

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

Date & time: Nos Fawrth 27 Chwefror 2018, 18.00-19.30
Tuesday 27 February 2018, 18.00-19.30
Venue: Ystafell Gynadledda C, Tŷ Hywel.
Conference Room C, Ty Hywel

Attendees: Dr Dai Lloyd AM (Chair), Tristan Humphreys (Secretary), Alison Jones, Dr Geraint Preest, Dr Jill Swift, Norma McGough, Rhun ap Iorwerth AM, Ryland Doyle.

No.	Item
1	<p>Apologies for absence</p> <p>Graham Philips, Dr Huw Jenkins, Simon</p>
2	<p>Minutes of last meeting</p> <p>Minutes were approved without amendments.</p>
3	<p>Additional Learning Needs Bill (Wales)</p> <p>a. Update (TH)</p> <p>Tristan Humphreys (TH) provided a brief update on the progress of the Additional Learning Needs & Education Tribunal (Wales) Bill, now the Additional Learning Needs & Education Tribunal (Wales) Act 2018.</p> <ul style="list-style-type: none"> The 'Additional Learning Needs & Education Tribunal (Wales) Act' was passed by the Welsh Assembly at the end of last year and received royal ascent in early 2018. The implementation deadline for the new system has now been put back to sept 2020 (was 2019). The Health in Schools Alliance (of which Coeliac UK is a member) submitted a joint response to the Welsh Government consultation on implementation of the new framework. Concern centred on whether medical needs will be allocated to Individual Healthcare Plans or Individual Development Plans (The only type so far referred to – This is picked up on p. 21 of the consultation report). Code of practice: the handbook for the legislation is being consulted on this year and Coeliac UK and partners will be recommending significant changes to the 'Healthcare needs' section. Timings were originally early 2018 though recent statements now suggest autumn for consultation with a view to final publication end of 2019. 'Supporting Learners with Healthcare Needs' guidance: Throughout the passage of the ALN Act, the implication has been that this will need to be re-written but this is yet to be confirmed. Sara Moran (Diabetes UK Cymru) is due to meet with Kirsty Williams staff in near future on behalf of the Alliance. <p>ACTION: TH to update group on progress at next meeting</p>

Wales Gluten Free Food Show

a. Review of the 2017 event (TH)

TH updated the group on the hosting of the inaugural Wales Gluten Free Food Show and thanked all those who attended. The charity had initially aimed to 500 visitors on the day with 15 gluten free exhibitors showcasing their products. In the event, roughly 1,400 attended and 20 companies were secured as exhibitors.

TH explained that there was a dropout rate of roughly 50% from those registered to attend and whilst the numbers were large, the bigger issue was the timing of arrival with 60% attending in the first hour and a half and many arriving an hour before the event opened. This led to a queue that snaked throughout the hotel and out on the street. It was felt that the venue was too small for these numbers but that the staff were very helpful.

The event unfortunately clashed with an Anthony Joshua fight title fight (announced 3 weeks prior) which led to difficulties with parking and securing hotel rooms in the city centre. Set up was also a challenge for exhibitors as much of this had to take place on the morning of the event & vehicle access at the venue was limited.

Talks were well attended and the panel debate (Chaired by Dr Dai Lloyd AM and with panellists including Norma McGough, Jill Swift & Alison Jones) and cookery demos were particularly popular. TH thanked Dr Dai Lloyd AM (DL) and the panellists for their support.

Coeliac UK would also like to thank the many volunteers who helped out on the day including Cross Party Group (CPG) member Graham Philips.

JS suggested re staggering times of registration to aid with the number of attendees for 2018. TH explained this is possible and one option that is being looked at and that the charity will be hiring a larger venue and will not be doing goodie bags which should also have a big impact. All in all, the turnout was very positive and the exhibitors were very happy so a successful first hosting of the show.

Geraint Preest (GPr) added that his receptionist had attended and thought the show was brilliant.

b. Update on plans for 2018 (TH)

The Wales Gluten Free Food Show 2018 will take place on the 8th September at the Cardiff City Stadium.

