

Grŵp Trawsbleidiol ar Glefydau Seliag a Dermatitis Herpetiformis Cross Party Group on Coeliac Disease & Dermatitis Herpetiformis

Date & time: Nos Fawrth 16 Mehefin 2020 18.00-19.00
Tuesday 16 June 2020, 18.00-19.00
Venue: via Zoom

Dr Dai Lloyd MS –Chair (DL), Heidi Urwin Director of Evidence and Policy, Coeliac UK (HU) standing in for Tristan Humphreys – Secretary/Coeliac UK, Ruth Passmore Head of Health Policy, Coeliac UK (RP)

Attendees: Alison Jones (AJ), Claire Constantinou (CC), Ieuan Davies (ID), Graham Philips (GP), Ian Severn (IS), Jill Swift (JS), Ryland Doyle (RD) (standing in for Mike Hedges MS), Sian Evans (SE), Rhun Ap Iorweth (RAI), Geraint Preest (GP)

No.	Item
1	<p>Apologies for absence:</p> <p>Jenny Pugh-Jones, Mark Isherwood and Mike Hedges</p>
2	<p>Minutes of last meeting</p> <p>a. Amendments and approval of the Minutes</p> <p>The Minutes were approved without amendment.</p> <p>b. Matters arising</p> <p>The letter to Health, Social Care and Sport committee regarding endoscopy services has been delayed and is still to be sent.</p> <p>Hospital food – RP provided an update on Coeliac UK resources for hospital sector catering:</p> <ul style="list-style-type: none"> • Free guidance which was developed with the Food Standards Agency which can be downloaded from the Coeliac UK website • Coeliac UK's training for caterers has recently been updated and is now on a new online platform. There is a specific module for hospital caterers. • Coeliac UK's Gluten free accreditation scheme has been running for several years and the commercial team at Coeliac UK are focusing on public sector catering, following success in the private sector. Currently three hospitals have gained accreditation. RP to share details with CC. <p>HU provided an update on the APPG and Scottish Parliament CPG. Coeliac UK plans to re-establish the APPG on coeliac disease and the Scottish Parliament CPG towards the end of 2020, current environment permitting.</p>
3	<p>Impact of Covid-19</p> <p>Impact of people with coeliac disease</p> <p>HU provided an update on Covid-19 and coeliac disease. There was a huge increase in questions from the community including 3 x the calls to Coeliac UK's Helpline and a 500% increased activity on social media.</p>

