

# DYNAMIC CONSENT WORKSHOP REPORT: Exploring new ways for patients to consent for research and use of health data.

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## Background

Reusing anonymised health data from patient records provides opportunities for advancing research, healthcare and knowledge. However, the media and certain sections of the public have flagged concerns about data initiatives (e.g. care.data) citing mistrust and lack of clarity regarding opt-out procedures and approved data recipients.

Our current area of research explores patient views on the use of anonymous electronic patient records for research purposes. In particular, we have been exploring a new model known as 'dynamic consent', which would allow individuals greater personal control over the use of their data.

## Dynamic Consent

Dynamic consent would enable patients to give consent to use their anonymised data for specific purposes (e.g. specific research projects). Importantly, patients are not restricted to giving a universal consent or universal 'opt out' for use of their data. Dynamic consent also allows patients to access feedback about research results, view who had access to their data and change consent status over time.

To explore the practicalities, we developed a prototype of an electronic 'dynamic consent' system for tablet devices that could be used in clinical settings.

*"The best thing about the workshop was the informative discussion on future plans for data sharing, and sharing views and knowledge with others having a whole range of experiences." - Workshop attendee*

The aim was to explore public views on an electronic dynamic consent system as a mechanism for consenting to participate in research, and the generation and use of anonymised health data.

We explained key concepts relating to dynamic consent and showed a short video. Two scenarios where dynamic consent could be used were introduced and discussed in small groups. Attendees also had the opportunity to test out a prototype of the electronic system using a tablet device (see Fig 1).



Figure 2: Screenshot from the 'dynamic consent' electronic system prototype.

## The Workshop

We held a workshop at The University of Manchester on 27th November 2014. In total, 30 members of the public attended, who were recruited by patient and public involvement groups and social media (see Figs. 1 & 3).



Figure 3: Workshop attendees discuss scenarios where 'dynamic consent' systems could be used.

## Future Plans

The findings from the workshop are currently feeding into a proposal for further research into developing and implementing a dynamic consent system for use in clinical settings.

The plans include proposals for using a co-design approach with patients and carer to make the system more user-friendly and provide appropriate information in suitable formats. A pilot study will also be designed, using private booths supplemented by support from staff and/or volunteers.

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Figure 1: Workshop attendees discuss a prototype of the electronic 'dynamic consent' system.

## Key Messages

The workshop discussions provided important feedback for the development of the prototype and our future research.

Positive feedback included:

- Attendees were positive about sharing anonymised health data for research purposes
- Many liked the idea of having greater control of their data and could see themselves using the electronic system
- The most valuable feature was personal feedback on how data had been used for research – this was seen as novel and would make people feel valued

Considerations and concerns raised included:

- Uncertainty about the degree to which people would actually specify consent preferences
- The need for technical support, in person, for new users and those with particular needs
- In clinical settings, a private space (or booths) should be available for people to use the system
- Information should be tiered and provided in appropriate formats (e.g. balloons and flow diagrams) to allow different users to access more or less information as needed
- Information and reassurance needed about data security and confidentiality within the system.