

7th December 2018

Consultation Response:

Health, Social Care & Sport Committee
Endoscopy Service
Coeliac UK – Health Charity

1. Introduction

- 1.1. Coeliac UK welcomes the opportunity to contribute to the committee's inquiry and hope the below information provides useful context with regard the importance of Welsh endoscopy services for the coeliac community.

2. Coeliac disease

- 2.1. Coeliac disease is a lifelong auto-immune disease, affecting around 1 in 100 people (c.30,000 in Wales)¹. It is caused by the immune system reacting to gluten and can lead to a range of symptoms in the short term including bloating, diarrhoea, nausea, wind, constipation, anaemia and severe mouth ulcers. The only treatment is a strict, lifelong gluten free diet. Left untreated coeliac disease can lead to long term associated conditions such as osteoporosis and in some cases small bowel cancer.

3. The challenge of diagnosis and the role of endoscopy

- 3.1. One in 100 people have coeliac disease yet only 29% of these have a diagnosis in Wales. This is lowest of any UK nation².

¹ West et al. (2014) Incidence and Prevalence of Celiac Disease and Dermatitis Herpetiformis in the UK Over Two Decades: Population-Based Study. *Am J Gastroenterol.* May; 109(5): 757–768. <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4012300/>

² West et al. (2018) Changes in the testing for and incidence of coeliac disease in the UK 2005 – 2015 (Abstract at Coeliac UK Research Conference, 2018). www.coeliac.org.uk/abstracts2018

- 3.2. On average it takes 13 years to receive a diagnosis for coeliac disease³ and 1 in 4 diagnosed with coeliac disease have previously been misdiagnosed with Irritable Bowel Syndrome.⁴
 - 3.3. There are an estimated 22,000 people in Wales⁵ with undiagnosed or misdiagnosed coeliac disease, who may be continuing to eat gluten and as a result feeling unwell and running the risk of long term associated conditions. Not only does this pose significant impacts on the health and wellbeing of the individual but it also leads to additional demand on resource from health services.
 - 3.4. In order to secure a diagnosis for coeliac disease there are two steps; an antibody blood test in primary care which, if positive, is followed by an endoscopy with gut biopsy in secondary care.
 - 3.5. The process requires the patient to maintain a gluten containing diet in order for the testing to be effective. Withdrawing gluten from the diet at this stage could lead to inaccurate results and a missed diagnosis.
 - 3.6. Lengthy waiting times between the blood test and endoscopy can not only result in prolonged period of illness for the individual but also risk them withdrawing gluten from their diet or deciding against having endoscopy to confirm diagnosis of coeliac disease, altogether.
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4. NICE Quality Standard on coeliac disease

- 4.1. It is within the above context that NICE Quality Standard (QS134) for coeliac disease was developed in 2016.⁶
- 4.2. It recommends that “People referred to a specialist who need an endoscopic intestinal biopsy to diagnose coeliac disease have it within 6 weeks of referral.”
- 4.3. We welcome the reduction in 8 week breaches in recent years however we are concerned that this 6 week quality standard is likely being missed in a number of cases.
- 4.4. We would therefore ask the committee to scrutinize whether Local Health Boards are meeting the requirement to provide endoscopic intestinal biopsy to confirm a diagnosis of coeliac disease within 6 weeks of referral, in line with the Quality Standard for coeliac disease from 2016.

5. Welsh endoscopy units & JAG accreditation

- 5.1. Endoscopy services are under mounting pressure in Wales and its clear there are a number of challenges to overcome. The Welsh Government committed to all 19 endoscopy units attaining JAG

³ Gray AM & Papanicolaou IN (2010) Impact of symptoms on quality of life before and after diagnosis of coeliac disease: results from a UK population survey. BMC Health Serv Res 10: 105. doi:10.1186/1472-6963-10-105

⁴ Card T et al. (2013) An excess of prior irritable bowel syndrome diagnoses or treatments in Celiac disease: evidence of diagnostic delay. Scand J Gastroenterol. Jul; 48(7):801-7. <https://www.ncbi.nlm.nih.gov/pubmed/23697749>

⁵ West et al. (2018) Changes in the testing for and incidence of coeliac disease in the UK 2005 – 2015 (Abstract at Coeliac UK Research)

⁶ NICE Quality Stand:

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T:02920499732 www.coeliac.org.uk

[idance/qs134](https://www.nice.org.uk/guidance/qs134)

(Joint Advisory Group) accreditation (an independent assessment of endoscopy unit standards)⁷ yet to date only 6 have achieved this standard. Two key barriers have been highlighted in our discussions with health care professionals; outdated clinical environments and waiting times.

- 5.2. Whilst clinical environments can be upgraded at unit level, there is a far more systemic challenge posed by long waiting times and we would ask that the committee examines what action the Welsh Government is undertaking to address drivers such as limited capacity, an ageing population, workforce training and challenges regarding patient travel.

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6. Coeliac UK

- 6.1. Coeliac UK is the national charity for people with coeliac disease and dermatitis herpetiformis (DH), the skin manifestation of coeliac disease, giving them support on healthcare and the gluten free diet. We campaign, research and offer support and advice to people with these conditions and those supporting them. We have over 60,000 Members across the UK and more than 3,000 in Wales.

- Coeliac UK is the national charity for people with coeliac disease –www.coeliac.org.uk