Consent process for medical research conflicts with standard UK practice

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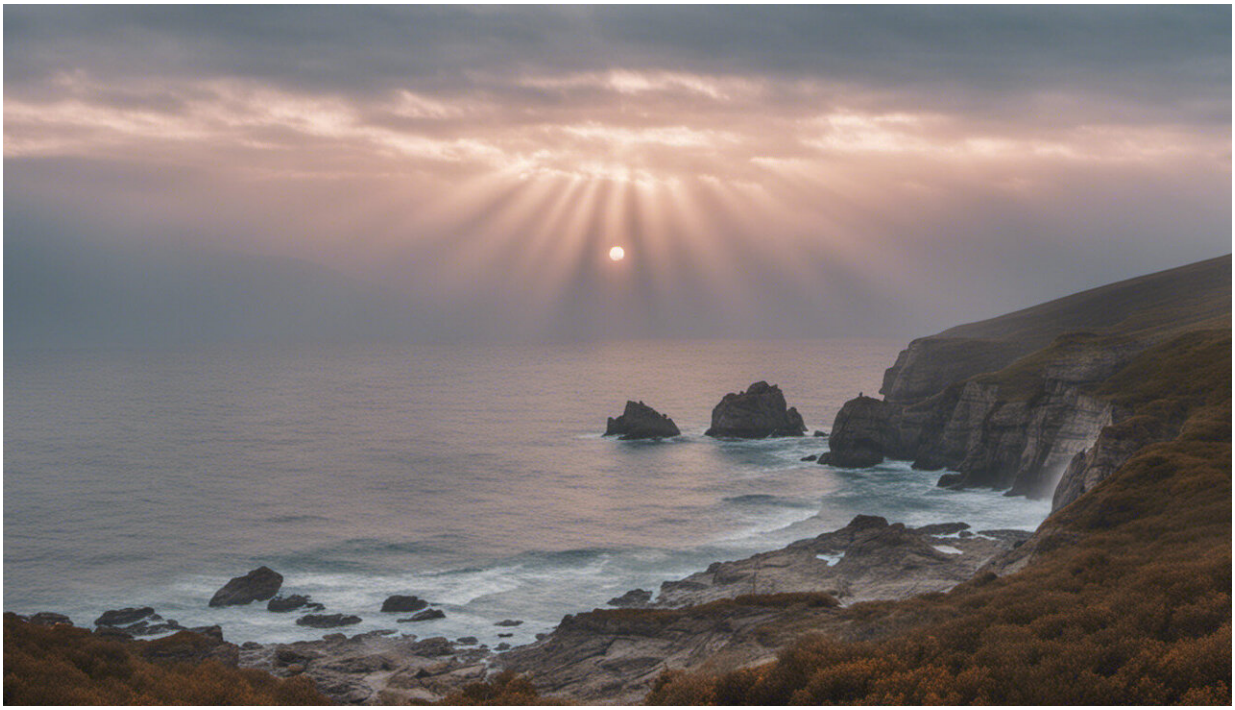

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A major investigation into the views of volunteers on the consent process for medical research has been found to conflict with the standard practice required for consent in the UK.

In the project led by the University of Exeter, sociologist Professor

Susan Kelly has found that trust and personal relationships appear to play an important role in shaping people's willingness to consent to research.

A survey of over 2,300 participants at a national biobank (TwinsUK) containing genetic and clinical information found that many of the volunteers' preferences regarding consent to participate in medical research conflict with the current 'gold standard' enforced by Research Ethics Committees in the UK.

The study published in *PLOS ONE*, shows that research participants were asked under what circumstances they would want to be re-contacted about the inclusion of their clinical data or DNA in future research studies. They were more willing to give their consent to cover future research if their information or DNA was going to be used by the original researcher than by another researcher. A large majority of the volunteers also stated that knowing the name and contact details of the main researcher running the study would enhance trust. This remained the same even if the disease under investigation varied.

As a result, this position challenges research ethics frameworks that require new consent for new studies. Moreover, 80% stated they were willing to complete consent online, instead of face to face, despite many Research Ethics Committees insisting on the latter.

Professor Kelly from the Centre for the Study of the Life Sciences (EGENIS), Sociology, Philosophy and Anthropology, University of Exeter said:"This study highlights the need to reconsider our ethics procedures in this context. Instead we need to focus on aspects that people say they really care about when they sign up to studies (e.g. who will use the data or samples, for what purpose, and who is likely to benefit). This study also resonates with calls to think of people's participation in health research as an act of solidarity."

Professor Barbara Prainsack, from King's College London one of the senior authors of this study said: "We need to move away from the idea that individual control over what happens with my research data every step of the way is the only solution – there are other governance frameworks that increase public benefit and ensure that risks for individual donors are minimal."

The findings show that this could also help to cut the number of samples that have to be unnecessarily discarded, reduce the increasing cost of bureaucracy and enable more money to go into research where it matters.

More information: *PLOS ONE*, DOI: 10.1371/journal.pone.0118027

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