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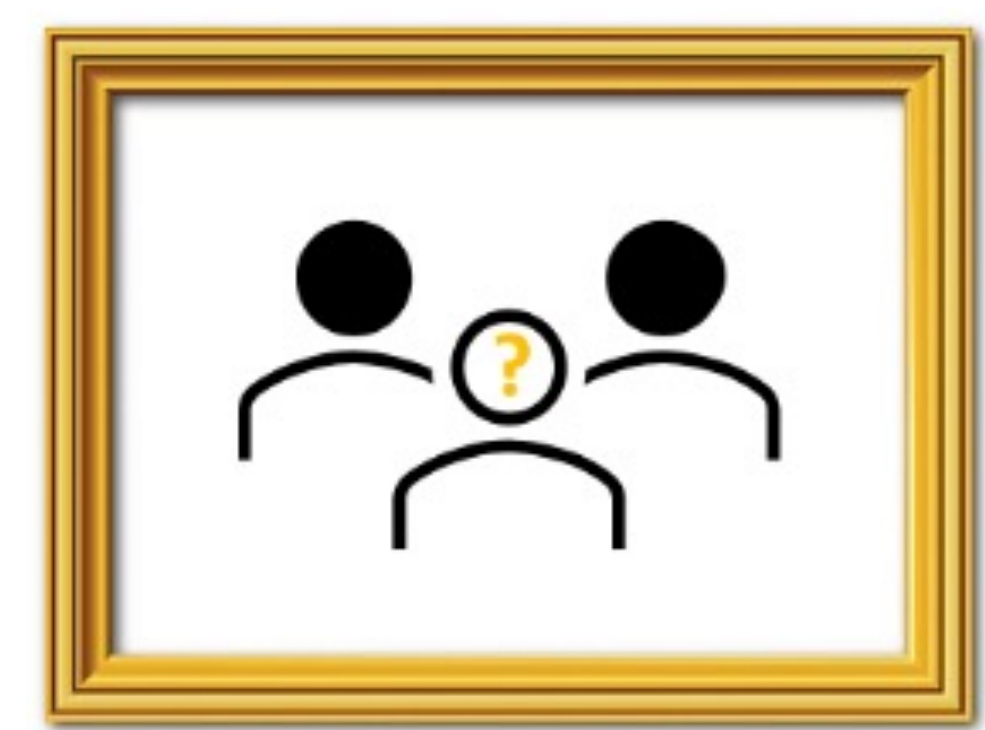
Putting the Person in the PICTuRE

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Background

Primary tumours of the brain and spine are classified as rare, accounting for less than 3 % and 1% respectively of all diagnosed cancers in the United Kingdom. Advancements in personalised medicine have been shown to shorten time to diagnosis, help improve oncology care, while providing genomic insights into cancer fundamentals. However, patient engagement within this field is limited, neurooncological biorepositories in the UK are sparse and often under donated, further research within this field is required to improve clinical outcomes. Therefore, there is a need to explore barriers to tissue donation through lived experience of the process.

STUDY PROTOCOL - Methods

Personalised Informed Consent in Tissue donation for Research lived Experiences..

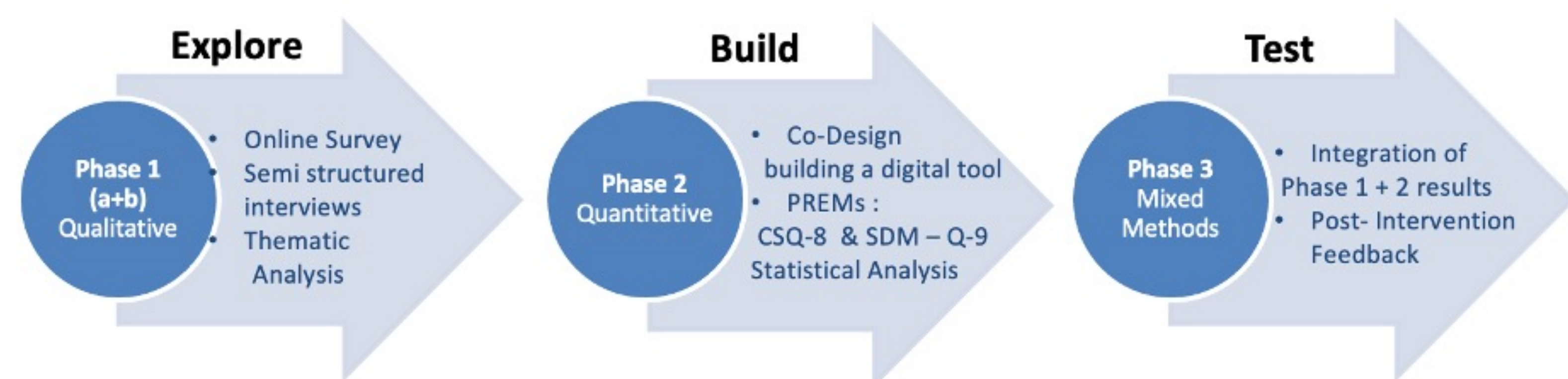
PICTuRE is a multistage mixed method exploratory sequential study set to explore lived experience of donating tissue for research.

