



Linking Social Care, Housing
and Health Data: Social Care Clients'
and Patients' Views

**LINKING SOCIAL CARE, HOUSING AND HEALTH
DATA: SOCIAL CARE CLIENTS' AND PATIENTS'
VIEWS**

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1 EXECUTIVE SUMMARY

Background

- 1.1 In order to plan effectively for social care, housing and health needs and to inform decision-making, better information and more robust evidence is needed. In particular, it has been identified that there is a need for information regarding the interactions between social care, housing and health and the ways in which these enable or prevent people to live independently in their own homes for as long as possible.
- 1.2 The Scottish Government, in collaboration with Information Services Division (ISD) Scotland, Scottish health boards and Scottish local authorities are developing a project which involves the linking of specific social care, housing support and health data in order to produce improved analytical evidence to enhance the delivery of these services. Further information about the project can be found here:
<http://www.scotland.gov.uk/Topics/Statistics/Browse/Health/Datalinking>.
- 1.3 This study aimed to explore the views of social care clients, patients and carers, on linking social care, housing support and health data for statistical research purposes and their perceptions of potential impacts on privacy.
- 1.4 The objectives of the project were to:
 - Assess social care clients and patients' awareness and understanding of the data collected on their use of services;
 - Explore social care clients and patients' perceptions of data linking;
 - Identify concerns around data linking and sharing of data between organisations;
 - Explore how any privacy concerns could be addressed;
 - Explore what information would reassure social care clients and patients about how their data will be used;
 - Examine understanding and perceived appropriateness of explanations provided to social care clients/patients as to how their personal information may be used and;
 - Explore the perceived impact of linking social care, housing and health data on social care clients and patients' and the public more widely.

Methods

- 1.5 The research was conducted through a series of three consumer panels involving between five and eight participants. These were semi-structured, group discussions which allowed participants to raise and discuss a range of issues.
- 1.6 The consumer panels were conducted in May 2011 in North Ayrshire, Edinburgh and Tayside. A total of 20 participants were recruited through Public Partnership Forums (PPFs) in the three areas. PPFs are voluntary organisations involving patients, service users, carers and the wider public.

The PPFs aim to engage local service users and the public in discussing how to improve health and social care services and to support wider public involvement in planning and decision making.

Findings

- 1.7 In general participants were supportive of the collection and sharing of information relating to use of health and social care services. It was frequently noted that this was necessary for improving understandings of particular conditions and/or improving services.
- 1.8 There was considerable support for data-linkage between health and social care services in relation to individual care. However, when asked to think about other purposes of data-linkage (e.g. audit, management or research) participants' responses were less certain (for example, they had concerns about how data might be used and what the implications of this might be).
- 1.9 It was considered important that data which is collected is used effectively and purposefully. This was often related to a belief that data should be used in ways which are of benefit to the wider public, or which will produce tangible (positive) outcomes. Therefore, communicating the purpose, and outcomes of data-linkage may be important.
- 1.10 There were mixed responses relating to data use by the Scottish Government. On the one hand most participants agreed that it was necessary and appropriate for the Scottish Government to collect and access data about health, social care and housing service users in order to plan and improve services. On the other hand there was some concern that data might be used for political purposes.
- 1.11 Participants were supportive of researchers, managers and the Scottish Government having access to statistics, but were often hesitant about (or opposed to) these stakeholders having more detailed information.
- 1.12 Many participants placed significant emphasis on anonymisation, and indicated that this was the main factor on which their support depended.
- 1.13 There were concerns about security of electronic databases to store data and the possibility of computer systems being hacked into, or data being lost or misplaced. However, whilst security was a salient issue within the consumer panel discussions, it was not a primary concern for the majority of participants.
- 1.14 There was concern that studies which seek to generalise about service users may lead to services which are designed to reflect general rather than particular needs and that individuals who do not "fit the mould" may not get appropriate or necessary care.

Feedback on Privacy Notices

- 1.15 Participants were asked to give feedback on three information leaflets relating to data use.

Draft Local Authority Privacy Notice

- 1.16 In general participants stated that they felt this notice was clear, and that it provided appropriate information. However, some participants felt that there should be explanation regarding who ISD are and what their role is.
- 1.17 Some participants also wanted further information about what data might be collected (i.e. what is meant by 'housing data').

