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

Caroline Sanders, Tjeerd Van Staa, Karen Spencer, Lamiece Hassan, Hawys Williams & William G Dixon

Patient and public collaborators: Jo Rose, Peter Rose, Ann Marie Lewis, Anne Brown, Steve Anslow & David Giles

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 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).

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 2).

Figure 2 Screenshot from the ‘dynamic consent’ electronic system prototype
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 carers 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.

**Future Plans**

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

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