	<p>Coeliac UK surveyed the community on access to gluten free food and received >3,000 responses of which 4% were from Wales. Coeliac UK mobilized food and retail industry and provided information via a coronavirus hub on the website.</p> <p>There has also been some ambiguity as to where people with coeliac disease (CD) fit within Government advice on at risk groups. People with CD are not an increased risk of viral infection but there is a possible risk of complications with secondary bacterial infection. Around 30% of people with CD are at risk of hyposplenism, but spleen function is not routinely assessed. The risk of hyposplenism probably relates to the number of years the condition went undiagnosed before treatment and therefore the risk to children is low. Because of the risk of hyposplenism, Public Health England recommends certain vaccinations (including flu vaccination) for people with CD.</p> <p>The current Government advice in Wales lists people with problems with their spleen as clinically vulnerable, but in England this group has been removed from the clinically vulnerable category, and in England people who are offered the flu jab are now considered clinically vulnerable. Coeliac UK (CUK) has written to the DoH, PHE, asking for clarity and uniformity. CUK has also responded to a recent call for evidence by the Scottish Parliament's Covid Committee.</p> <p>CUK's current advice is that people with CD may consider themselves to be within the clinically vulnerable group because the advice is provided to a community without information about their state of health, adherence to the gluten free diet, vaccination status etc.</p> <p>Action: DL and HU to draft a letter to the Health Secretary for Wales for clarification from the Welsh Government</p> <p>No biopsy strategy for adults</p> <p>Covid-19 has also had an impact on diagnosis of CD. GPs have suspended non-essential phlebotomy, only emergency endoscopies have been taking place and adults with high level antibodies and clinical suspicion have been initiated onto a gluten free diet.</p> <p>The BSG has issued pragmatic guidance on a no biopsy strategy for adults < 55 years, which could apply to ~ 40% of adults, in this age category, being offered a diagnosis without a biopsy.</p> <p>JS shared her experience with around 1000 people on the waiting list which will mean waiting times of 6-12 months. Referrals from GPs are being received with high tTGs and discussions on whether to treat with a gluten free diet or wait for endoscopy are happening with patients.</p> <p>CC noted the importance of access to dietetic support for anyone recommended to follow a gluten free diet, regardless of whether they have a biopsy. In some areas, videos are being used to provide first line support.</p> <p>IHD shared his experience on the impact of Covid-19 on paediatric CD services. The 2019 European Society for Gastroenterology, Hepatology and Nutrition (ESPGHAN) guidelines have now been adopted due to Covid-19. It is essential that care for children is reflected in national guidance. The National Endoscopy Plan had no information on children. When biopsies return unfortunately CD will be low on the priority list which will lead to long waiting times.</p>
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	<p>ACTION: HU and DL to meet outside of the CPG to draft letters to the Health Secretary on Covid-19 guidance and endoscopy services</p> <p>IHD provided an update on work with immunology colleagues to change the way coeliac serology is reported across Wales for children. This was needed to avoid common errors in the diagnosis pathway (such as initiation of gluten free diet before testing is complete), to meet NICE quality standards on coeliac disease and improve the diagnosis process for children and their families. Following on from this work, an All Wales Pathway for adults and children (including transition to adult services) is proposed to ensure that care meets the NICE Quality Standards.</p> <p>ACTION: HU and DL to meet outside of the CPG to draft letters to the Health Secretary on a patient pathway</p>
4	<p>Gluten Free Prescribing</p> <p>a. Update on the situation in England</p> <p>RP provided an update on gluten free prescribing in England. Between 2016 – 2019 the total prescribing cost for gluten free foods had reduced by 25-30% per year from £22.4 million in 2016 to £7.92 million in 2019. The main driver for this has been the introduction of restrictive policies by Clinical Commissioning Groups (CCGs). At the end of 2018 foods other than bread and flour mixes were blacklisted in England which has also led to a reduction in prescribing cost for gluten free foods.</p> <p>The number of CCG consultations on prescribing policies has reduced since the end of 2018. So far in 2020, no new consultations on gluten free prescribing have launched. From 1 April a number of CCGs have merged and this may lead to further restrictions as CCGs with different policies merge together. Of the 18 new CCGs, 7 have a mix of gluten free prescribing policies. Coeliac UK has written to NHS England to ask for clarity on the process required for CCGs to develop a new policy in these circumstances and is also monitoring the CCGs identified with conflicting policies.</p> <p>b. Oral update on Hywel Dda scheme</p> <p>AJ provided an update on the Hywel Dda scheme. The card scheme is being rolled out to eight new GP practice on an opt-in basis. Those joining the scheme will be provided with a card which is valid for three years and has contactless payment. Training videos for dietitians and nurses are currently being developed.</p> <p>Working groups had been suspended due to Covid-19 but are now beginning to meet again, including a finance group and outcomes group. The finance group is reviewing the amount allocated to each age group using a new methodology which is likely to lead to an increased amount for children, particularly for boys aged 15-18 years.</p> <p>Currently receipts are being audited for the scheme but another method for auditing needs to be developed. It is proposed that around 5% of participants will be audited every 6 months.</p> <p>CC commented on the need for transparency around the amount of time and resource required to manage the scheme as this will be important when other Health Boards consider adopting the scheme.</p> <p>c. Meeting with Chief Pharmacist</p>

	<p>RP reported back from the meeting that RP and TH attended with Andrew Evans (AE), Chief Pharmacist, in November 2019. The meeting was positive and AE confirmed that there is no desire to reduce gluten free food availability in Wales, and that there is an openness to a mixed model with both prescriptions and an alternative model, such as that being rolled out in Hywel Dda.</p> <p>AE confirmed that in Wales, the November 2018 list from the Advisory Committee on Borderline Substances (ACBS) will be retained as the prescribable product list. The ACBS will continue to review applications for new bread and flour mixes but not for other products such as pasta and crackers. As very few products are presented to the ACBS for consideration, it would be not be viable to develop a panel for new products (other than bread and flour mixes) in Wales. This is the same approach being taken in Scotland.</p>
5	<p>AOB</p> <p>Food banks in Swansea were commended for going above and beyond in supplying food parcels which meet special dietary requirements.</p>
6	<p>Dates for future meetings:</p> <p>Date TBC</p>

Action Points:

Action	Member
Letter to Health, Social Care & Sport committee with thoughts on endoscopy services	DL & HU
Letters to the Health Secretary on a CD patient pathway	DL, HU & IHD
Letter to the Health Secretary on Covid-19 guidance and endoscopy services	DL & HU