

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

Date & time: Wednesday, 3 December 2025, 10:30am-11:30am

Venue: Hybrid – Ty Hywel Video Conferencing Room/ MS Teams

Attendees: Rhun ap Iorwerth MS – Chair (RaI), Mabon ap Gwynfor MS (MaG), Rhys Hughes (RH), Tristan Humphreys (TH), Fiona Newsome (FN), Ian Severn (IS), Gwawr James (GJ), Claire Constantinou (CC), Sian Evans (SE), Khurram Hashmi (KH), Chloe Hutchinson (CH)

| No. | Item |
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| 1 | <p>Apologies for absence:</p> <p>Welsh government, Llyr Gruffydd, Ieuan Davies, Richard Cousins, Mark Isherwood, Mike Hedges.</p> |
| 2 | <p>Minutes of last meeting</p> <p>The minutes of the last meeting were approved.</p> |
| 3 | <p>GF Subsidy Card Scheme (GFSCS)</p> <p>TH gave an update on the GFSCS which is expected to roll out through 2026. The Delivery Board has met, with discussions described as positive. Implementation will take place at a health board level, with expected timelines and the establishment of implementation groups to be reported back at the next meeting in January 2026.</p> <p>There was a discussion about the importance of clear, transparent communication with patients, particularly around subsidy level setting. The general messaging from the Delivery Board was that patients should await guidance from their local health board.</p> <p>RaI asked about transition and whether there would be a cut off point for traditional prescribing. IS reported that the community is receiving mixed messages from dietitians regarding availability and timelines. TH reassured the group that there would not be an immediate cessation of GP led prescribing and that the Welsh Government has committed to a mixed model so those for whom the new model would not be appropriate (e.g care home residents) would still be able to access traditional prescribing.</p> <p>Research on costs undertaken by Cardiff University was referenced. It was noted that there is currently no intention to formally link the scheme with clinical pathways or broader dietetic support, which was highlighted as a potential missed opportunity, particularly in light of coming updated BSG guidance.</p> |

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| | <p>CC emphasised the importance of co-production with dietitians and confirmed that a mixed model will be implemented in Cardiff and Vale. CC also mentioned that patient voice should be represented on the Delivery Board, from both paediatric and adult perspectives. RaI highlighted that this discussion underlined the importance of patient voice in decision making.</p> <p>A question was also raised regarding what guidance or learning from Hywel Dda could be shared with other health boards.</p> <p>Update on Gluten Free Prescribing – England</p> <p>FN gave an update on the prescribing landscape in England.</p> <ul style="list-style-type: none"> • 16 (38%) have withdrawn • 11 (26%) where it is available – 3 looking to withdraw • 9 with mixed policy • 6 (14%) restricted to specific groups <p>Since 2022, there have been 10 consultations and reviews, including 7 in 2025. Decisions are being made due to financial pressure and inaccurate data, rather than clinical need.</p> <p>TH noted that the NHS in England is restructuring into 26 ICB clusters, which may be accelerating these decisions. In response to a question from RaI regarding regulation, TH confirmed there is no national guidance or expectation, aside from a policy allowing bread and flour to be prescribed as a maximum provision. Regular questions to the Minister have received consistent, non-committal responses. TH mentioned that a joint letter from RCPCH, BSG and BSGHPAN will be going out to the government on this issue.</p> <p>CUK is considering how it can help fill the gap in England. RaI noted how this context reinforces the importance of continuing the Welsh scheme and its role in cost savings. TH highlighted that the Welsh model is frequently referenced positively. It was also noted that awareness of post-diagnosis support can encourage individuals to seek diagnosis.</p> |
| 4 | <p>BSG Guidance</p> <p>TH shared that new BSG guidance is expected in early 2026 and is likely to include a shift towards increased use of no-biopsy diagnosis. Lessons from Scotland were noted, including the use of coeliac-specific endoscopy lists. TH highlighted the importance of laboratories, working with clinicians and having standardised accurate/clear testing. CUK has started conversations.</p> <p>Risks associated with no-biopsy diagnosis were noted, including the need for secondary care and gastroenterology oversight.</p> <p>CC noted that this presents an opportunity to develop a Wales-wide coeliac pathway. KH confirmed that work is underway via HealthPathways to develop an all-Wales pathway, working with local gastroenterology and coeliac specialists. Current system challenges include delays to endoscopy and diagnosis, patient confusion while awaiting diagnosis, monitoring gaps, and inconsistent annual reviews. Cardiff and Vale’s existing pathway is being adapted, with a focus on getting the pathway right first time.</p> |

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| | <p>CH highlighted the work done by Crohns & Colitis UK and partners to develop a lower GI pathway for primary care.</p> <p>CC highlighted the lack of investment in gastro dietetians across Wales and the need to empower patients to take a more active role in their care. It was suggested that links be made with clinical leadership groups at national level.</p> |
| 5 | <p>AOB</p> <p>TH thanked members for their engagement and hard throughout the parliament. On behalf of Coeliac UK, TH thanked RaI and RH for all their support in advocating for the coeliac community in Wales and wished them well for the coming year and election period. Hoping to bring the group together in the next Senedd.</p> |

| Actions | Member |
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| Circulate minutes | FN/TH |
| Seek clarity on patient involvement in GFSCS Delivery Board | TH/FN |
| Share contact details of Clinical Leadership Group Chair | CC |
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