

# ARE WE ASKING TOO MUCH? YOUNG PEOPLE'S VIEWS ON CONSENT AND DATA SHARING AFTER FERTILITY PRESERVATION

**Rebecca Mottram**, Richard Feltbower, Sheila Lane, Rod Mitchell, Richard Anderson, Adam Glaser.

*University of Leeds, Professor of Epidemiology University of Leeds School of Medicine/Leeds Institute for Data Analytics, Room 8.49, Worsley Building, Clarendon Way, Leeds LS2 9JT., Consultant Paediatric Oncologist Lead for Future Fertility Programme Oxford Oxford University Hospitals NHS Trust, Headley Way, Oxford, OX3 9DU, Professor of Developmental Endocrinology Room E1.43, MRC Centre for Reproductive Health, Queens Medical Research Institute, 47 Little France Crescent, Edinburgh, EH16 4TJ, Professor of Clinical Reproductive Science The Queen's Medical Research Institute, Edinburgh BioQuarter, 47 Little France Crescent, Edinburgh, EH16 4TJ, Professor of Paediatric Oncology and Late Effects University of Leeds School of Medicine/Leeds Institute for Data Analytics, Worsley Building, Clarendon Way, Leeds LS2 9JT.*

## **Abstract Body**

**Background and aims:** We are establishing a UK-wide register of stored ovarian and testicular tissue (UKSTORE) to support service development, clinical audit and research. We performed a series of patient and public involvement and engagement (PPIE) consultations to seek advice on our intended approach to consent and data collection and to review patient materials.

**Methods:** 11 young people aged 11-18, 3 parents, 3 adult patients and 2 PPIE volunteers were recruited via useMYdata, DATACAN, Leeds Research Owls, Candlelighters Trust, Children's Cancer and Leukemia Group and Teenage Cancer Trust. Following an overview of UKSTORE aims and objectives, participants were asked to give preferences on information-giving and consent, use of confidential data without consent, data linkage and drafted patient materials. Discussions and preferences were used to help inform decision-making.

**Results:** There was 100% consensus that a population-wide registry to store data about reproductive tissue was necessary and important. 88% of participants supported a model of data capture without patient informed consent and 75% approved of data linkage to enhance subsequent analyses. Where consent was required, electronic or paper methods were both felt to be secure. For information-giving, 100% of participants aged 11-18 years preferred face to face consultations to a video call or information by post or email. Adults prefer to receive information via a printed leaflet and young people prefer a mixture of written and web-based materials.

**Conclusion:** PPIE strongly influenced the UKSTORE approach to data collection, data linkage, method of information-giving and design of participant materials. Patient views on consent and data sharing for research purposes may differ in important ways from the standards for consent as set out in the common law duty of confidentiality.

**Acknowledgements:** We are grateful to all participants who attended the workshop events.