Easy to Read Version

- 1.18 Participants were then given copies of an easier to read version of the same draft privacy notice.
- 1.19 Several participants stated that they preferred this version to the first one. However, whilst some participants felt that it was very clear and used appropriate language and pictures, others felt that it may be viewed as condescending.

ISD Leaflet

- 1.20 Participants were given a copy of the NHS Information Services Division (ISD) leaflet entitled 'Protecting Personal Health Information: Information Guide for Patients'.
- 1.21 Many participants stated that they were not familiar with the CHI number, or that they did not expect most members of the public to be. It was therefore suggested that some explanation of this is necessary.
- 1.22 It was suggested that this leaflet should give examples of what information would actually be used.

Conclusions

- 1.23 The consumer panels found that participants were largely supportive of the aims of the 'Social care, housing and health data linking project'.
- 1.24 However, participants sought a number of assurances: Firstly; that data would be anonymous and that individuals would not be identifiable through data-linkage. Secondly; that data would be secure within electronic databases and would not be lost or misplaced. And thirdly; that data-linkage could be demonstrated to be for the benefit of patients, service users or the wider public.
- 1.25 These findings highlight key areas about which members of the public would like further information regarding how their data is used and for what purposes. Providing this information and the necessary assurances may be crucial for ensuring public support.

1 BACKGROUND

- 1.1 In order to plan effectively for social care, housing and health needs and to inform decision-making, better information and more robust evidence is needed. In particular, it has been acknowledged that there is a lack of information regarding the interactions between social care, housing and health and the ways in which these enable or prevent people to live independently in their own homes for as long as possible. The routine collection of individual level data on social care, housing support and health, provides an opportunity to link across these datasets for statistical/research purposes. This will ultimately enable service providers and planners to gain an improved understanding of the relationships between social care, health and housing support. To date such understandings have been limited.
- 1.2 The 'Social care, housing and health data linking project' will provide analytical evidence to help shape social care, health and housing policy. For example, one aspect of the project will explore whether people who have had multiple unplanned hospital admissions, have had any social care and /or housing support packages in place such as a home help or a community alarm. It is important for policy and service planners to understand how changes in support packages can reduce unplanned hospital admissions. This study aimed to explore the views of social care clients, patients and carers, on linking social care, housing support and health data for statistical research purposes and their perceptions of potential impacts on privacy.

Objectives

- 1.3 The objectives of the project were to:
- Assess social care clients and patients' awareness and understanding of the data collected on their use of services;
 - Explore social care clients and patients' perceptions of data linking;
 - Identify concerns around data linking and sharing of data between organisations;
 - Explore how any privacy concerns could be addressed;
 - Explore what information would reassure social care clients and patients about how their data will be used;
 - Examine understanding and perceived appropriateness of explanations provided to social care clients/patients as to how their personal information may be used and;
 - Explore the perceived impact of linking social care, housing and health data on social care clients and patients' and the public more widely.

Structure of this report

- 1.4 The following chapter of this report outlines the methods used in conducting and analysing the consumer panels as well as the composition of the sample. Chapter three then presents the findings of the consumer panels and is structured around the main themes influencing participants' responses, notably: the purposes of data-linkage; uses and users of data-linkage; levels

of information that are shared and/or linked; whether information is anonymous; to what extent security is ensured and; what the implications of research are for individual service users and members of the public.

- 1.5 Chapter four presents feedback from participants in relation to three privacy notices which were distributed during the consumer panels. Chapter five draws some comparisons between the findings of this study and those of a larger project which explored public attitudes and responses to the collection, sharing and use of personal medical information in the context of the Scottish Health Informatics Programme (SHIP). It is noted that the findings of the two studies are largely consistent. Finally, chapter six provides a summary and conclusions and offers some reflections on the implications of the study's findings for the 'Social care, housing and health data linking project'.

2 METHODS

- 2.1 Qualitative research methods were used as these are most appropriate for engaging with the subjectivities and complexity of public views and perspectives.
- 2.2 The research was conducted through a series of three consumer panels. The consumer panels each involved between five and eight participants and were semi-structured, group discussions allowing participants to raise and discuss a range of issues.
- 2.3 A topic guide was designed in collaboration with the Scottish Government (see Annex 1). This was used to guide the discussion and to ensure consistency across the different groups. However, it was highly flexible and allowed participants to raise issues which were not anticipated. This design enabled the research to fully reflect service-users' views, concerns and perspectives.

