Your Data and Health Research: SHIP Public Workshops

Background

The Scottish Health Informatics Programme (SHIP) is a Scotland-wide research and development initiative exploring ways of managing and analysing Electronic Patient Records for health research (including opportunities for linking health records with records from other sectors). As one of its four core programmes SHIP involves a package of public engagement activities. Through public engagement we aim to raise awareness about SHIP, and about the ways that personal medical data are used in research whilst also finding out what members of the public think about this and reflecting public preferences and/or concerns in SHIP. This will be valuable for informing the emergent governance framework and highlighting considerations to be addressed in order to develop ethically and legally robust systems within SHIP.

Public Workshops

In March 2012 we held a series of three public workshops (in Dundee, Edinburgh and Glasgow). These workshops were an opportunity for members of the public to hear more about SHIP and about the ways that personal medical data are currently used in research as well as being a chance for members of the public to contribute their own views. The workshops included presentations from representatives of SHIP and the Information Services Division (ISD) of NHS Scotland as well as small group discussions and anonymous electronic voting on key questions relating to how personal medical data is used in research. Themes which were explored included:

- What do members of the public think about the different forms of consent that are used in data collection and research?

- Do members of the public think privacy can be well protected?

- What do members of the public think are the best ways to ensure research is conducted ethically?

- What role can members of the public play in deciding how personal data is used and for what purposes?

Participants

The workshops were attended by a wide range of members of the public. There were 13 participants at the Dundee workshop, 19 at the Edinburgh workshop and 9 at the Glasgow workshop. At each of the workshops participants reflected a wide range of ages (from 20's to 70's) and a good split of male and female participants. Of those participants that completed an evaluation form after the workshops, 25 per cent described themselves as "an interested member of the public", 19 per cent as "a member of a patient group", 24 per cent as "a researcher", 21 per cent as "a member of a relevant organisation", 2 per cent chose "policy maker" and 2 per cent chose "other" (7 per cent gave no answer).

Discussion Points

The public interest

The majority of workshop participants were generally supportive of uses of medical data for health research purposes. For example, when asked in an early round of electronic voting whether they agreed that research using data from medical and/or other records was in the public interest the majority of participants at all three workshops agreed.

In small group discussions participants frequently noted that there may be a number of potential benefits to come from using personal medical data in health research and that research accessing this data was in 'the

public interest'. However, many participants noted that it was important to know that research would only be conducted for legitimate purposes and would not use unnecessary amounts of personal data.

Data-Linkage

Workshop participants typically acknowledged that linking data from medical records with other sources of data could be a valuable means for enabling research which might lead to better understandings of health and illness or better planning of services.

However, there were also concerns about data-linkage. In particular, many participants worried about who would be linking the data; how data-linkage would be controlled; who would have access to linked data and; what purposes this could be used for.

Who has access to data?

Public support for data-linkage or uses of personal data in health research appeared to be dependent on the extent to which people trusted the individuals or organisations handling their data, or making decisions about uses of their data.

The majority of workshop participants appeared to trust the NHS as an organisation, or particular healthcare providers (such as GPs) to safeguard their data. However, there was great concern about data being accessed outside of the NHS.

This generally high trust in the NHS reflected a wider trend of higher levels of trust in the public sector compared to the private sector. Many participants indicated that they were happy for their data to be used by public sector organisations but would be concerned if it was to be accessed by commercial organisations or private research bodies. Nevertheless, within some discussions there was an acknowledgement that commercial

research can play important roles in identifying and developing new treatments or medications, and therefore that private sector access to medical data could be considered appropriate and in 'the public interest'.

A further important consideration related to *where* data would be accessed or handled, and in particular whether it would travel outside of the UK. In several discussion groups participants expressed concerns that if data were sent overseas it may not be subject to adequate safeguards or governance mechanisms (such as those provided through UK data protection laws). Conversely, within some discussion groups it was acknowledged that limiting data access to those within the UK could restrict valuable research.

Anonymisation and confidentiality

There was widespread agreement on the importance of safeguarding individuals' confidentiality. Anonymisation of data was frequently noted to be a crucial condition for public support. In one discussion group a researcher described how he used data and that he did not tend to think of data subjects as being 'real people', this was described as being reassuring by another participant. Thus, anonymisation - or depersonalisation - of data was perceived as an important reassurance in relation to uses of personal medical data.

