

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

Date & time: Nos Fawrth 22 Tachwedd 2016, 18.00-19.45

Tuesday 22nd November 2016, 18.00-19.45

Venue: Ystafell Gynadledda 24, Tŷ Hywel.

Conference room 24, Ty Hywel

KEY: AM (Assembly Member) - CCG (Clinical Commissioning Group) - CD (Coeliac Disease) - CUK (Coeliac UK) - GF (Gluten Free) – GFG (Gluten Free Guarantee) - GP (General Practitioner) - HCP (Health Care Professional) – LHB (Local Health Board).

Minutes of meeting

1. Present: Chair - Dr Dai Lloyd AM (DL), Secretary - Tristan Humphreys (TH), Norma McGough (NMG), Graham Philipps, Sian Evans, Claire Constantinou (CC), Alison Jones (AJ), Mark Isherwood AM.

Apologies: Mike Hedges AM, Henry Wilkins, Jill Swift, Geraint Preest (GPr),

2. Introductions and opening remarks from the chair

DL welcomed attendees and introduced himself as the prospective Chair of the new Cross Party Group (CPG) on Coeliac Disease & DH and mentioned that he was the first Chair of the CPG in 2008 but was forced to step down in 2011 when he lost his seat. DL is also a CUK Governor.

DL gave a brief overview of the Assembly's remit and invited members to introduce themselves in turn.

3. Minutes of the Meeting (26th January 2016)

a. Amendments and approval of the Minutes

The minutes were accepted unanimously and no amendments were made.

b. Legacy report

TH gave a brief overview of the legacy report prepared by previous CPG. The key points from this report have been used to inform the agenda at this CPG meeting.

ACTION: TH agreed to send a copy of the report to the all Members following the meeting.

4. Election of officers

DL was duly elected Chair and TH elected Secretary. Both positions were elected unopposed.

Chair: DL (*Proposed: TH Seconded: AJ*) / Secretary: TH (*Proposed: AJ Seconded: CC*)

5. Updates:

a. Coeliac UK campaigns

NMG provided an update on Coeliac UK's (CUK) 'Is it Coeliac Disease?' diagnosis campaign and shared a document summarising achievements to date. She also updated the group on the re-launch of the Gluten Free Guarantee (GFG).

Is it Coeliac Disease? campaign

- Launched in summer 2015, the campaign aimed at raising awareness of coeliac disease (CD) amongst general public and Health Care Professionals (HCPs) in face of low diagnosis rates (UK – 24% / Wales – 22%)
- Encouraged people to visit an online assessment and seek a diagnosis.
- Engagement activities: Posters, Leaflets, Pop-up events (including one in Cardiff in July), mailings to GP surgeries, Linked In campaign to GPs. Digital campaign & TV advert. Next year will see continuation of digital campaigning and tv advert (Jan)
- Pharmacy pilot: Pharmacists trained to test high risk groups using POC tests across 15 community pharmacies.
- Evaluation planned for next year

Gluten Free Guarantee Re-Launch (Jan 2017)

- Scheme aimed at encouraged supermarkets to increase their Gluten Free (GF) range by signing up to a 'Gluten Free Guarantee'. Shops must offer a set basket of 8 products (4 if below 3000 sq feet) in order to attain the GFG.
- Re-launch reflects new 4 basket option for smaller super market stores with a focus on 'on the go' options and follows member & HCPs survey and discussions with supermarkets.
- This campaign is not necessarily a response to prescriptions challenges in England but there is clearly a link in terms of availability.

AJ asked for more information & NMG pointed her to the Campaigns and Research section of the CUK website <https://www.coeliac.org.uk/campaigns-and-research/>

Eating out Campaign

TH explained that the focus for CUK next year will be on eating out and the GFG will feed into this. The eating out campaign will be launched in Awareness Week in May 2017.

b. Informatica - update from CUK & GP

An update on the rollout of the Informatica software project in Wales will be provided for the next meeting. AJ raised concerns about the lack of communication with secondary care and the impact of the software on other services. E.g. one GP practice in Hywel Dda has gone from having 6 patients diagnosed with Coeliac Disease to 39 as result of the software. This is one practice with around 9,000 patients. If this was replicated across the other 56 practices in the Health Board this would pose a significant impact

NMG requested any additional information from AJ to help inform the approach. AJ is meeting with the practice shortly and agreed to check these figures with them.