Consent

- 2.4 All participants in the study were required to complete a consent form. This was handed out at the beginning of each consumer panel together with an information sheet. The information sheet explained the purpose of the project, the way in which the discussion would be recorded and how the information would be stored and used. The consent form asked participants to confirm that they had read and understood the information sheet and had the opportunity to ask questions. It asked participants to confirm that they were happy for the discussion to be recorded and for quotations of what was discussed to be used in research publications and presentations (with all identifiable material removed).

Analysis

- 2.5 The consumer panels were recorded and then transcribed. Before analysis began the transcripts were anonymised.
- 2.6 The consumer panels were analysed inductively using NVIVO software. The transcripts were coded in NVIVO and patterns or themes were then explored in order to identify areas of agreement and/or divergence within and between the discussions.

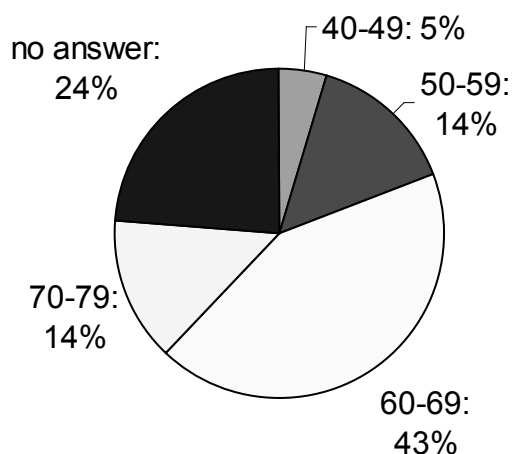
Sample

- 2.7 Three consumer panels were conducted by a researcher from the University of Edinburgh in May 2011. These were held in North Ayrshire, Edinburgh and Tayside. There were a total of 20 participants across the three consumer panels. Participants were recruited through Public Partnership Forums (PPFs) in the three areas. PPFs are voluntary organisations involving patients, service users, carers and the wider public. The PPFs aim to engage local

service users and the public in discussing how to improve health and social care services and to support wider public involvement in planning and decision making.

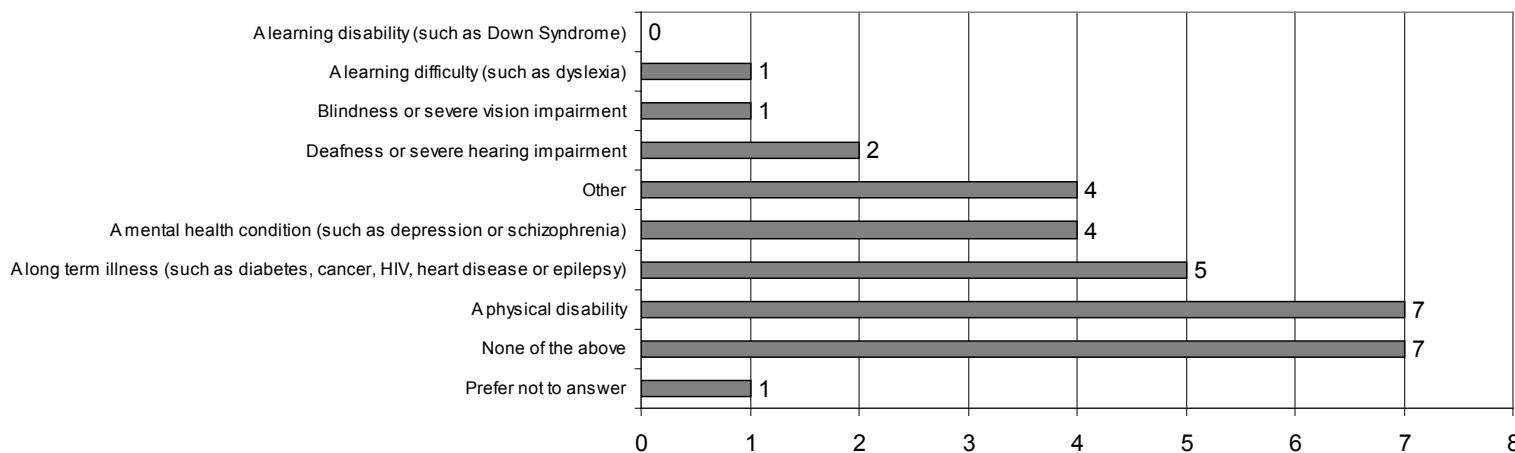
2.8 85 per cent of participants were female. The majority of participants (57 per cent) were over the age of 60; figure one illustrates the range of ages of participants.