Registered: ISRCTN12601034

Intervention

Aim : Provide people living with a primary tumour of the brain or spine optimal support for decision-making processes regarding donation of tissue for research.

The **outcome** will result in the development of a digital (online) consent and tissue donation tool, that will make participation in vital brain tumour and spinal sarcoma research easier for patients, clinicians and scientists trying to find better ways for tissue diagnostics and identification of new targets for treatment



The study consists of three phases:

- **Phase 1 (a)**: An online survey will capture lived experienced data that will take approximately 15 minutes to complete;
- **Phase 1 (b)** semi structured in-depth interviews will explore individual experiences. The interview will take place online and will last around 30 minutes. Thematic analysis of the data will identify key themes.
- **Phase 2**: Through co-design, patient reported experience data will be collected and statistically analysed to validate content for subsequent use in developing the digital intervention.
- **Phase 3**: Integration of phase 1 + 2 results will assist in refining the digital intervention. Post intervention feedback will inform future research.

Outcome Measures

Phase + Objective	Goal	Data source	Analysis
Phase 1 EXPLORE	Identify key lived experience themes of donating tissue for research	National online survey, Online semi-structured interviews	Qualitative: Thematic analysis
Phase 2 BUILD Intervention	Through co-design, gather user feedback. Identify statistical/ clinical significance/ impact	Patient-reported outcomes and experience (PREMs) questionnaires: CSQ-8 + SDM-9	Quantitative: Statistical analysis
Phase 3 TEST Intervention	Pilot interactive personalised digital platform. Propose a new standard of care	Evaluate intervention via semi-structured interviews + gather post intervention PREMs	Mixed Method: Thematic & Statistical analysis

Table.1.Study outcome measures, objectives, goals, data sources and methods of analysis.

Inclusion Criteria

To take part, you must be:

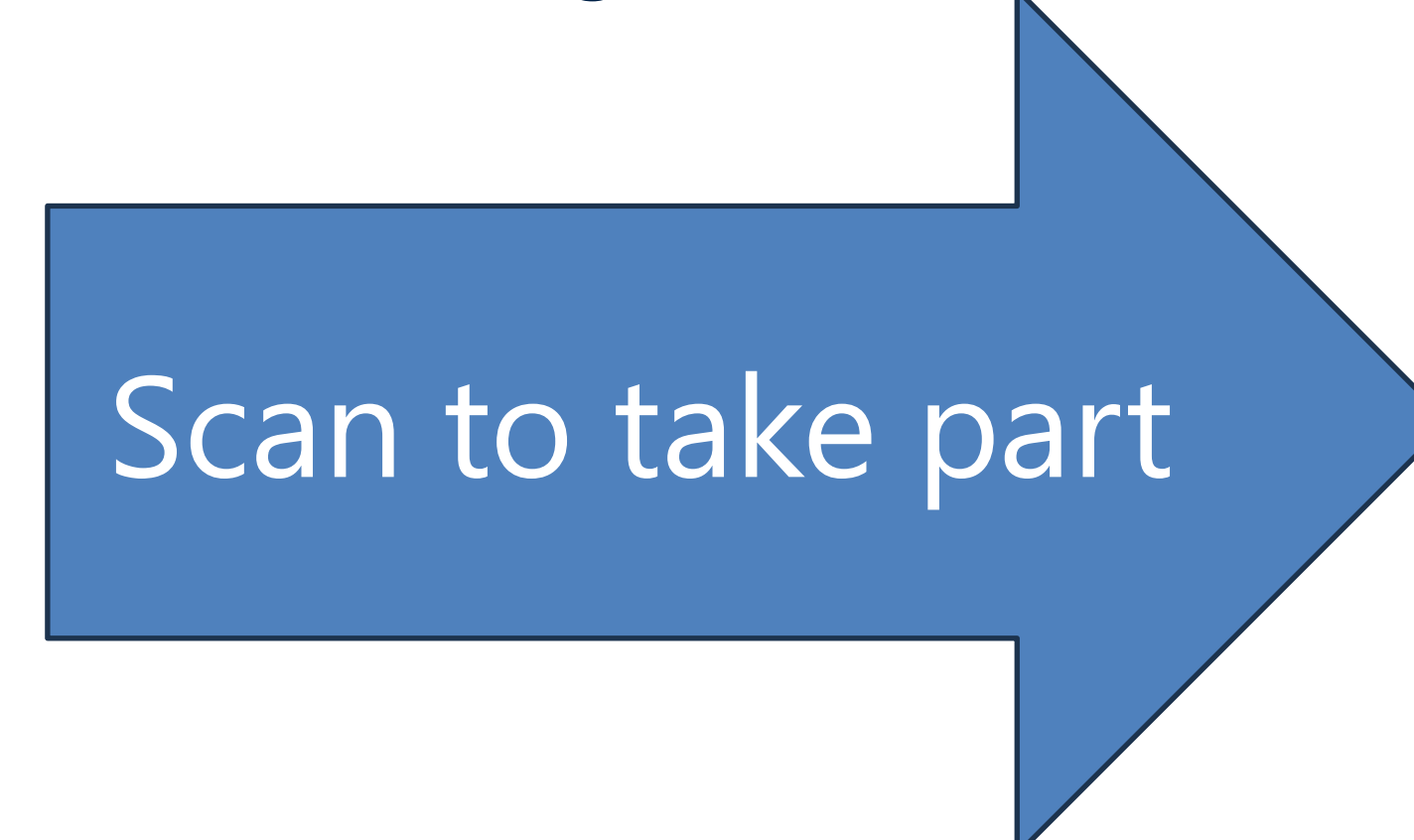
- 18 years or over & Live in the UK
- Have experience of living with a primary tumour of the brain or spine
- Be able to speak, read and write in the English language
- Have access to an internet enabled device



Next Steps...

What's involved?

1. Complete an anonymous online survey (10-15 mins)
2. If you would like to share your experiences further... Then, chat with a researcher online (30 mins)
3. Still interested, be part of a co-design group to develop a personalised digital consent tool.

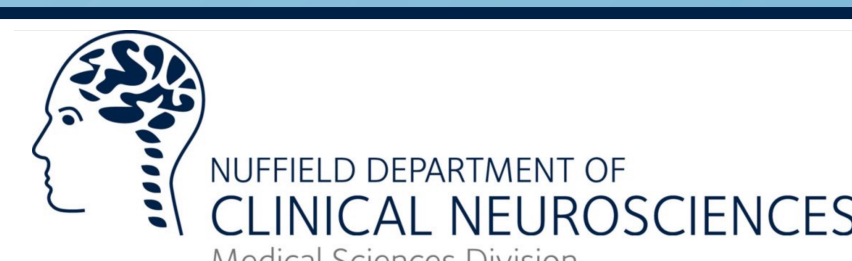
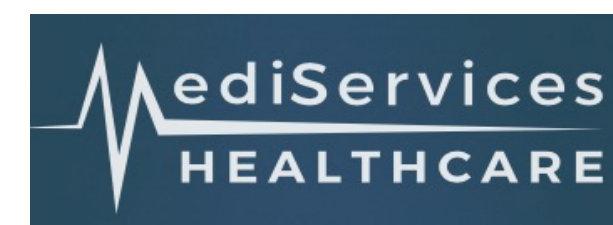


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