CC highlighted the likely uneven spread of diagnosed cases across Wales and that the increases in other areas could be even greater. For context CC explained that the increase referenced by AJ equated to several months worth of appointments at her clinic for all gastroenterological conditions not just CD. DL also raised the technological challenge posed by GP surgery computers not being able communicate with those in secondary care.

TH welcomed the information from AJ and explained that they had been limited by the inability to centrally check impact on referral rates through the software due to sensitives over centralised

auditing. It is with this in mind that CUK have been liaising with NWIS to try and implement an evaluation framework. The group agreed this should be a priority going forward and will discuss it further at the next meeting.

(Edit: A meeting between CUK & NWIS has now been agreed for December).

ACTION: AJ to check the figures from GP practice

ACTION: TH to follow up with AJ on figures

ACTION: TH & NMG to report back to group on meeting with NWIS (see above)

c. NICE Quality Standard

NMG highlighted the publication of the new NICE quality standard on CD. This provides targets for HCPs & commissioners. First time there has been a standard for CD. CUK has been involved closely in helping shape this. It includes a series of statements on the below:

- Sets out importance of identification of CD
- Sets a standard for endoscopy including a 6 week waiting time standard
- Statement about access to HCP that is specialist in GF diet
- Highlights importance of access to GF for those with CD
- Highlights importance of annual review

CC said she felt the annual review element was interesting as there is an inequity in how this is done across Wales, even within her own health board. It's something Cardiff & Vale LHB have been trying to address and they have begun work on a pathway but there is a challenge with regard to dietetic resource. Dieticians probably are best placed to be deliver this and much cheaper than GPs.

NMG agreed but argued there was a lack of evidence base underpinning many of these statements around who was best placed to deliver the annual review and that CUK was supporting research in order to help address this.

CC pointed to the limited understanding of CD amongst community dietitians noting this was understandable given the limited numbers they were dealing with. Important we recognise this is quite a specialist resource. CC also pointed to the role annual review plays in avoiding waste for example with regards prescriptions and ensuring patients are getting the support they need.

DL suggested the group look at developing a pathway as a priority. NMG agreed and suggested work being done in Scotland on a unified patient care pathway for Coeliac Disease may be of interest.

ACTION: CC to present on the pathway at the next meeting

ACTION: NMG to provide info on Scottish patient pathway

d. Prescriptions – update and discussion

NMG provided an update on the development in England with regards GF prescriptions.

- CUK are firefighting in face of significant limitation or withdrawal of provision from Clinical Commissioning Groups (CCGs) in England. Of 209 CCGs 50% have either removed or restricted GF provision. Of those 20% have stopped completely and most of the rest have gone to PrescQIPP <https://www.prescqipp.info/resources/send/81-gluten-free/1586-bulletin-69-gluten-free-prescrbing>
- CUK has been writing to CCGs in England to highlight the challenges re: access, availability and cost. The Charity is also looking at the options around judicial review.
- CUK carried out a survey of members on their prescription habits and views which we will use to inform our position.

- Kevan Jones MP produced an Early Day Motion in May and led a Westminster debate on prescriptions in November. Kevan has also written to the Department of Health to arrange a meeting following on from the Westminster Hall debate when David Mowat MP mentioned there would be a review of prescribing policies in England within the next six months.
- CUK increasingly fighting to ensure follow up and measurement of impact on health of patients with coeliac disease where prescriptions are being withdrawn.
- Briefing paper available on the Coeliac UK website. <https://www.coeliac.org.uk/gluten-free-diet-and-lifestyle/prescriptions/prescription-policies/>

CC asked NMG whether CUK had noticed any increase in availability of GF products in supermarkets in those areas where prescriptions had been withdrawn. She has had discussion with AJ about voucher schemes and has concerns around access. e.g her patients complained that whilst local shops stocked a wide variety of GF Cakes, there was a lack of staple GF products such as bread and pitta available. How does this therefore fit with a healthy eating agenda? Real problem is not the short term costs associated with limiting prescribing but rather the longer term impacts of non-adherence and poor health.

