

68th Meeting of the Privacy Advisory Committee
Thursday 12th March 2026
MS Teams

Present: Colin Harper (Chair),
Dr Frances Burns,
Prof Ian Young,
Michael McKenna
Geraldine Reynolds

In Attendance: Lorna Elliott, (Secretariat)

1. Welcome and Apologies

Colin Harper welcomed all attendees.
Cathy Cole apology was noted.

2. Minutes of previous meeting

Minutes of the 06 November 2025 meeting were approved.

3. Matters Arising

No matters arising.

4. Chairman's update

Updates are addressed under the relevant agenda items.

5. Update on encompass

Pushed to next meeting

6. Update on Legislation

Legislation: Frances Burns speaking to Health Committee this month then paper will be taken and introduced this mandate.

Regulations: update provided but ultimately cannot set a timeline at the moment.

7. Development of Privacy Advisory Committee

The Committee discussed the need to formalise its processes, including membership arrangements and information governance, particularly in relation to the encompass programme.

Members noted the requirement for clear procedures covering communication, bespoke email use, and data storage. Frances Burns has identified a resource to support the development of bespoke email address, a website, and appropriate storage solutions.

The Committee also reviewed membership proposals, highlighting the importance of achieving a balanced composition, including increased representation from researchers and potential members from outside Northern Ireland.

Action: Frances to provide contact details for resource to Colin Harper

8. Communication and Restraint Reduction (CARR) Study

Focused on research in acute mental health wards, particularly the use of body cameras for specifically for research purposes.

Ethical and legal concerns were raised about consent, especially for patients under treatment or lacking capacity.

The Committee debated the timing and validity of consent, the ability to withdraw consent, and the handling of confidential information.

There was consensus that consent in principle should ideally be sought at admission if the patient has capacity, with alternative procedures if not.

The Committee agreed that clarification is needed in relation to

- data controller and processor roles, and concerns about the proposed 20-year data retention period, especially if consent is withdrawn.
- Clarification needed on the use and storage of data collected via body cameras

Action: Colin Harper to draft a letter and circulate to the Committee.

9. NEWBIE Surveillance - Incidence of Neonatal Diabetes in the United Kingdom and Republic of Ireland.

Colin gave a brief introduction and was agreed to invite to present at the next Committee Meeting.

Action: Colin to invite to present to the Committee next month.

10. Guidance on Information Sharing for Child Protection Purposes

- The Committee reviewed guidance focused on data protection and discussed the appropriateness of seeking consent in child protection cases.
- There was debate about professional regulatory guidance and the assumption that consent has not been sought.
- The committee agreed on the need for careful wording and to consult with the BMA for further clarification.

Brendan O'Neill was tasked to follow up with the BMA regarding incompatibility with common law for further review of possible Guidance changes. Since Brendan has retired, the current status is unclear.

Action: Colin Harper to draft slight change in wording to guidance and submit to the Department for consideration.

Action: Lorna to investigate re BMA.

11. Any Other Business

- Frances Burns provided an update on the **NICON** audit.
- Colin Harper expressed his gratitude to Professor Ian Young for his contributions to the committee and extended best wishes as he moves on to his upcoming position.

12. Date of Next Meeting

Date of Next Meeting is 12th April 2026.

Actions:

Responsible Person	Agenda Item / Topic	Action	Completed
Frances Burns	Development of Privacy Advisory Committee	Provide contact details for the identified resource to the Chair	
Colin Harper	CARR Study	Draft a letter and circulate it to the Committee	
Colin Harper	NEWBIE Surveillance – Neonatal Diabetes Study	Invite the presenter to attend the next Committee meeting	
Colin Harper	Guidance on Information Sharing for Child Protection Purposes	Draft minor wording changes to the guidance and submit to the Department	
Lorna Elliott	Guidance on Information Sharing for Child Protection Purposes	Follow up with the BMA regarding common-law compatibility concerns	