Fig. 1: Age of participants



2.9 The study aimed to reflect the views of different health and social care service users. Therefore it was important to involve individuals with a range of health and social care needs. Within an equalities monitoring form, 60% of participants stated that their day-to-day activities were limited either a little or a lot because of a health problem or disability which has lasted, or is expected to last, at least 12 months. Figure 2 illustrates the range of conditions that participants declared.

Fig. 2: Do you have any of the following...



Scottish Health Informatics Programme

- 2.10 The author of this report is involved with the public engagement work stream of the Scottish Health Informatics Programme (SHIP). SHIP is an ambitious, Scotland-wide research platform for the collation, management, dissemination and analysis of Electronic Patient Records (EPRs).
- 2.11 The public engagement work stream of SHIP is conducting a series of activities to explore public views, preferences and concerns in relation to the collection, sharing, linkage and analysis of information from EPRs.
- 2.12 Between October 2010 and February 2011 a series of eight focus groups were held across Scotland with a diverse range of public groups. These focus groups had considerable cross-over with the consumer panels conducted in this study. Therefore, the report will summarise how the findings of these two studies relate to one another and where there are areas of agreement and disagreement.

3 FINDINGS

- 3.1 This chapter presents the findings of the consumer panels and highlights the main discussion points influencing participants' attitudes and responses towards the aims of the 'Social care, housing and health data linking project'.

General Support for Data Collection and Sharing

- 3.2 In general participants were supportive of the collection and sharing of information relating to use of health and social care services. It was frequently noted that this was necessary for improving understandings of particular conditions and/or improving services. For example, one participant stated that:

"The thing round the table is you have people who have kind of grown up with or become part of a culture where they can see use for it, this happening, would either benefit from it or there is people who benefit from it."

(North Ayrshire – Female5)

- 3.3 Similarly, another participant contended that:

"[data] needs to be collected for planning and other purposes, and it needs to be collected in an efficient and cheapest way possible."

(Edinburgh – Female6)

- 3.4 However, it was also noted that, as members of PPFs, participants in the consumer panels represented individuals with particular interests in health and/or social care services, and therefore their views perhaps did not represent those of the wider general public:

"I think us round the table are quite open to it because we work in conjunction with the health board trying to implement services that are coming out, so I would say everybody round the table is quite happy with the majority of everything that we have [discussed], what the general public would say could be a totally different thing, some will say there is too much information getting shared about us already and others will probably give two monkeys, so I think it really depends who you're going to be speaking to, but speaking to groups like this I think most of them will be quite happy with information sharing, because we can see an outcome for it at the end. Others you might get a different point of view."

(North Ayrshire – Female2)

- 3.5 Nevertheless, across the consumer panels support for data sharing was rarely unconditional. Participants raised a range of considerations relating to, for example, how data is collected, what data is collected and how/by whom this might be accessed. These considerations and how they influenced participants' responses will be outlined below.

Responses to Data-Linkage

- 3.6 Participants were asked to think about what information may be collected about individuals accessing health care and social care services and what might happen to this information. It was widely felt that information relevant to an individual's care should be shared amongst professionals involved in delivering that care. As such there was considerable support for data-linkage between health and social care services in relation to individual care:

"I'm sick fed up running round everybody, this person or you yourself or somebody who is a service user or carer, the amount of information you have to pass to each independent person, even though the systems are in place, sorry allegedly the systems are in place, it doesn't still quite work that way the person who is the service user or the carer still has to do the running around, I think the information sharing has to get better."

(North Ayrshire – Female2)

"You need like a shared database then, don't you, between the agencies, so that the relevant information, on a need to know basis, is put on that particular database."

