

Date: 8<sup>th</sup> May 2025  
Ref: CORP 2025 - 076

Dear xxx

**Freedom of Information request: Community/patient public involvement on research board (NHS Trusts non-BRC) (CORP 2025 – 076)**

Thank you for your request for information which the Trust received on 31<sup>st</sup> March 2025.

Your Request:

1. *Does your NHS Trust/Board have an executive board where health research strategy for the hospital/s is set? e.g a Research and Innovation Board or other relevant high-level board.*
2. *If yes, is there a PPIE (patient public involvement engagement) representative on this board with the specific remit to provide insights into research agenda setting from the perspective of a patient with lived experience of health issues or as a member of the public/community? [I am not referring to the presence of a lay chair].*
3. *Is there a PPIE advisory structure (e.g. board, committee, panel) which provides PPIE insights to inform the work of the executive board? (not within individual study groups- I refer to high level feedback into your research strategy meetings).*
4. *If yes to question 2, 3, 4 or 5, please provide the most recent minutes/agenda with a list of members with designated roles/remits (not names).*
5. *Are PPIE representatives remunerated?*
6. *Do you require PPIE representatives to do any training? If yes, please specify e.g NIHR training or in house-training.*

Please find the Trust's response below:

**1. Does your NHS Trust/Board have an executive board where health research strategy for the hospital/s is set? e.g a Research and Innovation Board or other relevant high-level board.**

Yes. Research strategy and oversight are primarily managed through the Research, Development & Innovation (RD&I) Sub-Committee, which reports into the Strategic Development Committee and the Quality, Safety, and Performance Committee of the Trust Board.

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**2. If yes, is there a PPIE (patient public involvement engagement) representative on this board with the specific remit to provide insights into research agenda setting from the perspective of a patient with lived experience of health issues or as a member of the public/community? [I am not referring to the presence of a lay chair].**

The Trust has an established Patient and Carer Partnership Board (PCPB) that meet monthly to discuss a range of topics providing lived experience into the direction and operation of the Velindre Cancer Service (VCS). This includes discussions around RDI that feed into the mechanisms described below. The Chair of the PCPB also attends the Trust Board which is the ultimate Committee within the Trust's governance structure

Yes. The Research, Development & Innovation (RD&I) Sub-Committee Terms of Reference include Service User / Lay Representatives, intended to provide insight from the public and patient perspective. However, we note that these representatives have not attended recent meetings.

In addition:

- The Velindre Research & Development Strategic Leadership Group includes public representatives, who contribute to strategic direction-setting and discussion.
- The Welsh Blood Service (WBS), hosted by the Trust, coordinates a pan-Wales Involvement and Engagement Panel for PPIE. This group is a resource to be utilised by researchers and actively involved in planning and preparation of research projects and patient materials. It is operationally supported by the WBS RD&I Services Team.

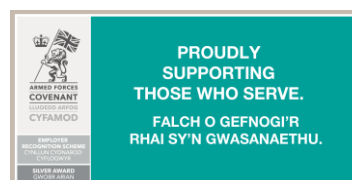
The Strategic Development and the Quality, Safety, and Performance Committees welcome attendance at meetings from Llais (Citizens Voice Body). The Trust also benefits from input via Velindre Voices [<https://velindre.nhs.wales/velindreecs/engage-with-us/velindre-voices/>], a growing PPIE community of patients, carers, and members of the public who provide feedback across a range of areas.

These structures reflect a wider organisational commitment to embedding public and patient involvement into research strategy and delivery across the Trust and hosted organisations.

**3. Is there a PPIE advisory structure (e.g. board, committee, panel) which provides PPIE insights to inform the work of the executive board? (not within individual study groups- I refer to high level feedback into your research strategy meetings).**

Yes – The PCPB as described above.

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Whilst the PCPB's focus is not solely on advising the RD&I Sub-Committee, PPIE insights are also gathered from multiple routes:

- Public representatives on the RD&I Strategic Leadership Group.
- Lay membership on the RD&I Sub-Committee (albeit not recently attended).
- The Welsh Blood Service PPI Panel, which offers consistent structured input.
- The Velindre Voices network, which is consulted on a range of projects, including involvement opportunities and communication materials.

