

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

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

Item
<p>Apologies for absence</p> <p>Heather Stephens, Carol Carpenter, Llyr Griffiths AM, Dr Huw Jenkins, Dr Geraint Preest.</p>
<p>Minutes of last meeting</p> <p>a. Amendments and approval of the Minutes</p> <p>The minutes were approved.</p> <p>b. Matters arising</p> <p>All matters arising were included in the agenda.</p>
<p>Additional Learning Needs Act (Wales)</p> <p>a. Update (Tristan Humphreys)</p> <p>Tristan Humphreys (TH) provided an update on progress regarding the Additional Learning Needs Act 2018 and associated guidance. A consultation on the draft code of practice will be launched in early December with a closing date of March 22. Coeliac UK is chairing the Care in Schools Alliance (CISA) and will be coordinating a joint response from CISA. The current plan is for the code to be published by the end of 2019. CISA has some concerns around the proposed draft and would encourage anyone with an interest in this area to engage with the consultation either through the group or individually.</p> <p>ACTION: TH to submit consultation on behalf of CISA and report back to group at next meeting.</p>
<p>Prescriptions</p> <p>a. Update on progress of DHSC Task & Finish group and new regulations (NMG)</p> <p>Norma McGough (NMG) reminded the group of the Department of Health & Social Care's (DHSC) consultation decision from earlier this year to maintain support for gluten free prescribing in England but to limit it to bread and flour mix. There has since been a consultation on the resulting regulations for England and as of December 4th the revised drug tariff for England will come into force. This follows a comprehensive process and it was felt that rationalising of the list, if not resulting reduction, was very welcome. NHS England will be sending out a communication to Clinical Commissioning Groups (CCGs) regarding the perceived postcode lottery of gluten free provision in England and promoting the new guidance. Currently one third of CCGs have completely removed gluten free prescribing, one third have restricted and one third are still using National Prescribing Guidelines. This will change as a result of the new regulations. Unfortunately NHS England have today (27/11/18) put out a press release that</p>

confuses and conflates the issues of low value prescribables and gluten free as well as making reference to products such as donuts and pizzas that have never been available on prescription. This was picked up by the Daily Mail and [the charity has had to clarify the position.](#)

The Department of Health is also looking again at the number of recommended units per patient in view of the restriction to bread and flour mix only; it no longer seems appropriate to conflate prescribing of part of the diet with total units required. There are already alternative recommendations and guidance from PrescQIPP, the policy body in England that advocates a reduced number of units. Ian Severn raised concerns about the likelihood of CCGs heeding the advice of central government from his experience as a Local Group Organiser in England.

Coeliac UK is looking closely at the implications for the devolved nations as these regulations do not apply to Wales, Scotland and Northern Ireland yet there is concern there could be unforeseen knock on impacts in these nations. For example, the Advisory Committee on Borderline Substances (ACBS) list is currently used by the devolved nations yet the recent updated version has been streamlined to reflect changes in England. The AWPAG (All Wales Pharmaceutical Advisory Group) remains the authority on prescribing in Wales but moving forward one of the potential challenges may be regarding the review of those GF products that are still available on prescription in Wales but that are no longer party to the continuing monitoring or regulation by the ACBS. Alison Jones (AJ) suggested there is a need to get a clearer sense of what actual ACBS regulation means and that perhaps we should be looking at an alternative approach.

A secondary concern was raised that with the devolved nations representing a small part of the UK prescriptions market, that companies will have reduced commercial incentive to maintain and develop products not included on the ACBS list thus limiting availability of products in an indirect way. This might therefore result in a list that is not just static but potentially regressing. In the meantime, AJ has updated the [All Wales Guide to Prescribing Gluten Free Products](#) has been updated with reference to Coeliac UK's list of prescribable products and this could be continued going forward.

Clare Constantinou (CC) asked how Scotland were approaching this and if they had done any work that we might learn from in Wales. Scotland tends to be very proactive with regards coeliac disease and for example are in the process of developing a clinical pathway for patients with coeliac disease as well as running a central pharmacy led prescribing scheme incorporating annual health checks for patients. Scotland is similar to Wales in that it has a more centralised health service and has shown a longstanding commitment to the provision of gluten free prescriptions as a necessary means of supporting those with coeliac disease. TH agreed to speak with Scottish counterpart and feedback on the Scottish situation at the next meeting.

TH informed the group that a mailout from Pharmaceutical Services Negotiating Committee (PSNC) regarding the new regulations had led to some confusion amongst Welsh pharmacists as it failed to clarify the changes related to England only. Coeliac UK has as a result been in touch with both PSNC and Community Pharmacy Wales (CPW) asking them to clarify the situation to their members. CPW have since sent their own clarification to all their pharmacies to clarify the changes do not relate to Wales.

