

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

Date & time: Nos Fawrth 19 Mawrth 2019, 18.00-19.30  
Tuesday 19 March 2019, 18.00-19.30  
Venue: Ystafell Gynadledda C, Tŷ Hywel.  
Conference Room C, Ty Hywel.

Attendees: Dr Dai Lloyd AM –Chair (DL), Tristan Humphreys – Secretary/Coeliac UK (TH), Alison Jones – Hywel Dda University Health Board (AJ), Claire Constantinou – Cardiff & Vale University Health Board (CC), Dr Geraint Preest – Pencoed Medical Centre (GPr), Ian Severn – Cardiff Local Group (IS), Jenny Pugh-Jones – Hywel Dda University Health Board (JPJ), \*Norma McGough – Coeliac UK (NMG), Rhun ap Iorwerth AM (RAI) \*Ruth Passmore – Coeliac UK (RP), Sian Evans – Cardiff & Vale University Health Board (SE) \*Joining by Skype

No.	Item
1	Apologies for absence Henry Wilkins, Simon Scourfield, Graham Philips, Heather Stevens, Jill Swift, Dr Huw Jenkins, Llyr Gruffydd AM.
2	Minutes of last meeting a. Amendments and approval of the Minutes The minutes were approved without amendment. b. Matters arising Tristan Humphreys' (TH) Care in Schools Alliance update to be provided at next meeting. All other matters arising were incorporated into the agenda.
3	Hywel dda prescribing pilot a. Presentation of report from Alison Jones (Clinical Lead Prescribing Support Dietitian – Hywel Dda University Health Board) Alison Jones presented an overview of the Hywel Dda Prescribing Gluten Free Scheme. The Pilot ran from June to December 2018. Instead of Gluten Free food on regular prescriptions participants were given a pre-paid card, loaded quarterly with funds to cover the cost difference of Gluten free and gluten containing equivalents when purchased. A service evaluation via questionnaire was undertaken in November and December 2018. 189 people were approached and 120 people agreed to participate in the pilot. Out of the 120, 104 opted to continue and 17 returned to prescriptions. <i>Demographics of participants</i> Most participants (71%) were female and the vast majority (88%) had been diagnosed more than 3 years. There was an equal split between those from urban and rural dwellings and the pilot covered areas of deprivation-Pembroke Dock, Milford Haven, Carmarthen and S.Ceredigion.

*Usage:*

Most used the card in supermarkets (Tesco, Morrison, M&S and Co-op) to purchase bread, cereal, alternative breads, rolls and savoury products which accounted for 72% of purchases.

There were very few issues with the card with over 2,000 successful transactions. There were no issues checking balances and the card company and health board worked very well together.

*Level of subsidy:*

Participants received £1 for every unit of gluten free they are entitled to on prescription (E.g. Male aged 19 – 59 years, monthly unit entitlement = 18. Monthly card load = £18 → £54 / quarter).

Feedback suggested that some participants were unclear that the money was a subsidy rather than equivalent to the full cost of goods.

*Benefits of card:*

Among participants surveyed:

- 75% of comments were positive, with ease of access and choice highlighted.
- 85% of those taking part preferred the scheme to the current system.

Most felt there were few, if any, benefits of regular prescriptions over the card though some did highlight access to preferred prescription product brands. Generally participants commented on quality of products being at least as good, if not better, than prescribable alternatives. Some raised issue of local shops not having a great supply though most had no problems.

*Considerations;*

*Online shopping:*

There were some issues with online grocery shopping as you can't split payment between two cards and minimum order required. This is reflected in small percentage of participants shopping online. This was a particular issue for mums with small children.

*Prescription only products;*

Difficulty getting prescription products in retail was one of the frustrations for participants. There was also some negative feedback when cost of specialist prescription products revealed. Rhun Ap Iorwerth (RAI) raised concerns about individuals being able to demand specific products where costs are greater.

