

Can we use consent to protect privacy?

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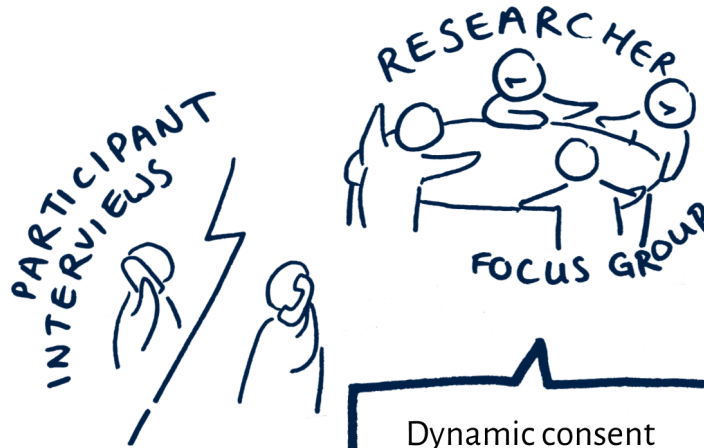
Background

Cybersecurity is where consent and privacy come together. Developed to protect against abuse^{1,2}, informed consent has lost its meaning because people are no longer informed over time^{3,4}. Such communication is important—literature suggests that engagement make research more relevant⁵. Dynamic consent⁶ is a theory that models engagement as 2-way communication, but has little empirical support. I show that feedback increases research participation in an online study, and provide a model for researchers to use.

- Engagement = interest + knowledge + active participation.
- Researchers have a duty to protect data:
 - "I think you've got to... ensure that not just anybody can access that data", P11.
 - "I'm giving you the authority to use what I give you... keep it safe", P14.
- Data-use should be confidential, private and legally compliant:
 - "Nothing is going to ever be totally secure but I would put my trust in them to share my data securely and appropriately", P13.
- Many were interested in the study because their condition isolated them, but they did not expect to engage with the study.
 - "It's just an email, isn't it?", Po2.

Research aim 1

Observe and evaluate an existing implementation of dynamic consent.



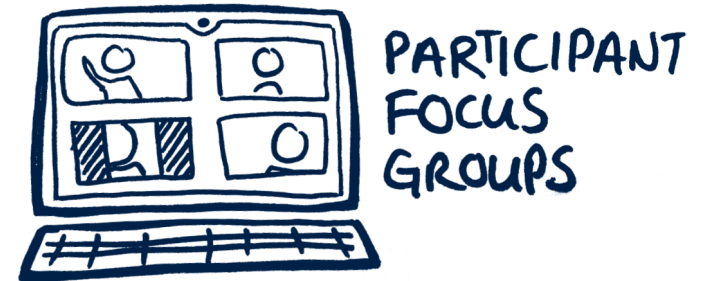
Dynamic consent practices: online, editable consent options and a forum.

Researchers prioritised engagement, reporting that they had learned valuable lessons from participants.

Interviews showed a distinct lack of participant engagement with the study. I then asked, in focus groups, what they wanted to know about the study.

Research aim 2

Empirically strengthen dynamic consent's justification for engagement.



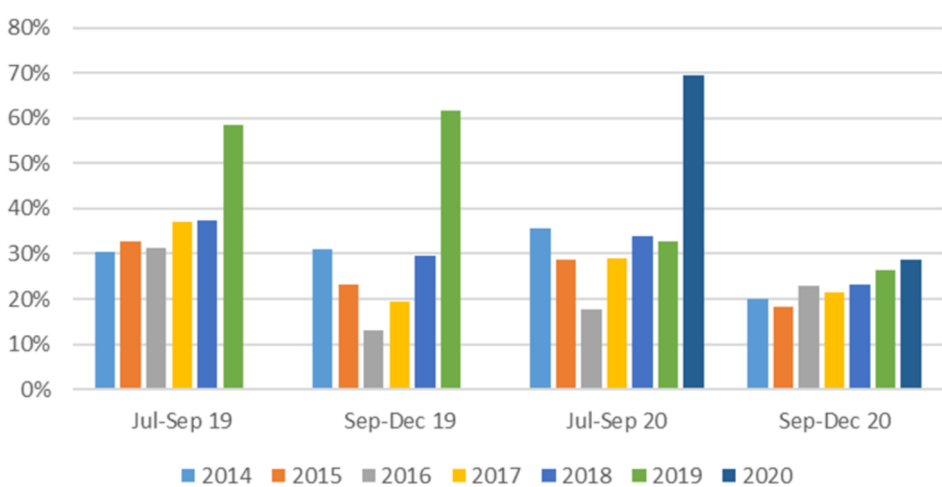
The website should signpost key information.

Email reminders should highlight participant contributions.

Tasks should describe how data is used.



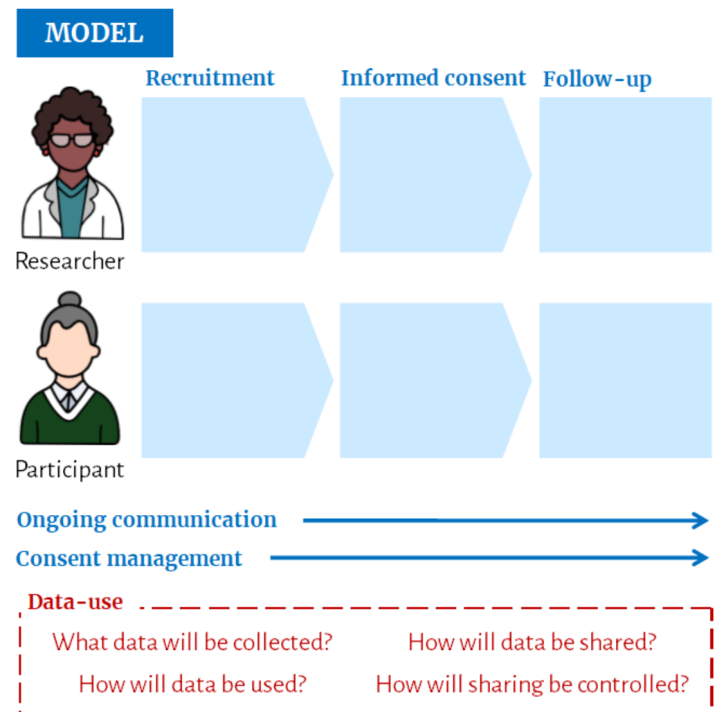
Intervention study (analysis ongoing)



Graph showing the effect of enhanced feedback on questionnaire completion (excludes 2 weeks of data). Note a more even distribution of data post-intervention (Sep-Dec 2020) from participants who signed up to the study in different years. This indicates participant retention rather than the drop-off we would expect to see.

Research aim 3

Practical guidelines for dynamic consent.



References

1. Nuremberg Trials 1947, Nuremberg Code.
2. World Medical Association 2001, Declaration of Helsinki. Ethical principles for medical research involving human subjects. World Health Organisation. 79, 373.
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4. O'Neill, O., 2003. Some Limits of Informed Consent. Journal of Medical Ethics. 29, 4—7.
5. O'Brien, H. L & Toms, E. G., 2008. What is user engagement? A conceptual framework for defining user engagement with technology. Journal of the American Society for Information Science and Technology. 59, 938—955.
6. Kaye, J., Whitley, E., Lund, D., Morrison, M., Teare, H., Melham, K., 2015. Dynamic consent: a patient interface for twenty-first century research networks. European Journal of Human Genetics. 23, 141-146.