

“Who am I giving that data to?”: Barriers and Facilitators to Young Adults Participating in Clinical Research Involving Biological Sample Collection

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WHAT DID WE DO?

Recruitment challenges are frequently encountered in clinical research, especially in studies involving the collection of biological samples, such as saliva, blood and stool.

These challenges may be amplified in studies focusing on young adults, who may have more ‘ick’ factor in relation to these samples, and in mental health research when mental health symptoms may present additional challenges to engagement. With growing awareness of data security, concerns about how personal data and biological samples may be used, stored, and shared may also contribute to hesitancy.

We conducted 15 semi-structured interviews with 18-25 year olds. The sample comprised 8 females, 5 males, 1 non-binary participant, and 1 transgender participant; 7 with an anxiety and/or depression diagnosis, and 8 with no mental health diagnosis.

Reflexive Thematic Analysis (Braun & Clarke, 2021) was carried out, and four themes are presented below.

THEMES

TRUST,
TRANSPARENCY,
AND
INSTITUTIONAL
SAFETY

SOCIAL AND
EMOTIONAL
BARRIERS TO
PARTICIPATION

PSYCHOLOGICAL
BARRIERS

COMPENSATION
AND
RECIPROCITY

“Who could see that? Like you know, who am I giving that data to?”

WHY IS IT IMPORTANT?

Improving recruitment and retention in clinical studies requires understanding both what motivates participation and prevents it.

For young adults, clarity and transparency are key, especially around how samples and data will, and *will not* be used. Trust in the institution conducting the study, such as a university, also plays a central role.

Psychological, social, and emotional barriers matter too. Fear of judgement, or embarrassment around weight, bodily processes, or health conditions can discourage involvement. Fatigue, avoidance, or feeling overwhelmed, may make participation difficult, though for some, the opportunity to contribute to mental health research was motivating. Participants emphasised the importance of recognition for their time and effort, through incentives and by receiving study updates and findings that show the value of their contribution.

These insights highlight ways to make research more transparent, accessible, and engaging.

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