For many participants it was important to distinguish between 'personal information' (which was typically understood to be information which could potentially identify an individual) and 'plain stats': Research using 'plain stats' was considered less concerning.

Consent

For many participants the ability to consent to uses of their data was crucial. This was described as being a means of respecting individuals and also of showing common courtesy to people whose data might be used.

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Across the discussion groups participants frequently suggested that their willingness to consent would depend on what type of research was being conducted and/or who would be accessing their data. Accordingly, participants often expressed a preference for forms of consent which would enable individuals to set particular priorities or express particular objections.

However, a number of participants suggested that research which involves access to personal medical data may not require consent so long as the data do not identify or harm individuals: Simple 'number-crunching' or analysis of 'plain stats' were often not considered to require consent.

Workshop participants frequently commented on challenges associated with consent. For example, it was contended that members of the public would not appreciate being contacted frequently to ask for consent. Furthermore, participants acknowledged that in some instances requiring consent from all individuals whose data might be used could create challenges for conducting valuable research (e.g. since certain groups may be less likely to give consent and this could lead to potentially relevant gaps in the data).

Authorisation

Participants often acknowledged that whilst consent was preferable this was not straightforward and that there may be instances where an alternative approach to decision-making was appropriate. For many participants, this led to support for an authorisation model of governance, whereby decisions relating to requests to access personal medical data are taken by authorising bodies rather than with the consent of individuals.

However, participants typically had questions about authorisation, for example relating to who is on authorising committees. It was commented that the composition of authorising bodies was important since these ought to reflect the diversity of public interests. As such it was often contended that the membership of bodies such as the Privacy Advisory Committee should be widened. In particular, it was felt that if they were to consider linkages with non-medical data they would need to include people from a variety of professional backgrounds to which the data relates.

Thus, while participants typically acknowledged that authorisation had a role to play, there was frequently concern about how decisions would be taken by authorising bodies and to what extent these bodies represent the interests of the wider public.

Security

Across all the workshops it was frequently contended that breaches of security and misuse of data were an inevitability and that it would be impossible to guarantee that such errors or abuses would never occur. Managing and responding to potential breaches was therefore of the utmost importance. Participants sought reassurances that breaches would be responded to appropriately and that governance procedures would be in place to ensure an adequate level of protection.

Public Engagement

Participants appreciated the opportunity to learn more about the ways in which their data might be used in research and to discuss related issues and/or concerns. Many participants suggested that there ought to be more awareness raising activities to promote greater understanding of uses of medical data in research. Additionally, a number of

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participants contended that members of the public would be interested to have greater information about how their data is being used and what its use has achieved.

In addition to receiving information about how data is used, it was also argued that members of the public should be involved in governance processes or should play a role in overseeing uses of personal data in research. In particular, there was a preference that members of the public play a role in determining which research is done (i.e. through setting research priorities).

Feedback & Evaluation

The feedback provided by participants after the workshops indicated that the events had been found informative and interesting. Additionally, the vast majority of participants noted that they had enjoyed participating in the workshops. In particular, participants commented that they had enjoyed the small group discussions and had found this an interesting experience.

The evaluation form asked participants whether the workshop had changed their views in any way. A number of participants responded by indicating that they felt more reassured about the ways that data are used in research as a result of the workshop.

Summary & Conclusions

The workshops were very successful in bringing together diverse groups of public participants to discuss issues relating to uses of personal medical data in health research. Participants were very enthusiastic to hear more about this topic and to engage in discussions. These discussions highlighted a variety of preferences and concerns which it will be relevant for SHIP to address as it moves forward.

In general, the majority of workshop participants were largely supportive of uses of personal medical data in health research and this was often described as being in 'the public interest'. However, this support was conditional on a number of factors, for example; what research would be conducted; who would have access to personal medical data and; how this would be controlled.

The workshops were welcomed by members of the public who frequently commented that they found these events to be both enjoyable and informative. There was some evidence that the information provided through the workshops served to increase public confidence in current practices. Yet, regardless of the impact on people's attitudes towards SHIP or to uses of personal medical data in research, the workshops had great value in facilitating dialogue and deliberation. The vast majority of participants indicated that they would be interested in participating in further events and would like to be kept informed of developments in SHIP. This highlights the potential to facilitate wider public involvement in SHIP and within research governance processes.

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