ACTION: TH to speak with Lead in Scotland regarding approach to ACBS list in Scotland

b. Update on Hywel Dda Prescribing pilot (Alison Jones)

AJ gave an update on the Hywel Dda Prescribing scheme which has now come to an end. 194 people were originally approached across nine demographically representative practices in Carmarthenshire, Pembrokeshire and Ceredigion with 123 taking part (64%) in the top up card scheme.

Due to its popularity 104 of the 120 (87%) who took part have opted to continue on the card until it runs out in May. The remaining participants will return to prescribing as before. Evaluation questionnaires have gone out to all participants as well as those who chose not to participate. One of the main reasons stated for not taking part include access to Juvela bread mix and there are suspicions that part of the reason for this is their high cost. With this in mind, Andrew Evans (Chief Pharmacist for Wales) has written to Juvela to ask them to make their products available to supermarkets at a more reasonable price.

Across the nine practices there has been a saving so far of £11,000 over the three months which equates to £24,000 across the year. Provisional estimates suggest a £250,000 saving if rolled out across the entire health board rising to as much as £500,000 if GP time is included.

This is based on enrolment of just those currently taking up prescriptions. Approximately 36% of those with a diagnosis of coeliac disease chose not to take up prescriptions and so AJ has been looking into the implications of increased uptake on the savings. Early estimates suggest even with a 100% uptake there is still a saving, albeit slight. Further investigation and modelling including necessary healthcare input is required to understand the economic impact of the approach. AJ expects to be able to present the report to the CPG and Hywel Dda Health Board Executive Board in March.

ACTION: AJ to present report at next meeting.

c. Questions & discussion

CC suggested that annual review needs to be built into this approach and queried whether this would work for all demographics, particularly vulnerable groups. AJ made clear there will always be a need for prescriptions for some and argued that quality of service from pharmacies would greatly improve for those who were still receiving prescriptions as they will have greater time and space to deal with it.

AJ will be going through the receipts and participants have stuck to gluten free staples. Feedback has been very positive regarding availability and we have seen participants 'shopping around more'. Those who were less willing to look around were more likely to go back on to prescriptions.

Coeliac UK will be including an update on the scheme in the next edition of Crossed Grain magazine.

Wales Gluten Free Food Show

a. Feedback on Wales Gluten Free Food Show 2018 (Tristan Humphreys)

TH gave an update to the group on the hosting of the Wales Gluten Free Food Show at Cardiff City Stadium on the 8th September this year.

20 Gluten Free exhibitors took part on the day alongside cookery demos, 1:1 dietetics clinics, a research talk and panel debate. There was also gluten free catering and a childrens area.

1,404 attended through the day (Of 2,998 registered to attend – a 53% drop out rate) with more than 200 through the door in the first hour alone. 68% of those attending were non-members and it was the largest show Coeliac UK has hosted.

The response was very positive with many correspondents complementing the choice of venue compared to last year. A feedback survey was sent out with roughly 10% of attendees responding and 85% of respondents rating the event eight out of ten or more.

Very positive coverage in the media as well with features on the BBC website, S4C Newyddion, ITV Wales evening news, Radio Cymru and Radio Wales.

Thanks; Coeliac UK would like to thank all those who helped make the show a success and particular thanks goes to those who helped out on the day.

- Sian Evans and Alison Jones for promoting the show to their networks.
- Dr Dai Lloyd AM, Dr Jill Swift, Claire Constantinou, Norma McGough and Martin Sutherland for taking part in what was a very useful and popular panel debate.
- Sian Evans, Amy Bolton, Kath Singleton for supporting our dietetics clinics on the day.
- To Graham Phillips, Abi Moore, Brachann Davies, Sonya Sotirova, Julia Barrington, Michael Benjamin, Jan Jones, Marion Mardell, Jan & Ian Severn for all their hard work on the day.
- To Ian Severn for his fantastic support on the day and in the build up as well.

There are plans to run the event again next year.

Endoscopies & gastroenterological services in Wales.

a. Discussion

This was deferred to the next meeting.

AOB

Informatica

TH & NMG met with Simon Scourfield and identified need for a case study. Alison Jones has volunteered a practice in Hywel Dda.

ACTION: AJ to speak with practice manager

ACTION: TH to add to agenda of next meeting

Timings of future meetings:

A discussion was had over timings and locations of future meetings. A member has

requested meeting outside of Cardiff in the future and whilst this is difficult, it was suggested a teleconference could be an alternative way to the resolve this.

ACTION: TH & DL to investigate teleconferencing options for future meetings.

Dates for future meetings:

March 12 6-8pm

Action Points

Action	Assigned to
Submit consultation on behalf of CISA and report back to group at next meeting	TH
Speak with Lead in Scotland regarding approach to ACBS list in Scotland	TH
Add Gastroenterological services & Informatica discussion to agenda for next meeting.	TH
Investigate teleconferencing options for future meetings	TH/DL
Present report on Hywel Dda prescribing scheme at next meeting	AJ
Speak with Hywel Dda practice manager about volunteering as an Informatica case study.	AJ