These structures provide public perspectives into research priorities, delivery, and public engagement at both operational and strategic levels.

**4. If yes to question 2, 3, 4 or 5, please provide the most recent minutes/agenda with a list of members with designated roles/remits (not names).**

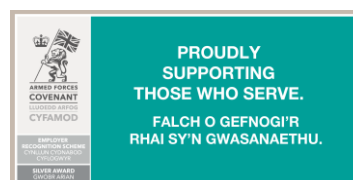
Where relevant, we provide information as follows:

- Public committee meetings including those where research matters may be discussed (such as the Strategic Development Committee and RD&I Sub-Committee), are published via the Velindre University NHS Trust's Board and Committee webpages: <https://velindre.nhs.wales/about-us/board-and-committee-structure/>
- Velindre Voices is the Trust's public involvement network. Information about this group, is available at: <https://velindre.nhs.wales/velindrecs/engage-with-us/velindre-voices/>
- The WBS Involvement and Engagement Panel is a flexible, pan-Wales resource available to researchers. It contributes to the planning and preparation of research studies and review of patient-facing information. It meets on an as-needed basis (typically no more than two hours per quarter). The group is operationally supported by the WBS RD&I Services Team. We are providing a copy of the Terms of Reference for this Panel.
- The Velindre Research & Development Strategic Leadership Group is an internal Trust group with responsibility for strategic oversight and collective accountability in delivering Velindre's overarching Cancer Research and Development ambitions. It ensures alignment with Velindre University NHS Trust's strategic plan and wider national/local priorities.

As this is an internal management group, minutes are not published online and they list attendees by name only, without their designated roles.

However, we are providing the Terms of Reference for these groups for your information.

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## 5. Are PPIE representatives remunerated?

No, PPIE representatives are not currently remunerated. They participate in a voluntary capacity. The Trust offers reimbursement of reasonable travel and subsistence expenses, where appropriate, in line with public involvement policies.

## 6. Do you require PPIE representatives to do any training? If yes, please specify e.g NIHR training or in house-training.

The PCPB members are recruited, trained and managed via the Velindre University NHS Trust's Volunteer Framework. This includes a mandatory training programme and an ongoing offer of supplementary educational opportunities. The current lay members of the Trust's RD&I group were recruited before this Framework was in place but there are plans to ensure they are managed and supported in the same way.

Where appropriate, the Trust also offers access to:

- Internal orientation and informal training, supported by Trust staff.
- External learning opportunities, including training from Health and Care Research Wales and the NIHR.
- Resources and guidance through Trust platforms.

The approach is flexible, recognising the diverse backgrounds of participants and the need to support meaningful engagement.

I trust this answers your request for information, however, should you not be satisfied with the information supplied or the process of supplying it, you have a right to complain and request a review. Please note that you must submit a request for a review within 40 days of the date of this letter.

You should forward your complaint to:

Mr Ian Bevan via [FOI.VUNHST@wales.nhs.uk](mailto:FOI.VUNHST@wales.nhs.uk)  
Head of Information Governance  
Velindre University NHS Trust  
2, Charnwood Court  
Heol Billingsley  
Parc Nantgarw  
Cardiff, CF15 7QZ

Should you wish to take your complaint further, if you are still unhappy with the decision after review, you can contact the:

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Prifysgol Felindre  
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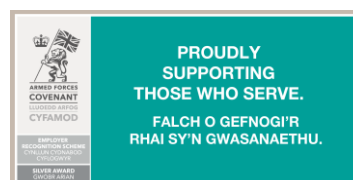
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<https://velindre.nhs.wales>

Information Commissioner's Office - Wales  
2nd Floor,  
Churchill House,  
Churchill Way,  
Cardiff, CF10 2HH  
Telephone: 0330 414 6421/email: [wales@ico.org.uk](mailto:wales@ico.org.uk)

Yours sincerely

**Non Gwilym**  
**Interim Director of Corporate Governance**  
Velindre University NHS Trust  
2 Charnwood Court  
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Cardiff, CF15 7QZ

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