Exploring the future of reproductive health data

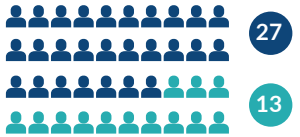
NIHR | Policy Research Unit Reproductive health

Summary of recommendations from a public deliberation run by the NIHR Policy Research Unit in Reproductive Health in June and July 2025 to discuss creation of a linked reproductive health data resource for research to drive improved services and reduce health inequalities, while protecting personal privacy, fairness, and trust.

40 participants* were recruited from across London and South East England to attend three workshops. The process included plenary sessions, table discussions and recommendation forming, concluding in voting.

Age

Ethnicity**

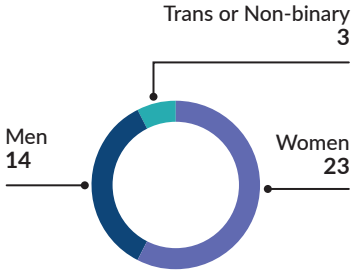


White British

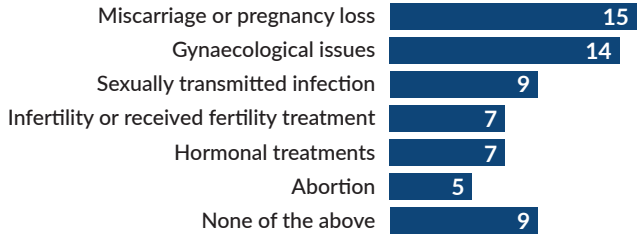
Black, Asian or other ethnic group

Education attainment and employment status were representative of the UK population

Gender

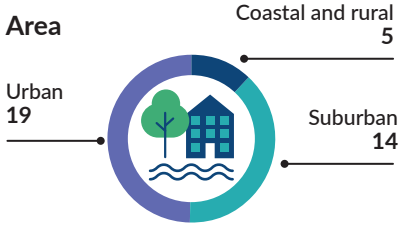


Reproductive health experience



Attitude to data use by NHS or for innovation***

Area



*Workshop attendance varied: 39 workshop 1 (online), 37 workshop 2 and 29 workshop 3 (both in person). A review of the cohort lost to follow up confirmed distribution of key characteristics remained in the cohort of 29 that attended the final workshop, with slight attrition of Black British participants in particular.

**Minoritised ethnicities and cis-women/trans and non-binary participants were oversampled compared to UK population.

***Categories based on aggregate scores to questions used in previous data engagements. Unconcerned = most positive to data use. Pragmatist = medium, ambiguous towards to data use. Absolutist = negative towards data use.

There was widespread support for linking reproductive health data if the following conditions are met:

Scope of dataset

What types of reproductive health data should be included?

- Linking different reproductive health data should be enabled where clear public benefit is demonstrated and privacy is protected
- A wide range of reproductive health data, including currently unlinkable data, should be included and linked to other health data where relevant
- All data types should have tight access controls, such as only accessing data needed for the research and researcher training
- Opt-out should remain standard to maximise inclusion, but more public information is needed to help people make active choices

For consideration

- All data can be considered for inclusion. An access panel should always review personal and cultural sensitivity, as there is not one dataset or topic that is always more or less sensitive than others

Support for recommendations

Access and governance

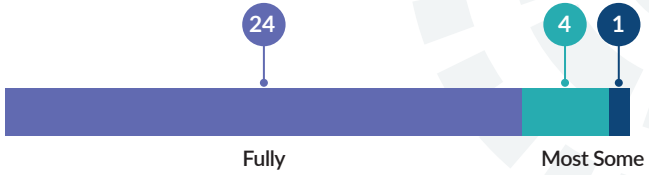
What rules, controls, and safeguards should govern who can access the data and why it is used?

- Access decisions should be made by independent panel of professionals and public representatives
- Decisions should be based on the purpose of the research and the sensitivity of the data requested
- Organisations requesting data must demonstrate trustworthiness and clear commitment to public benefit
- Requests should be prioritised based on:
  - Public benefit and scope of impact
  - Potential to reduce inequalities
  - Addressing research gap or underserved area of research
- Transparent/publicly available register of projects, data accessed, breaches, research outputs
- Process for ensuring data accuracy
- Data storage and safeguards in line with best practice

For consideration

- Access for politically driven purposes was not supported

Support for recommendations



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