TH has looked at a number of venues and decided on Cardiff City Stadium as the best available. It has 1,500 complimentary parking spaces and allows for access the day prior. The venue also regularly hosts large numbers of attendees and so should be better prepared to deal with this.

With a new, larger venue and experience of the challenges last year Coeliac UK plan on delivering a bigger, better show in 2018. With this in mind the charity will seek to expand to 25 exhibitors on the day. Promotion and

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	<p>commercial communications should be produced earlier this year as the templates for these were produced in the run up to the 2017 show. The programme for the event is be developed in the coming weeks but the group will be updated at the next meeting. In the meantime, you can register for free at our Eventbrite page.</p> <p>ACTION: TH to update group on progress at next meeting.</p> <p>ACTION: ALL to save the date (8th September 2018) for attendance at Wales Gluten Free Food Show 2018.</p>
5	<p>Prescriptions</p> <p>a. Update on result of NHS England consultation (NMG)</p> <p>Norma McGough (NMG) briefed the group on the recent NHS England consultation on gluten free prescribing in England. The Department of Health & Social Care launched the consultation in March and closed in June of 2017. There were 3 options considered as follows:</p> <ol style="list-style-type: none"> 1. Make no changes: Make no changes to gluten free prescribing in primary care in England 2. Effectively, end prescribing of gluten free foods in primary care by blacklisting all gluten free foods in Schedule 1 in England 3. Restrict prescribing of gluten free foods in primary care to bread and flour mix in England. <p>The decision was announced earlier this month with the Department for Health & Social Care endorsing option 3 – the continuation of gluten free prescribing on a limited formulary (bread and flour mix). Coeliac UK welcomed the decision as the charity was braced for the complete blacklisting of gluten free products which would have been a considerable blow to people with coeliac disease in England. However it should be noted that this does not affect Clinical Commissioning Groups’ (CCGs) ability to set their own policies and they can continue to restrict gluten free prescriptions beyond what is recommended by the Department for Health & Social Care’s decision.</p> <p>As it stands roughly one third of CCGs are continuing to prescribe in line with national prescribing guidelines, a further third have restricted either in line with PrescQIPP recommendations (50% of the unit volume in National Prescribing Guidelines and products restricted to bread and flour mixes) or in other ways such as through employing a narrower formulary and finally the remaining third have stopped routine prescribing completely. Coeliac UK has strongly opposed complete removal of access to gluten free food on prescription and has pushed back on CCGs to enable use of clinical discretion to identify patients where their condition was being adversely affected by removal to continue to be supported by gluten free food on prescription, due to the higher cost of gluten free foods like bread.</p> <p>Following the decision, Coeliac UK have written to all those CCGs where current policies fall below the recommendations as laid out in the Department for Health report, requesting information on if and how they will be taking account of this.</p>

Sarah Sleet (Chief Executive – Coeliac UK) and NMG sit on the Department of Health working group tasked with scoping out the work needed as a result of this decision. They are joined on the group by representatives from the RCGP, BDA, NHS England, CCGs, the ACBS and BSNA¹. The group is reviewing the gluten free products listed in the drug tariff, blacklisting all gluten free products that do not fit into the definitions of 'bread' and 'flour mix.' Clear definitions of 'bread' and 'flour mix' have been agreed. For example it was agreed that rolls, loaves of bread & flatbread would all be included but pizza bases would not. This reflects the response Coeliac UK received during its Gluten Free Guarantee consultation in which the charity engaged members & dietitians about what staple products they felt were most important to be able to access. Pizza was considered on the margins during that consultation, is often deemed controversial in the mainstream press and coupled with the lower cost differentiation compared to other bread products, it was felt this could be excluded.

NMG cautioned that it was very early days but that the approach would be broad sweep. All manufacturers will be asked to opt in to the new regulations rather than complete a new application. It is felt this is an overdue opportunity to refresh the formulary as this has not been done before. The new listing is due to come out in November.