NMG explained GF prescriptions market is worth £26m and the bulk of the market is not driven by people with coeliac disease so withdrawal of prescriptions is unlikely to have a huge impact on demand. CUK would recommend patients lobby local stores to stock more staple products but fresh bread is more perishable than breakfast cereals, cakes and biscuits and so there will be a tendency to have better stores of the longer-life products in stores. Discussion was had about fortification of bread and NMG explained there is no standard for fortification of iron and calcium in gluten-free breads and this is something CUK has been lobbying for.

Currently all LHBS in Wales are signed up to [National Prescribing Guidelines](#). There was some debate as to the best way to deliver prescriptions going forward with DL arguing in favour of pharmacy based system whilst AJ advocated the Vale of York's voucher based scheme.

AJ is looking to run a pilot scheme in Hywel Dda based on the model used by Vale of York in England.

- Pre-paid card provided to 'supplement the cost of GF foods purchased in the supermarket'
- Subsidise the cost of GF food for patients with coeliac disease
- Cuts cost of GP time, out of pocket expenses, handling charges etc.
- Vale of York has had v. favourable outcomes.
- AJ has applied for clinical research award and will find out December 2016 if she has been successful.

DL welcomed the pilot but said he would favour its use in pharmacy as this maintains a health promotion link and gives the patient a health professional point of contact for any queries they might have. AJ suggested one option could be mandating that patients must attend annual review in order to receive the pre-paid card.

CC highlighted Wales' unusual population spread and the challenge posed by rurality and geography. Ensuring equal access is v important. Hywel Dda offers a good opportunity to test this as they have a mix of rural and urban areas and this pilot can help feed into this.

AJ raised concerns about costs of pharmacy based provision compared to supermarkets. Community pharmacy route does not deal with this cost. CC suggested an all Wales procurement process as a means of limiting these costs. Cardiff did a prescribing scheme previously and as part of this pharmacies involved had to align delivery timings etc and gave a ceiling to how much they could be reimbursed. CC welcomed AJ's work as really beneficial as we need to look at what works for Wales

and that may be something in between.

ACTION: AJ & CC to present at the next CPG on their experiences on-going work re prescriptions.

e. Gastroenterology & endoscopy service

TH suggested looking at this at the next meeting alongside the Informatica discussion.

f. Support for Learners with medical needs

TH provided an update on developments since the last meeting. Current guidance for schools was up for review earlier this year and CUK took part in that consultation along with others in the room. CUK have been invited to attend a roundtable session with Welsh Government on the updated guidance on 7th December and expect this new guidance to be published shortly after that.

Alongside that there is the Additional Learning Needs Bill (2016) going through the Welsh Assembly. This is important as unlike in England there is no statutory duty on schools & Local Authorities to abide by the above guidance currently and this could be provided by including medical needs in the Bill. Currently, the Welsh Government do not plan to do this but CUK and partners are lobbying for a change of position.

ACTION: TH to update at next meeting

6. Launch event

TH suggested a CPG reception in the Oriel as part of CUK's Awareness Week activity in May. TH has spoken with Charlton House and they are happy to support the Eating out campaign during the week by offering increased GF options on the menu and promoting the campaign to customers.

ACTION: TH to liaise with DL & Charlton House over booking Oriel

7. Group discussion on priorities for the group and next steps

The group felt this had been covered and suggested focussing on the following:

Patient Pathway (CC to present on CD Pathway)
Prescribing (AJ to present on proposed voucher scheme)
Informatica & secondary care/impact (GPr/CUK)

8. A.O.B

CC has been working on video summarising key information at diagnosis. This will be shared at the next meeting.

9. Date of next meeting (TBC)

DL suggested Feb/March for the next meeting.

ACTION: TH to liaise with CC, AJ and GPr over dates as they will all need to be present.

7.45pm - Close