

COLONOSCOPY WAITING TIMES OCTOBER 2009 - APRIL 2016



Source: Diagnostic and therapy services waiting times, NHS Wales Informatics Service (NWIS)

	Number of Weeks Waiting for Colonoscopy				All
	Up to 8 weeks	Over 8 and up to 14 weeks	Over 14 and up to 24 weeks	Over 24 weeks	
Oct-09	1836	276	91	5	2208
Apr-16	1891	481	467	256	3095

Source: Diagnostic and therapy services waiting times, NHS Wales Informatics Service (NWIS)

These are extremely worrying statistics which is why Crohn's and Colitis UK would like to see the Health, Social Care and Sport Committee look into endoscopy waiting times when investigating NHS waiting times.

PRIMARY CARE

The Welsh Government Strategy Primary Care services for Wales up to March 2018 (February 2015) recognises the growing service demand on the NHS, and primary care in particular, driven by a combination of a population which is living longer, but accompanied by higher levels of chronic long term conditions.

The previous Welsh Government recognised that action is required to move the balance of care and resources - including workforce and funding - out of hospitals into the community so people only go to hospital where this is appropriate. The Welsh Government is committed to developing the role of 'clusters' - groups of GPs, working with other health and care professionals to plan and provide services locally - as a means of transforming primary care.

While Crohn's and Colitis UK broadly welcome initiatives to move the balance and care of resources to Primary Care, the scope of any plans to provide more services locally would need consideration of the needs of patients with long term conditions such as IBD.

IBD is primarily managed in secondary care therefore should more management be undertaken outside the traditional hospital setting, people with IBD would need to be able to access specialist Secondary Care services when their health needs required and often at short notice. Due to the fluctuating nature of IBD, rapid access to specialist services in times of flare up of the disease is essential. This rapid access will often be access to a service, such as specialist nurses who run specialist phone lines, rather than an inpatient appointment.

These needs would require consideration, therefore, in the planning process to be given to the Primary and Secondary Care interface and to the greater use of emerging e health solutions to enable rapid access when required and to assist patients to self manage their own condition as much as possible.