

Minutes – Advisory Committee on Borderline Substances

10 and 11 March 2026 | By teleconference

Attendees:

Alison Smith (AS) - Chair
Anne Daly (AD)
Clare Denning (CD)
Charlotte Ellerton (CE)
Charlotte Howard (CH)
Gemma Phillips (GP)
Ghazala Yousuf (GY)
Ian White (IW)
Jane Murphy (JM)

Melanie Hill (MH)
Lauren McVeigh (LM)
Suzanne Ford (SF)

Apologies:

Sarah Britton (SB)
Jas Khambh (JK)
Shamin Jiwa (SJ)

1. Introductions and apologies

Apologies are listed above. [REDACTED] and [REDACTED] left the meeting early on Monday, while guests [REDACTED] gastroenterology dietitian at Sheffield Teaching Hospitals, [REDACTED] from BSNA, and [REDACTED] from Vitaflo joined for specific items of business.

[REDACTED] announced the joining of new members and full introductions were carried out.

2. Declarations of Interest.

[REDACTED] read out the declaration of interests and urged members who had not submitted theirs yet to do so. Several of the new members reported technical issues accessing the form, which the Secretariat agreed to investigate. The interests declared are at appendix A.

3. Minutes of the 10 and 11 November 2025 meeting

The minutes were agreed and ratified.

❖ Secretariat to redact and publish the minutes

4. Business

a. Gluten free prescribing [REDACTED]

[REDACTED] provided background on recent correspondence requesting inclusion of gluten ataxia as an ACBS indication. [REDACTED] agreed that this should be brought to the committee for discussion at the March meeting to consider whether the current indication ("for the dietary management of Coeliac Disease and Dermatitis Herpetiformis") remains sufficient or should be extended.

To provide additional information about the condition, [REDACTED] joined the discussion and provided a comprehensive overview of the condition, its diagnosis and treatment. [REDACTED] explained that diagnosis is largely centred on specialist neurological input, with TTG6 testing available only in limited centres, and that published evidence is concentrated in a small number of specialist institutions, particularly Sheffield. [REDACTED] highlighted the potential impact of the condition on quality

of life and food insecurity, while acknowledging that gluten ataxia is not universally recognised and that further research is ongoing.

The committee discussed the national reduction in gluten-free prescribing since 2018 and the trend of Integrated Care Boards adopting zero prescribing policies for gluten free foods. Members raised concerns about setting a precedent by expanding indications without adequate, independent evidence, noting the absence of an internationally agreed diagnostic definition or disease coding for gluten ataxia, the limited research base which is confined to a single specialist centre, and a lack of robust multicentre or international studies.

Given these limitations and the decommissioning of gluten-free prescribing in many areas, the committee decided not to add gluten ataxia to the ACBS indication at this stage, with the option to revisit the decision if a stronger evidence base emerges.

b. IMDs acceptability study requirements [REDACTED]

The Committee considered the revised position statement from the British Inherited Metabolic Disease Group (BIMDG), following the agreed review of the 2022 changes to acceptability study requirements for IMD products. According to the BIMDG review, the change has not achieved the intended aim of making acceptability studies easier to undertake and new protein substitutes more accessible for patients with IMDs. The BIMDG review concluded that product applications continue to be constrained by recruitment challenges.

[REDACTED] and [REDACTED] supported BIMDG's stance, noting that current requirements hinder IMD application submissions. The committee raised concerns about adult metabolic centres being approached less often than paediatric ones for acceptability studies. [REDACTED] and [REDACTED] agreed to get feedback from clinical teams about recruitment patterns and share insights, acknowledging ACBS's preference for both adult and paediatric participation when appropriate and possible.

Members supported adopting BIMDG's revised approach, with potentially a further review after two years. Secretariat to liaise with BIMDG to confirm the revised statement and proposed wording, then share a final version with BSNA for comments prior to publication. The Committee discussed implementation via the existing joint working group route [REDACTED]
[REDACTED]

- ❖ Secretariat to seek confirmation from BIMDG on the revised position statement and proposed wording
- ❖ Secretariat to share the final statement with BSNA for comments prior to publication

c. ACBS indications and Joint Working groups update [REDACTED]

[REDACTED] and [REDACTED] provided an update on the restart of the Joint Working Groups with Industry. The first item of discussion will be ACBS indications, which have been manufacturer-led to date, and often inconsistent. The aim of this working group is to develop clearer, simple, standardised indications aligned with BNF categories.

[REDACTED] reaffirmed the intention to proceed with this work, starting with standard adult oral nutritional supplements, based on the previously agreed draft indication (February

2020). Members were invited to contribute expertise to future workstreams covering enteral feeds, paediatric products and specialist categories.

d. Aveeno Cream unsanctioned price increase

Consideration of Aveeno Cream was deferred to 10 March due to [REDACTED] early departure on 9 March. The NHS Business Services Authority (NHS BSA) advised the Secretariat that Aveeno Cream, an ACBS-listed product, appears to have been subject to price increases implemented in July 2025 and other dates prior to that without ACBS approval. The Secretariat requested further information from NHS BSA regarding the number and scale of the unsanctioned price increases, which were revealed to be significantly over the threshold.