*Evaluation of those who chose not to take part;*

68 people chose not take part in the pilot of which 30 responded. The vast majority had been diagnosed more than 10 years and were over 61 years of age.

Most felt it was easier on a prescription, they preferred the products and they didn't want to have to keep receipts.

*Financial assessments:*

	<p>Financial assessments suggest the card could be given to all 1050 patients entitled to support and it would still be £3,005 cheaper annually than prescriptions for 750 people. Opportunity costings suggest further significant savings.</p> <p><i>Conclusions;</i></p> <p>There is an appetite for change and of those that tried it out, most wanted to continue. It was mostly used for its intended purpose and choice was particularly highlighted as a benefit of the scheme.</p> <p>Very few problems were reported with the card – it was mostly used for its intended purpose to purchase equitable products to regular prescriptions.</p> <p>Some concerns were raised as to whether the level of subsidy is correct and this is something that will need to be considered further. Rural access doesn't seem to be a problem but this will need to be further interrogated with any future roll out. It was cheaper to run and administer than existing prescriptions.</p> <p style="text-align: center;">a. Questions and discussion</p> <p>Discussions covered monitoring of the pilot and whether the existing prescribing system may need to be maintained for some vulnerable groups. The level of subsidy was also debated with agreement that this needed to be further interrogated going forward.</p> <p>Next steps</p> <p>AJ will submit her report to Hywel Dda University Healthy Board for decision on next steps. The group agreed to maintain a watching brief and will look at the outcomes at a later date prior to any potential further roll out. RAI stated that some concerns still remained within the group and that prior to any potential national rollout there would be a thorough process of scrutiny and consultation needed through the Assembly. A further update will be provided at the next meeting.</p> <p>The group commended AJ on her hard work and look forward to hearing more at the next meeting.</p> <p><b>ACTION: AJ to provide update at the next meeting</b></p>
4	<p>Changes to prescribing regulations in England and potential impacts in Wales.</p> <p style="text-align: center;">b. Update on situation in England (NMG) c. Update on ACBS list administration in Scotland (TH)</p> <p>TH provided an update from the Lead in Scotland (Coeliac UK); There is no Scottish link now to the ACBS list. They instead now have all prescribable gluten-free food products listed in the Scottish Drug Tariff instead.</p> <p>In order to add any new product a manufacturer they will have to apply to add the product into the Scottish Drug Tariff. However, there is a need to set up a new system first to enable the assessment of products as being suitable for NHS prescription to replace the previous ACBS role of assessing products and are hopeful of perhaps working collaboratively with our Welsh Government counterparts who are in the same position. AJ explained that Wales are</p>

	<p>currently using the Coeliac UK list for reference but going forward will need to have a new system in place.</p> <p>d. Update on ACBS list administration in Wales/plans going forward (AJ)</p> <p>AJ suggested possible formation of a Welsh ACBS. DL proposed a letter to the Minister of Health and to the Chief Pharmacist for Wales.</p> <p><b>ACTION: TH to liaise with DL over letter to the Minister.</b>  <b>ACTION: TH to request meeting with Chief Pharmacist Andrew Evans</b></p>
5	<p>Letter from BSNA and GDPR concerns</p> <p>a. Discussion</p> <p>A number of members have received letters from BSNA regarding the Hywel Dda prescribing scheme. It is not clear how individual's email addresses were identified and concerns were raised with regards GDPR. The group felt this was not an appropriate way to engage with the group and it was agreed that the Chair would respond accordingly.</p> <p><b>ACTION: DL to send response to BSNA</b></p>
6	<p>AOB</p> <p>None.</p>
7	<p>Dates for future meetings:</p> <p>6.30pm June 11<sup>th</sup></p>

Action	Member
<b>Liaise re: letter to the Health Minister</b>	<b>DL &amp; TH</b>
<b>Request meeting with Chief Pharmacist, Andrew Evans</b>	<b>TH</b>
<b>Reply to BSNA</b>	<b>DL</b>