(Tayside – Female7)

- 3.7 Participants generally thought about data-linkage in relation to information sharing about individual patients/service-users and potential benefits for treatment/care. Data-linkage for this purpose was widely supported. However, when asked to think about other purposes of data-linkage (e.g. audit, management or research) participants' responses were less certain. Whilst, as noted above, there was generally wide support for data sharing for research or planning purposes, participants raised a number of concerns about the practicalities and implications of this. These concerns will be discussed below.

The Purpose of Data-Collection/Sharing/Linkage

- 3.8 It was considered important that data which is collected is used effectively and purposefully:

"I would agree that data used properly can be very beneficial, but [...] the NHS is very good at gathering data but it seems to disappear into this black hole and nobody knows what happens to it, is it going to be used or is it just an exercise they've gone through, I think if you can show a purpose, an outcome that will make it easier to sell it to the public."

(Edinburgh – Male1)

- 3.9 This was often related to a belief that data should be used in ways which are of benefit to the wider public, or which will produce tangible (positive) outcomes:

Male1: See again, this comes back to data collection. Data collection is fine if there is a purpose.

Female2: And a positive outcome, or indeed an outcome that can create positive addressing of it.

Male1: But the trouble now is very much in the service use; data is collected; nobody has really any idea of what is going to come of it.

(Edinburgh)

- 3.10 It was felt that use of data relating to individuals' use of health and/or social care services needs to be fully-justified and relate to improving services and/or achieving wider public benefits. Therefore, communicating the purpose, and outcomes of data-linkage may be important.

Uses and Users

- 3.11 As noted above, participants were largely in favour of data being linked and/or shared between health and social care services in relation to an individual's care. There was also generally support for data to be used for planning and improvement of services:

"How are they going to get the services for the future if they don't get what's happening now? Even in housing, when you need so many houses that are capable of taking elderly disabled people in an area, rather than building tower blocks or something for...planning for the future of what the society is going to need. And we all know and we've all heard about that we're all getting older and living longer and so on. So there needs to be statistics found and so on for planning for the future. [...] you need to have information of knowing what is required in any community for the future."

(Tayside – Female2)

- 3.12 Similarly, there was support for data-sharing/linkage for research purposes. However, this was typically conditional on research being aimed at benefiting patients and/or improving services:

Female7: I think if you're going to do research on people's medical history or social needs, then they need to be benefiting from that in some way or another; it shouldn't be just for an individual's PhD or whatever. They should have an assurance that yes, that information will be used in some way to enhance that person's life.

Female1: Well maybe not that particular person, but somebody further down the line.

Female7: Yeah, or somebody with that condition.

(Tayside)

Scottish Government

- 3.13 Thinking about particular users of data, there were mixed responses relating to the Scottish Government. On the one hand most participants agreed that it

was necessary and appropriate for the Scottish Government to collect and access data about health, social care and housing service users in order to plan and improve services. On the other hand there was some concern that data might be used for political purposes, for example one participant stated:

“As long as it’s not used politically, as long as it’s used beneficially for the good of the forward planning and future. But not to be used politically from the point of view that somebody says oh, you know, we’ve done so and so, now we’ve got more housing for elderly, we’ve got more people staying at home. That is not the purpose of the exercise. If the Scottish Government is using it for the purposes of the benefit of society then that’s fine, but not as a statistic to say “look what we’ve done”.”

(Tayside – Female2)

- 3.14 Additionally, several participants maintained that there are limits to what the Scottish Government needs to know. For example, it was asked:

“Does the government need to know the things that health services and social services need to know?”

(Edinburgh – Female2)

- 3.15 For some participants it was important that the Scottish Government only had access to anonymous data (the topic of anonymisation will be expanded on below):

Male1: Obviously the health department need to know what’s happening for medication, but [...] I don’t want any random MSP just being able to type me up and read my health problems.

Female4: He might find it interesting you never know.

Male1: Yes.

Female1: But if it was anonymous?

Male1: Anonymous stats yes why not.

(North Ayrshire)

Levels of Information

- 3.16 This relates to a strong theme which ran through all of the consumer panels: that there are different levels of information which are appropriate for different people/organisations to access. Participants were supportive of researchers, managers and the Scottish Government having access to statistics, but were often hesitant about (or opposed to) these stakeholders having more detailed information. For example, when asked if they thought the Scottish Government would have access to information from notes made on health service users, participants in one consumer panel responded by saying:

Female5: Well if it’s anonymous, it’s figures for doing stats that’s fine, because that’s what they do at the moment.

