

# Public attitudes towards the sharing of health and care information: headline findings

Report to the Health & Social Care Data Integration Programme Board

12 March 2015

## 1. Background and context

1.1. Through our involvement with the Information Sharing work stream of the Better Care Fund Programme, we have been working with colleagues from health and social care to gather evidence about people's views on the way health information is collected, recorded and shared. This was in order to inform the way information sharing arrangements are communicated to patients and the public, now and in relation to future changes.

1.2. We knew that the sharing of personal information is an important issue for some people and that public confidence in NHS information sharing arrangements is low following the high-profile communications mishandling of 'Care.data' last year. We wanted to find out more about what most concerns people in Hertfordshire with regard to information sharing; how their understanding of practice matches reality; and the most effective way of explaining arrangements to people so that they have the right amount of information at the right time to reassure them.

## 2. The research

2.1. The following research activity was carried out:

- A Focus Group on 26<sup>th</sup> January with the Healthwatch Mental Health and Learning Disability Group.
- A Focus Group event on 2<sup>nd</sup> February, involving 30 members of the public.
- An online survey aimed at younger people which was completed by 72 people.

2.2. Focus Group participants discussed the following:

- Groups considered and evaluated examples of literature from around the country produced to explain information sharing arrangements to patients and the public.
- Groups considered a range of health and care scenarios and discussed the information sharing implications in the context of these.

2.3. The Focus Group discussions were recorded and transcribed. The transcripts and survey responses were analysed to identify key themes.

### 3. Key themes

The following reflects the themes that were identified by the above research.

#### 3.1. **The benefits: “*what’s in it for me?*”**

- People want to understand how the sharing of information benefits them using real life examples. People find it hard to talk about information sharing and express a view when it is discussed in abstract terms.
- Group discussion of the scenarios demonstrated a lot of differences of opinion around principles of information sharing and in many cases people changed their minds through discussing the issues within the framework of a real example.
- People found it easier to see the benefits of information sharing in the case of people with complex conditions i.e. where multiple professionals from different organisations are involved in a person’s care.
- People could generally see the benefit of sharing patient-level information in order to directly improve the patient’s care e.g. a GP sharing information about a condition with a hospital in order to make a referral. People were able to see the benefit of secondary information sharing to improve care at a service level e.g. sharing anonymised information with the commissioner in order to understand and improve performance. People were much less understanding about external secondary use of information where there is no clear link to improving care e.g. the suspicion that information is being shared with outside agencies such as insurance companies.

#### 3.2. **Honesty and transparency**

##### 3.2.1. Security

Although it can be mitigated, there will always be some level of security risk around the storage and transfer of a large volume of personal data. People said they wanted more honesty about the risks and measures in place to control them.

##### 3.2.2. Secondary use

People feel this needs to be more clearly defined. People understand the benefits of using anonymised data at a service/organisational level for the purpose of improving services; but are much more suspicious of external sharing for the purpose of research or marketing. More clarity about when and why this happens may help.

The research showed a particularly low understanding of secondary use among younger people, with 60% of young people surveyed believing that information is not shared beyond people directly involved in their care.

### **3.3. Accountability**

3.3.1. There were questions about the regulatory framework and the ‘rules’ that organisations, as data controllers, are subject to. This included charities and private sector providers of health and care services. Are there different expectations for different sorts of organisation? This was a particularly important point for the Mental Health and Learning Disability Group.

3.3.2. The ‘quiz’ exercise demonstrated that 18% of people did not know that there is a route for reporting and escalating concerns about inappropriate sharing of information. The focus group discussions showed that while most people assumed there is was a route for escalating a concern, they didn’t know what that route was.

3.3.3. People want to feel that there is a robust regulatory framework to steer activity and ‘consequences’ when rules are breached.

### **3.4. Control**

3.4.1. A lot of concern and anxiety seems to come from people’s lack of knowledge and understanding of exactly what information is held about them and who sees it. There was concern that information shared is not accurate or relevant to the situation. This was particularly a concern for the for the Mental Health and Learning Disability Group.

3.4.2. The research suggests a lack of knowledge about people’s rights to view and challenge the information held about them.

3.4.3. If people could easily (or *knew* they could easily) access their record to see what is included and add their own comments, this might help to reduce the concern about information sharing generally. The research showed that 81% of young people surveyed thought you cannot edit information held about you.

3.4.4. People felt strongly that consent to information sharing should be on an ‘opt in’ basis. There was also a strong feeling that consent must be explicit, not just implied.

### 3.5. Method of communication

3.5.1. People felt that organisations should not attempt to provide all information in a single document. Rather they should offer limited ‘priority’ information in written form and make it clear how people can find out more detail if they need to.

3.5.2. Priority information was generally considered to be:

- What are the benefits of information sharing to me personally?
- What are the risks associated with the sharing of my information and what is the organisation/system doing to minimise them.
- How can I find out more?
- What can I do if I am unhappy/unsatisfied

3.5.3. People felt that all frontline staff should have a basic knowledge of their organisation’s information sharing policy, so that they are able to answer patient questions.

3.5.4. People said they would prefer to be told about information sharing:

- before an appointment (e.g. a leaflet with the appointment letter or given to them by a receptionist)
- and/or during a consultation, via a discussion with the health/care professional. Conversations with frontline staff were considered to be particularly important by the Mental Health and Learning Disability Group.

3.5.5. There was the suggestion of targeting people who are likely to benefit more from information sharing e.g. people with complex conditions. They might need more details and require a more detailed discussion.

## 4. Suggested next steps

The Board may wish to discuss and consider the following recommendations:

4.1. Agree consistent messages and explore the idea of a distinct local brand for information sharing. This could help to reassure people around some key areas, for example:

- What is the relationship between the national programme and local initiatives and how does this impact on use of services outside Hertfordshire?
- Are different sorts of organisation subject to different standards/regulatory frameworks for different organisations e.g. charities, private companies delivering care services?

- 4.2. Consider reviewing the Hertfordshire literature (posters, leaflets, website content) in light of the framework that this research provides. Could this help to produce a standardised suite of material to be used across organisations?
- 4.3. Consider seeking a patient/public representative (possibly a participant from this research) to have an on-going role in supporting development of communication material.
- 4.4. Consider reviewing staff training regarding information sharing - 'data protection' is only one aspect, could training look at the positive messages and how to talk to patients about their concerns?