TH & NMG addressed concern regarding the potential knock on impact on Wales, Scotland & N. Ireland as whilst the ACBS comes under Department of Health, the list is used throughout the UK. TH was concerned that legislative changes in England could therefore inadvertently result in limitation of products available to patients in Wales, essentially leading to policy change through the back door. AJ mentioned that she had spoken with the Chief pharmacist for Wales who raised the same concern.

NMG cautioned that there is plenty more work to do and there will be opportunity to address this. She also highlighted that flour mixes and breads are the products that are most commonly obtained on prescription and also the most costly products to the consumer in retail.

TH asked AJ how aware pharmacists in Wales were of these changes & AJ confirmed this is a big concern. The Chief Pharmacist for Wales is concerned this won't actually make much difference in cost and made clear that they are under pressure to reduce costs. NMG explained that some of the new information that will be collected will be around cost to the NHS and retail costs as well as looking at nutritional attributes. The group is also looking at fortified products as currently there are no fortification standard in place for gluten free bread and products.

This is phase 1 but Dept. of Health will also be looking at amounts of gluten free food on prescription and alternative supply routes in phase 2. Evidence Coeliac UK put forth including regarding impact of non-compliance and additional cost to NHS clearly had an impact on the minister and NHS England & commissioners were unhappy with the final decision.

¹ RCGP- Royal College of General Practitioners; BDA – British Dietetic Association; ACBS – Advisory Committee on Borderline Substances; BSNA – British Specialist Nutrition Association

ACTION: NMG & TH to scope out potential impact of changes in England on application of ACBS list in Wales & update the group at the next meeting.

b. Update on Hywel Dda Prescribing pilot (AJ)

AJ updated the group on the progress of the Hywel Dda Prescribing pilot. Since the last meeting the tender for providing the electronic card has been awarded to a company called 'allpay' who have experience of providing social care cards and are used to working with authorities.

Letters & packs have gone out to 197 patients currently receiving gluten free prescriptions across 9 practices in Pembrokeshire, Carmarthenshire & Ceredigion inviting them to take part. AJ is expecting consent forms back by 12th March. AJ has visited 6 of the practices already to talk to patients in person and has phoned everyone who received a letter. Of those that she's spoken to there is about 67% opt in rate. One sticking point has been around access to bread mixes with Juvela pointing to a lack of willingness from retailers to stock them. Otherwise there has been a very positive response.

Those less willing to take part in the pilot appear to be those that are receiving the maximum available on their prescriptions. Others have reported they are happy to buy it themselves where they feel they can afford to.

AJ is hoping to start the pilot in the first week of April for 6 months. The research project would then run June - August.

c. Questions & discussion

JS asked how AJ was ensuring the patients taking part were representative of the wider cohort that are currently receiving prescriptions. AJ reassured JS that the practices had been picked to cover a cross-sample of the Hywel Dda patient population taking into account factors such as rurality and rates of deprivation. AJ will also be contacting those that chose not to take part to ascertain their reasons so as to ensure this is also considered in the evaluation.

TH followed up discussion on the need for tracking what has been bought. AJ explained that the requirement for patients to submit receipts has not been an issue and they have been very happy to commit to doing so. Rhun ap Iorwerth (RaI) said he would love it in their house and AJ confirmed parents have been very pleased.

TH asked for clarification on what will and won't be limited on the card. AJ explained this will be limited to grocers, pharmacies & online grocers. She has had some requests as to whether it can be used for example on an Marks & Spencer gluten free sandwich on the go or gluten free quiche and this is fine. RaI welcomed this flexibility.

NMG asked for clarification on when the data will be available. AJ is hoping to hold consultation events at end of the project with a surveys going out 5 months in she should have some data in advance of the end of the project.