Female1: Yes so statistic aggregate.

Female4: But not be involved as such surely, I would be alarmed if I thought anybody was, well I'm not, but I would be saying to myself golly, is that going up there, and do they know all about me, I wouldn't like that.

(North Ayrshire)

- 3.17 Similarly, participants felt that researchers should only have access to limited information (relevant to the particular study):

"It would depend how you access the information. If you were given my medical files, and that's for research or whatever, I don't know that I would want you to have everything in there because it's not relevant for a start off, plus it would take you months to get through so there wouldn't be any point. So it would be dependent on what information you have access to. If it's to say how many people, I don't know, smoke, because that was one of the things they did before, they do this regularly, don't they? Your GP will ask if you smoke so he can feed those figures back to whoever is collecting those figures, the Scottish Government probably. [...] that's fine, don't have a problem with that; you know, just specific bits of information."

(Tayside – Female7)

- 3.18 Participants frequently made a distinction between 'plain stats' and more detailed, descriptive information and indicated that whilst they were comfortable with statistical information being shared they were often less certain about more detailed information.
- 3.19 Nevertheless, it was acknowledged that more detailed information could be valuable to improving understandings of particular conditions or the ways in which people accessed services. However, many participants contended that some information was more sensitive and hence should not be shared equally. It was suggested that patients with stigmatising or embarrassing conditions would not want this information to be shared (either within or beyond the health service). Several participants therefore suggested that service users should be able to specify which information they are not happy to share. For example, one participant asked:

"Would the patient have the ability to say I will discuss this with you, but I do not want it accessed or would you assume that everything you go and talk to the doctor about will be accessible?"

(North Ayrshire – Male1)

Anonymisation

- 3.20 Many participants placed significant emphasis on anonymisation, and indicated that this was the main factor on which their support depended. For example, when asked who they would be happy with having access to linked data from health and social care, participants in one focus group responded:

Female3: Anybody as long as it's anonymised.

Female4: Yes.

*Male1: As long as there is no way of identifying who or what or where, anybody.
(North Ayrshire)*

- 3.21 Participants frequently emphasised the importance of privacy and not being identifiable through data that is accessed/linked. However, it was also acknowledged that anonymisation can be problematic and that removing key identifiers (such as names, dates of birth and addresses) does not necessarily mean that individuals can never be identified:

Male1: There would be the odd chance you could recognise somebody by

Female3: If you were very local or it was local.

Male1: Yes if you were local you could recognise them by their symptoms and who they are

Female3: Yes there were only three people in the country.

Male1: I think it's a minimal worry.

(North Ayrshire)

*"I think you're right enough, it's anonymised. But then if you're dealing with particular areas, that again kind of cuts in to the anonymous factor, because if you're looking at maybe, let's say, a housing estate, so there's only so many people, so it's not...I don't think there's anything that's truly anonymous; I think everything can be found out if you've got the wherewithal and the curiosity to find things out."
(Tayside – Female1)*

Security

- 3.22 There were concerns about security of electronic databases to store data and the possibility of computer systems being hacked into, or data being lost or misplaced. For example, one participant stated:

*"what I find concerning is that the government are showing themselves incompetent at keeping the data safe as we just saw last year tens of millions of people had their data lost."
(Edinburgh – Male1)*

- 3.23 Some participants viewed this as a major concern, whilst others regarded it as equal with many risks which they accepted on a daily basis:

*Female3: It doesn't make me feel any better because any hacker can get into anything so it's a case of are you willing to accept that risk
[...]*

Male1: But then you accept that risk every time you switch on your PC, every time you go into your Smartphone.

(North Ayrshire)

- 3.24 Some participants rebuffed concerns about security by stating that they had confidence in the systems in place:

Female2: It happens just now if a doctor goes into notes at the minute and it's not his patient or it's nothing to do with him, it flags up and it shows up they don't have that level of information available to him.

Female3: That protection is there.

Female2: Absolutely it is there and that's even at a GP level.

