

SHIP Public Engagement: Summary of Focus Group Findings

Introduction

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). The public engagement strand of SHIP is a programme of research and public engagement activities aimed at understanding the Scottish public's preferences, interests and concerns relating to the sharing of health data for research and their acceptance and attitudes towards the aims of SHIP. This will help to ensure that SHIP operates transparently and in the public interest.

Methods

The first stage of public engagement was a series of focus groups with members of the public across Scotland.

A total of eight focus groups took place between October 2010 and February 2011. These open-ended group discussions explored public awareness, attitudes and responses to the collection, sharing and use of medical data, and to SHIP.

Sample

Groups of participants were selected so as to represent a range of perspectives.

- The groups took place across Scotland (in Edinburgh, Glasgow, North Lanarkshire, West Lothian, Aberdeen, Inverness and Moray).
- The youngest participants were 16 and the oldest in their 70s.
- There were 27 female and 23 male participants.

Key Findings

Conditional Support

Overall participants were generally supportive of data-sharing for research purposes (although this support was never unconditional). Many participants felt that in principle this was a good idea, but typically stressed the importance of safeguards to protect patient confidentiality.

Participants acknowledged a number of benefits of data-linkage and sharing for research purposes. For example, it was noted that the richness of the information contained in medical records could provide valuable insights which might lead to improved understandings of conditions or of how particular treatments/drugs worked.

Public benefits

Many participants' responses to SHIP were dependent on the extent to which they perceived this to have benefits for patients and/or the wider public. The majority of participants felt that research would (at least probably) ultimately lead to benefits for healthcare. For many people this was the basis of their support.

However, some participants perceived the benefits to be largely for researchers and administrators as opposed to patients.

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Security

A major concern across all the focus groups was security. There was widespread acknowledgement of the fallibility of computing systems and the difficulty (or even impossibility) of making a system which is 100 per cent secure.

In particular, there was widespread concern that information which is stored electronically could be hacked into. Across the focus groups it was frequently stated that it would be impossible to guarantee that this would never happen.

For many participants the main concern was not how secure the system was but rather who would have access to this system and the extent to which it could be protected against abuse or misuse. There was concern that people could misuse personal information (for example for fraudulent purposes) or that individuals with access to personal information could act unprofessionally and access/use information inappropriately.

Who has access?

Who would have access to data was an important consideration. There was widespread (although not unanimous) support for sharing of personal medical information between health practitioners in relation to individuals' treatment or care. However, participants were often hesitant regarding whether they would extend this support to data-sharing for research. To a large extent this depended on who the researchers were:

- **Academic researchers:** Some participants demonstrated high levels of trust in academic researchers and suggested that the involvement of

universities gave them greater confidence in the systems in place.

- **NHS:** Some participants demonstrated high levels of trust in the NHS and were satisfied for data sharing/linkage to be governed from within the NHS. However, others disagreed with this position and raised concerns that personal data might be misused by people within the NHS.
- **Government:** Many participants were not happy with personal data being held by Government bodies. For example, it was argued that the Government is not transparent in how it handles/shares information.
- **Commercial actors:** The greatest concerns related to the possibility of commercial actors having access to personal information.

A number of participants expressed discontent that personal medical information might be accessed by researchers or professionals but that they did not feel that they themselves had equal access to this information.

Linking Health and Non-Health Data

An area that proved highly controversial across the focus groups was the possibility of linking up health and non-health data for research purposes.

There was some acknowledgement that linking health and non-health data could lead to valuable insights for understanding patterns of health and illness. However, there was considerable concern about how linked data would be used. Many participants contended that the collection of large

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amounts of data was indicative of a “big brother society”.

A major concern regarding the linkage of health and non-health data centred on potential implications of research. There was concern that this could be used to produce generalisations that categorised members of the public, and that this in turn could result in discriminatory treatment and/or stigma. It was felt that generalising about groups may lead to policies and/or interventions or treatments which did not adequately consider individual circumstances and needs.

Anonymisation

When participants were asked how important they thought anonymisation was in relation to sharing of information from medical records for research purposes, initial responses often suggested that this was of great importance. However, participants often then stated that anonymisation was less important than consent. Many participants may be willing to allow their information to be accessed for research purposes without being anonymised so long as they are fully informed about this and give their consent.

Across all focus groups there was an acknowledgement that the importance of anonymisation depended on who was accessing the information and for what purposes.

➤ **Anonymisation and Consent**

Participants largely did not view anonymisation as a substitute for consent and generally felt that they would still like to be informed about research using their anonymised records and to have the option to consent/withhold consent for this. However, some participants suggested that they would

be more likely to consent if the information was anonymous.

Consent

Across all the focus groups there was agreement that individual control over how personal data is used is very important. However there was no unanimous agreement about what this required.

The majority of participants initially stated that they would want to be asked for their individual consent each and every time their records might be used for research. However, through discussion many participants revised their initial position and noted that requiring consent from every individual each time their records may be used could be inconvenient and/or impractical.

Accordingly, many participants expressed a preference for a system of periodic consent and review (e.g. on an annual or bi-annual basis). There was also a preference for varied consent which would enable individuals to give consent for their records to be used for some types of research or by some types of researchers and not others. The majority of participants indicated that they would prefer a consent procedure which allowed them to express preferences and/or objections.

However, a minority of participants maintained a strong conviction that individuals should always be asked for their explicit consent each and every time their records might be accessed. Some participants were concerned that a general consent form (even with varied options) would be open to interpretation and enable people's information to be used more widely than they wished.

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Summary & Conclusions

The focus groups covered a range of topics and highlighted the enthusiasm and competence of members of the public to engage on this subject.

There were a range of considerations influencing attitudes towards data sharing and/or linkage, for example: what is the purpose of data collection/sharing; what is data used for; who has access to the data and; how is it safeguarded against misuse.

A theme which emerged consistently from all the focus groups was that individuals want control over how their information is used and who accesses it. This control was understood in different ways; for some it meant that individuals' consent should be needed for any potential use of their data; for others, models of periodic and/or varied consent were appropriate; whilst others regarded it as sufficient to be kept informed about potential uses and to have the option to opt out. However, despite the different levels of control suggested there was agreement about the importance of control.

Control was generally viewed as being more important than anonymisation of data. Confidentiality was an important consideration, however, participants suggested that they may be happy for identifiable, or potentially identifiable data to be used so long as they had control over this and trusted the individuals or organisations accessing the data.

A major area of contention was the extent to which data-linkage/sharing will benefit patients and/or wider society. It was noted that research can be used in both positive and negative ways. Participants frequently called

for greater openness and transparency about how data is collected and used.

These findings have highlighted a range of considerations which will be explored further in future public engagement work (for example, how control and confidentiality are understood by different members of the public and what this implies for SHIP).

These findings will also be valuable in informing the emergent governance framework. They have highlighted a number of considerations to be addressed in order to develop ethically and legally robust systems within SHIP and the Information Services Division (ISD) Scotland of NHS National Services Scotland. In particular, further work is needed to explore the scope for facilitating individual control and how this could operate in SHIP.

As SHIP moves forward it will be necessary to address and balance diverse concerns and interests in order to ensure that SHIP operates in the public interest and with the necessary high levels of transparency.

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