

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

Date & time: Nos Fawrth 26 Medi 2017, 18.00-19.45
Tuesday 26 September 2017, 18.00-19.45
Venue: Ystafell Gynadledda A, Tŷ Hywel.
Conference Room A, Ty Hywel

Attendees: Dr Dai Lloyd AM (Chair), Tristan Humphreys (Secretary), Alison Jones, Dr Geraint Preest, Graham Phillips, Dr Jill Swift, Norma McGough, Rhun ap Iorwerth AM, Sara Moran (Diabetes UK), Sian Evans.

No.	Item
1	Apologies for absence Henry Wilkins, Dr Huw Jenkins, Mark Isherwood AM.
2	Minutes of last meeting Minutes were approved without amendments
3	AGM <ul style="list-style-type: none"> a. Election of officers Dr Dai Lloyd AM was re-elected as Chair of the group <i>Nominated by: Graham Philips / Seconded by: Jill Swift</i> Tristan Humphreys was re-elected as Secretary of the group <i>Nominated by: Alison Jones / Seconded by: Dr Dai Lloyd AM</i> b. Review of accounts and annual report The annual report and review of accounts was submitted to the group for approval with any queries or amendments to be raised with the secretary by 4 October. ACTION: Tristan Humphreys to submit Review of Accounts and Annual Report to table office.
4	Supporting Learners with Medical Needs Tristan Humphreys (TH) welcomed Sara Moran (SM) from Diabetes UK to the meeting and provided a background on Coeliac UK's involvement with the health in schools alliance (an alliance of around 25 health charities operating in Wales). Initially this had focussed on engaging with the updating of all Wales guidance for children with medical needs (Supporting Learners with Healthcare Needs) and has progressed onto work with the Additional Learning Needs (Wales) Bill. SM was invited to provide an overview of the alliance's work and progress to date.

	<p>SM has coordinated the alliance for the last two years. It has responded to a number of consultations and provided verbal evidence to the Children’s Young People and Education Committee in March 2017. Rights and entitlement are unclear under the current system and many children with diabetes rely on current SEN system to access vital support. Thus changes proposed under the Additional Learning Needs (Wales) Bill (ALN) could lead to significant disruption to these children. The ALN bill also provides the opportunity to alleviate many of the challenges faced by children with medical needs who are not supported under existing legislative framework.. In recognition of this, the Welsh conservatives have tabled an amendment that defines medical needs on the face of the bill. This amendment clarifies that disabilities as defined under the Equality act 2010 may result from medical needs, however it does not extend the reach of the bill to those medical conditions not encompassed by the Equality act 2010. This raises a concern for Coeliac UK as there is at the very least ambiguity over its status under the Equality act 2010. This is also an issue for other conditions such as allergies and asthma.</p> <p>Unfortunately this does result in a somewhat uncomfortable line being drawn between some conditions. The amendment is however non contentious as it states a legal fact and has support of parties. It would also be a significant achievement and put Wales ahead of other home nations in respect of support for medical needs in school. This will secure funding, as well as confidence and security for support staff and unions.</p> <p>NMG explained that coeliac disease per se is not generally considered a disability as defined under the Equality Act though this has not been tested in court.</p> <p>One option to clarify this for coeliac disease is to ensure that the Code of Practice references coeliac disease and contains a strong, broad, healthcare needs’ section. This should then provide a basis for support for coeliac disease in schools. TH asked Dr Dai Lloyd (DL) and Rhun ap Iorwerth (RaI) in particular for their views with regard to the Equality act.</p> <p>DL explained that, whether Equality act or not applies, coeliac disease should still be included as an additional need. RaI highlighted that management of coeliac disease using the gluten free diet may be seen to require a lower level of support compared to other conditions.</p> <p>TH said that Coeliac UK was pleased with progress over ‘Supporting learners with healthcare needs’ guidance.</p> <p>ACTION: TH & SM to continue to liaise and explore options for supporting coeliac disease in any new framework in the future stages of negotiation around the bill.</p>
5	<p>Informatica</p> <p>a. Update on progress (NMG/TH)</p>

TH provided an update to the group on Coeliac Informatica software. TH met with Simon Scourfield from NHS Wales Informatics Service (NWIS) to discuss progress on central collection of data from cluster level. Unfortunately the DQS committee is on hiatus at the moment but SS has said he can get the chairman's approval on this, so, Coeliac UK now needs to put together an application to the committee. Assuming it is approved the collection capability can be turned on very quickly. NWIS are looking at updating the dashboard and have asked for the Charity and Dr Geraint Preest (GPr) to provide feedback on the module (e.g what are the key things GPs want to see on that dashboard?). Coeliac UK is also to provide an avatar for the module as well as copy for the video's webpage on the NWIS site. NWIS agreed to develop a 'How do I resource' on how to operate the software and is looking at a recorded webinar that could be shared with GPs.

The meeting also highlighted both technical and behavioural barriers. On the technical side, roughly half of the practices run EMIS software which does not have Audit+ automatically installed on it. Essentially this means, whilst audit+ will be installed on at least one practice PC, it will not necessarily be on all of its PCs. In order for this to be available across the practice, a specific request would need to be made to NWIS and the software 'flood loaded' on to all the practice PCs.

TH has been in touch with Local Health Boards (LHB) across Wales to request Protected Learning Time (PLT) sessions on the software. Cwm Taf Health Board warned the lead in time for PLT is very long and this was backed up by Simon Scourfield who talked about waiting up to 18 months. Cwm taf did however send it out to all their practices in a mail-out. TH is still waiting to hear back from Cardiff & Vale University Health Board but information did go to each cluster lead in Abertawe Bro Morgannwg University Health Board and TH had some responses from surgeries. Some technical issues were raised with accessing the software and in particular it was highlighted that the Inpractice systems hotline was unable to offer any advice re audit+ software. TH has more work to do on this and very apparent that much more promotion required.