(North Ayrshire)

- 3.25 Whilst security was a salient issue within the consumer panel discussions, it was not a primary concern for the majority of participants.

Implications for Individuals

- 3.26 Several participants raised concerns that using data to identify patterns or trends in health, illness or service use could potentially have negative implications for atypical individuals:

"I think research maybe tends to lump everybody together, and there must be individuals that would be totally different [...] so it could lump everybody together and maybe that's not what we want. If the job's individual, it needs to be treated different."

(Tayside – Female4)

- 3.27 There was concern that studies which seek to generalise about service users may lead to services which are designed to reflect general rather than particular needs and that individuals who do not "fit the mould" may not get appropriate or necessary care. It was therefore argued that service users' needs should be assessed on an individual basis and that identifying general trends was inappropriate:

"I don't think that is necessary at all; you don't need data to decide research on how to deal with people; all you need is to see the problem at source, and I think that is a waste of time, resources and money; what is wrong with going to see a patient and seeing what they need?"

(Edinburgh – Female2)

- 3.28 Moreover, it was suggested that studies based on data, as opposed to direct observation of individuals, can lead to depersonalised services:

Female2: And what worries me about the data that has been collected is into personal home care with the elderly and the trip wires and the things that can sense or tell them over a megaphone, you need to take your medication; this is horrendous, this is robotic, and that's been correlated from research that patients need this, patients results. Others don't remember to take their meds, what do we do, and they have collated

this, and what do – they send a transmission through to a house.

Male1: They don't see the person as a human being.

Female2: And it's de-personalisation, and it's dealing with the thing at source regimented theoretically, they have forgotten there is an individual there.

(Edinburgh)

- 3.29 As such there was some concern about how data might be used and what the implications of this would be for individual service users. As noted above, participants indicated that they would like more information about how their data is used, for what purposes and how this might benefit patients, service users or the wider public.

Summary

- 3.30 Overall participants were generally supportive of the aims of the 'Social care, housing and health data linking project'. It was widely acknowledged that data is very important for understanding patterns of health and illness or social care needs, and for planning and/or improvement of services.
- 3.31 However, participants sought assurances that data would be handled sensitively and confidentially. Protecting the identities of individuals was particularly important.
- 3.32 Additionally, participants indicated that they would like further information about how their data is accessed and by whom. In particular, they would like to be informed of the purpose and/or outcome of studies. It was considered important that data was used for purposes with clear benefits for patients, service users or the wider public.

4 FEEDBACK ON PRIVACY NOTICES

- 4.1 Participants were asked to give feedback on three information leaflets relating to data use. Participants were asked whether they found the leaflets to be clear, whether the information was appropriate, whether there was anything that they felt should be added and whether the leaflets reassured them about how their data might be used.

Draft Local Authority Privacy Notice

- 4.2 Participants were given a copy of a draft privacy notice designed to be delivered to social care service users by local authorities.
- 4.3 In general participants stated that they felt this notice was clear, and that it provided appropriate information. However, the following points were made:
- Not everybody knows who ISD are, the full name (i.e. Information Services Division) should be given.
 - Some participants also said they would like more information about who ISD are and what they do.
 - In one consumer panel participants wanted more information about what was meant by 'housing data'.
 - The privacy notice stated that:
'All pieces of information which could identify you, such as names, dates of birth and postcodes, will be removed before the data is used by Scottish Government and ISD Scotland statisticians'.

In two consumer panels there was some discussion about whether removing all identifying information might reduce the value of the data for research. In particular, several participants felt that it may be relevant to keep geographical information such as postcodes.

Easy to Read Version

- 4.4 Participants were then given copies of an easier to read version of the same draft privacy notice. The following comments were made:
- Several participants stated that they preferred this version to the first one.
 - However, in two consumer panels there was some discussion regarding the tone of this version. Some participants felt that it was very clear and used appropriate language and pictures, whilst others felt that it may be viewed as condescending. For example, it was stated:

"Now depending on who you hand this out to, some people would feel that you are talking down to them.[...] "they collect lots of numbers and these numbers are called statistics". I just feel that's a wee bit condescending."
(Tayside – Female1)

- However, several participants who had experience of working with young people or people with learning difficulties stated that they felt that the information was clear, accessible and appropriate.
- The notice states that:
“The Scottish Government and the National Health Service will try to make sure that the information they get about you is always kept safe.”