[REDACTED] all proposed price increases require formal Committee approval, and must be within the threshold set by the RPIx for a given month. Price increases implemented within one year of Drug Tariff inclusion and outside of policy may place ACBS status at risk.

[REDACTED] provided some context around the relevance of the product: [REDACTED] described the formulation as a traditional oatmeal based emollient and outlined emerging safety concerns, noting evidence from paediatric dermatology and allergy practice, particularly in France and the UK, that topical application of oat containing products may be associated with the development of oat allergy in children with atopic eczema. [REDACTED] advised that allergists generally discourage the application of food proteins to the skin.

The committee also discussed economic concerns, observing that the product is no longer cost effective, with anomalies in pack pricing and significantly cheaper, near identical colloidal oat creams available in Part IX of the Drug Tariff.

The Committee unanimously agreed to remove Aveeno Cream from Part XV of the Drug Tariff, as the unsanctioned price increases were outside ACBS policy and the product is not essential given the availability of cheaper, clinically equivalent alternatives in Part IX.

e. ACBS Governance and Committee Processes

[REDACTED] outlined steps taken in the past year to strengthen governance arrangements. These measures have included the formal appointment of co-opted members [REDACTED] as well as a brief review of committee processes at the November meeting. Efforts have also been made to increase committee capacity through the recruitment of additional members. A formal induction for new members is scheduled to take place between March and April, and all members will be strongly encouraged to participate.

As part of these efforts, [REDACTED] also announced the re-introduction of annual performance reviews in line with expectations for publicly appointed advisory committees. Members were reassured that reviews would focus on engagement, attendance and responsiveness.



d. Meeting date for November 2026

The committee agreed to set a meeting for 08 and 09 March 2027. The following dates were also confirmed: 14 July 2026 and 16-17 November 2026.

- ❖ Secretariat to put the meeting dates in diaries and update the schedule on Gov.UK

5. Product submissions

Product submissions were discussed. A record of this conversation is at appendix B.

6. Submissions processed mid-term

Appendix 2 of the meeting papers provided detail on the submissions processed mid-term. No amendments or comments were raised.

Table of actions

Action	Responsible
The Secretariat to liaise with BIMDG and Industry representative to progress work on acceptability study requirements for IMD products [REDACTED]	Secretariat
Secretariat to seek confirmation from BIMDG on the revised position statement and proposed wording.	Secretariat
Secretariat to share the final statement with BSNA for comments prior to publication.	[REDACTED]
Members to confirm acceptance of their formal appointment letters	ACBS members
Secretariat to put meeting date for July 2026 in the diary	Secretariat

Appendix A – Declarations of interest

Name	Name of organisation	Nature of interest
Melanie Hill	Nutricia	Dietetic department at Sheffield Teaching Hospitals NHS Foundation Trust are involved in an acceptability study for new metabolic product. I am the PI on this trial. I will remove myself from ACBS committee meeting when this product application is discussed, likely application in 2027.
Melanie Hill	Nutricia	I will be attending DMIMD study day on 22nd April, accommodation in London and travel will be provided

Suzanne Ford	Nutricia	I will attend the Dietary Management of Inherited Metabolic Diseases meeting on Wed 22nd April 2026 at Royal Soc of Medicine; travel, plus 1 night accommodation + subsistence will be provided by Nutricia. NB My NHS Trust has entered contract w Nutricia (I am not a decision maker re this).
Jane Murphy	Multiple	I co-lead REFRESH trial, (https://www.plymouth.ac.uk/research/penctu/refresh-trial) a large cRCT to investigate how best to treat malnutrition in older care home residents, all costs for ONS and foods are funded by NIHR. I also provide advice as Consultant Dietitian at The Adam Practice, Dorset as a NIHR Primary Care Commercial Research Delivery Centre (PC-CRDC) and UK site for a number of commercially funded clinical trials investigating new weight loss medications for people living with obesity. I am aware that The Adam Practice has participated in acceptability trials for new products submitted to ACBS but declare no involvement. I received honorarium from Dairy Council NI for an invited presentation in 2025 and receive fees as NIHR peer reviewer for research applications.
Charlotte Ellerton	Multiple	The nutrition & dietetic department at UCLH are involved in numerous acceptability studies for nutritional borderline substances from a variety of different manufacturers. I have no personal involvement in these studies.
Charlotte Ellerton	Nutricia	A colleague in my team is currently in the process of setting up an acceptability study as PI for a Nutricia product. I am not actively involved in the study but am offering support for my colleague regarding local research processes, and may be involved in data collection for patients if this is required. Inclusion of our site (UCLH) will be declared in the acceptability study.
Alison Smith		No interests to declare.
Ian White	L'Oreal	No honoraria, travel, hospitality, unrestricted grants, consultancy fees or any other exposure. L'Oreal (and its companies Vichy, La Roche Posay, CeraVe) is a regular sponsor of the Royal

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