TH also conscious of challenges around behaviour and incentivising where the software is installed, it still requires an individual GP to have alerts turned on and given the number of potential condition specific alerts this could lead to 'alert fatigue'. It is possible to set up only coeliac module alerts but this requires significant engagement from the user.

Alison Jones (AJ) raised concerns over the impact of Informatica on secondary care and asked what was being done to ensure there was no adverse impact.

TH agreed it was a very important point. He felt we were further away than we thought in terms of usage but this is something Coeliac UK is very aware of and will feed into our communications plan going forward. It's also true that once DQS sign off is secured, we can have a far clearer sense of impact of this software.

ACTION: TH & NMG to submit application to DQS committee for central collection of coeliac module data

ACTION: Coeliac UK to provide avatar and copy for Coeliac module and video

	<p>ACTION: GPr & TH to feedback to Simon Scourfield on graphical improvements to the module dashboard.</p> <p>ACTION: Make contact with JAG (Joint Advisory Group) on GI Endoscopy Standards</p>
6	<p>Prescriptions</p> <p>a. Update on NHS England consultation (NMG)</p> <p>Norma McGough (NMG) explained that Department of Health in England has closed its consultation on the prescribing of gluten free foods and that Coeliac UK had a meeting with the Department on 20 June. They were receptive to Coeliac UK's arguments against blacklisting gluten free prescribing in primary care and the postcode lottery many with coeliac disease face in England, and associated health inequality challenges.</p> <p>There are now roughly 30% CCGs that have fully withdrawn gluten free prescribing, 30% restricting and 30% still using national prescribing guidelines. The consultation report is due to be published in the Autumn and The Department of Health has said they will speak with Coeliac UK prior to publication. The formal response will require Whitehall approval. Coeliac UK is now considering action and is focussed on protecting the vulnerable. The challenge is that this potentially puts onus on overworked GPs to identify vulnerable patients. Coeliac UK has been working in partnership with the BMA's Prescribing Lead, Dr Andrew Green who provided an article providing the case of need for gluten free prescribing in the Conservative party conference magazine. Coeliac UK are also in contact with around 50 MPs who have previously been supportive of local members around this issue.</p> <p>b. Hywel dda prescribing pilot (AW)</p> <p>AJ provided an update on the Hywel Dda gluten free prescribing pilot following a presentation she gave in March. The pilot is looking at taking gluten free foods off prescription and instead providing a top up card which subsidises the difference in cost between gluten and non-gluten containing products. It has received a research fellowship so will be thoroughly evaluated.</p> <p>There have been concerns around limiting the use of card to gluten free products and as such patients in the pilot will be asked to provide receipts for their purchases. The original plan was to launch with Sodexo as the card provider however it has since been decided a full tender process needs to be carried out. 4 companies have come forward and bids are being scored on the 28.09.17. Some of these are able to restrict the types of products that can be bought with the card, for example the purchase of alcohol, cinema tickets, restaurants etc can all be restricted. AJ explained she is hoping to start in January with 100 patients across 9 GP practices.</p> <p>From AJ's experience in Hywel dda there is very little awareness of the prescriptions situation in England however when patients hear of this they tend to be much more interested in engaging with the pilot. Initial data should be available around July/Aug with full research data available around Sept/October. AJ has had some interest from other health boards and reports a desire from GPs in Hywel dda to see a change. AJ plans to be in a position to make recommendations this time next year.</p>

	<p>TH asked whether the tender process had revealed the card system to have greater technical potential than was originally assumed and AJ agreed and said that in some ways going through procurement has been very helpful.</p> <p>ACTION: AJ to update at next meeting.</p> <p>ACTION: Coeliac UK to update on Department of Health consultation results at next meeting.</p>
7	<p>AOB</p> <p>a. Gluten Free Food Show update (TH)</p> <p>The inaugural Wales Gluten Free Food Show will take place on 28 October from 10-4 at the Radisson Blu in Cardiff.</p> <p>So far around 2,000 have registered to attend. There will be a panel debate as well as talks on research etc. Coeliac UK is looking for volunteer so if you are available then please do get in touch with Tristan at Tristan.humphreys@coeliac.org.uk .</p> <p>You can register here now.</p> <p>b. Diabetes Cymru</p> <p>SM flagged that there is a company operating under the name Diabetes. Cymru and posing as a charity. It is run by Eryl Vaughan and has a Green and white logo. They are running a conference in Carmarthen. Some have been in touch as have given money, mistakenly under the impression it was Diabetes UK Cymru.</p> <p>ACTION: TH to update on success of event at next meeting.</p>
8	<p>Date of Next Meeting:</p> <p>6pm, Tuesday 28 November</p>

Action Points

Action	Assigned to
ACTION: Tristan Humphreys to submit Review of Accounts and Annual Report to table office.	TH
ACTION: TH & SM to continue to liaise and explore options for supporting coeliac disease in any new framework.	TH/SM
ACTION: TH & NMG to submit application to DQS committee for central collection of coeliac module data	TH/NMG
ACTION: Coeliac UK to provide avatar and copy for Coeliac module and video	TH/NMG
ACTION: GPr & TH to feedback to Simon Scourfield on graphical improvements to the module dashboard.	TH/GPr
ACTION: AJ to update at next meeting.	AJ
ACTION: Coeliac UK to update on Department of Health consultation results at next meeting.	TH/NMG
ACTION: TH to update on success of event at next meeting.	TH