RaI queried whether it will be possible to know how much the scheme costs in comparison to normal prescribing & AJ confirmed she has been collecting

	<p>scripts in order to do this.</p> <p>ACTION: AJ to update the group at the next meeting</p>
6	<p>Informatica</p> <p>a. Update on progress (TH/NMG)</p> <p>TH & NMG provided an update on the Informatica software. They have been unable to get hold of Simon Scourfield at NHS Wales Informatics Service (NWIS) and so there has been no progress. They have drafted an application for the DQS committee but without NWIS input this is very difficult.</p> <p>GPr confirmed there was little progress on the ground and that at this stage further progress is probably not possible.</p> <p>AJ mentioned this was a shame as practices using it in Hywel Dda have seen benefit.</p> <p>Scotland are looking into launching similar decision support software and GPr has also had an enquiry from David Bellamy (a GP from Shropshire) about using the software in his surgery.</p> <p>JS suggested using the software as a teaching resource and this was supported by GPr who is happy to produce another video on that basis. NMG explained the CUK is looking to engage with GPs this year as a particular focus and so this does fit in with the charity's priorities.</p> <p>NMG queried what decision support software is currently being used and GPr explained there was nothing uniform in use. A New IT system is being brought in and GPs will have a choice between Vision or Microtest as EMIS will no longer be in use. GPr made the point that because GPs are self-employed, they have choice to decide on their own systems which makes it more difficult to integrate across the system. He raised concerns therefore that this will prove a missed opportunity to deliver a properly intergrated system.</p> <p>Further GPr explained that coeliac disease was unfortunately very low on priority lists for GPs and given the pressure they are currently under, they are very defensive are reluctant to take on anymore responsibilities that could result in increased workload. For example, in Bridgend it has been decided that NOACs will no longer be initiated in primary care and will instead need to be prescribed through secondary care.</p> <p>Similarly, JS described the challenges she is having with getting GPs to take back patients once they have been discharged from the coeliac clinic. GPr reiterated that the system was at breaking point and not just in primary care.</p> <p>TH inquired about the technology and whether Microtest would have audit+ pre-loaded as EMIS did not have the software pre-loaded and this was a stumbling block. GPr will check this.</p> <p>It was felt we had unfortunately reached an impasse with Informatica and further work on this in its current form was unlikely to be worthwhile at this time.</p>

	<p>ACTION: TH & NMG to draw up suggested next steps and present to next meeting</p>
7	<p>AOB</p> <p>a. Coeliac UK's Crossed Grain Magazine TH asked the group if they were happy for Coeliac UK to notify its members about future CPG meetings in its quarterly Crossed Grain magazine. The group was happy with this. RaI queried whether an Eventbrite page or email in advance would be needed and TH agreed. TH will look into the best way to administer this.</p> <p>ACTION: TH to submit meeting dates to Crossed Grain editorial team. ACTION: TH to agree process for managing CPG attendance as a result.</p> <p>TH drew attention to a feature on the CPG and former Swansea Group Organiser, Lyndsay Morgan, in the current edition of the Crossed Grain magazine.</p> <p>b. Timings of next meeting:</p> <p>The group discussed the best times for future meetings due to the challenges posed by votes overrunning. It was agreed we would continue meeting at the same time and if voting overruns, TH will start meeting in chair's absence.</p> <p>c. Awareness week:</p> <p>Coeliac UK are looking to host another event in the Welsh Assembly, likely in the canteen in the same vein as last year. TH will keep group updated.</p> <p>ACTION: TH to liaise with DL on Awareness Week plans. ACTION: TH to report back on event/activities at next meeting.</p>
8	<p>Dates for future meetings: 6pm, Tuesday 19th June</p>

Action Points

Action	Assigned to
Update the group on Hywel Dda prescribing pilot at the next meeting	AJ
SAVE THE DATE: 8 th September 2018 for attendance at Wales Gluten Free Food Show 2018, Cardiff City Stadium.	ALL
Scope out potential impact of prescribing changes in England on application of ACBS list in Wales & update the group at the next meeting.	TH/NMG
Update group on ALN progress at next meeting	TH
Update group on progress at next meeting.	
Submit meeting dates to Coeliac UK Crossed Grain editorial team	
Agree process for managing CPG attendance requests from members/general public	
Liaise with DL on Welsh Assembly Awareness Week plans.	
Report back on Awareness Week event/activities at next meeting.	