

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

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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.

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