

Proposal by
Professor Adam Glaser, Professor Richard Feltbower and Rebecca Mottram



UK REGISTER OF STORED OVARIAN AND TESTICULAR TISSUE (UKSTORE)

PPI MEETING

online: 1 hour, date TBC

Did you know?

The treatment given to a small number of children and young people with rare diseases can negatively impact on fertility. These patients are offered fertility preservation which allows them to freeze testicular or ovarian tissue for future fertility. So far, around the world, only a few hundred babies have been born using ovarian tissue, but none from testicular tissue. The technology to use tissue in this way is still developing.

What do we want to do?

We propose a national register of everyone aged 0-25 in the UK who has, or chooses to have, tissue preserved for future fertility. We want to track fertility from diagnosis through to reproductive outcomes to understand the risks and benefits of this approach. We want to use sensitive, identifiable data from health records and link this to national datasets. We believe it is vital that everyone is included (whole population) in order to get complete information on activities and outcomes.

How do we plan to do this?

To create the register, we propose to seek special legal permission to capture and link a limited data set on all patients who have undertaken, or do undertake fertility preservation tissue storage in the UK. This means patients will not need to consent to us using their data. When patients subsequently present to clinical team as per standard follow-up practices, they will be given information and the option to opt out if they wish. When they are 18, we will seek consent for ongoing participation.

We need your help to understand:

- The acceptability of our approach
- What information we should give people and the best way to tell them about what we are doing.



We are Adam Glaser, Richard Feltbower and Rebecca Mottram. Adam is a Professor of Paediatric Oncology and Late Effects, University of Leeds. Richard is Professor of Epidemiology, University of Leeds. Rebecca is Senior Research Nurse, NHS.