Some participants commented that this was not a strong guarantee that data would be kept safe. It was acknowledged that it would be impossible to give 100 per cent guarantees of this however it was stated that this was “not promising anything”.

- It was suggested that for individuals requiring an easier to read version of the privacy notice it would be most appropriate to deliver this orally and to allow people the opportunity to discuss it and ask questions.

ISD Leaflet

4.5 Participants were given a copy of the NHS Information Services Division (ISD) leaflet entitled ‘Protecting Personal Health Information: Information Guide for Patients’. The following comments were made:

- Many participants stated that they were not familiar with the CHI number, or that they did not expect most members of the public to be. It was therefore suggested that some explanation of this is necessary.
- It was commented that the blue printed text was clear and easy to read.
- Regarding the section on The Data Protection Act, it was commented that although you have the right to object to use of your information this may not be valid if you do not know until after the information has already been used.
- It was suggested that this leaflet should give examples of what information would actually be used.

5 COMPARISON WITH SCOTTISH HEALTH INFORMATICS PROGRAMME FINDINGS

- 5.1 Eight focus groups were conducted for the public engagement work stream of SHIP¹. These groups included a total of 50 participants recruited through pre-established groups such as patient support groups (relating to diabetes and mental health), a youth centre (with both young people and youth workers), an organisation representing black and ethnic minorities, a group of nursing researchers and friendship groups from a variety of professional backgrounds (including law, social work and social science research). The groups took place across Scotland (in Edinburgh, Glasgow, North Lanarkshire, West Lothian, Aberdeen, Inverness and Moray) and included a diverse range of age groups (the youngest participants being 16 and the oldest in their 70s), a roughly even split of genders was achieved (with 27 female and 23 male participants).

Key Areas of Agreement

- 5.2 In common with the findings of this study, overall participants in the SHIP focus groups were generally supportive of data-sharing for research purposes, although this support was never unconditional.
- 5.3 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.
- 5.4 Also in line with the findings reported above, many participants' responses to SHIP were dependent on the extent to which they perceived this to have benefits for patients or the wider public. The majority of participants felt that research would (at least probably) ultimately lead to benefits for healthcare and for many people this was the basis of their support for the sharing of medical data.
- 5.5 As in this study, each SHIP focus group raised at least some concerns about security in relation to the storage and accessing of electronic data. 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. Given these concerns safeguards to protect individuals' identities were considered to be crucial (for example, this was used to reinforce the importance of protecting confidentiality).
- 5.6 In both studies participants raised concerns that research looking for health patterns from linking health and non-health data would be used to generalise about groups and may ultimately lead to policies and/or interventions/treatments which did not adequately consider individual circumstances and needs.

¹ For more information about this study please visit: www.scot-ship.ac.uk

Areas of Disagreement

- 5.7 Whilst the findings of the two studies were largely consistent there were some areas of disagreement. For example, in this study participants frequently noted that different levels of information should not be shared equally, and in particular that sensitive information (i.e. relating to stigmatising conditions) should not be shared. Within the SHIP focus groups there were varying opinions relating to 'sensitive information'. Whilst some participants felt that sensitive information should not be shared, others contended that all information is equal and of potential relevance. These participants tended to place greater emphasis on who was accessing the information and for what purposes rather than *what* that information was.
- 5.8 A second area of difference between the two studies relates to the importance of anonymisation. Whilst in this study significant emphasis was placed on anonymisation, within the SHIP focus groups it was frequently contended that anonymisation was less important than consent. Some participants in the SHIP study suggested that they would be more likely to consent to data-sharing if their information was anonymous. However, participants generally stated 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. As such the SHIP focus groups emphasised consent (or individual control) over anonymisation.

6 CONCLUSIONS

- 6.1 The consumer panels found that participants were largely supportive of the aims of the 'Social care, housing and health data linking project'. It was widely acknowledged that data is very important for understanding patterns of health and illness or social care needs, and for planning and/or improvement of services.
- 6.2 Data-linkage was recognised as being important both in relation to individual care and also for research and planning purposes. However, participants were concerned about how much data would be linked and what form this would take (i.e. "just plain stats" or more detailed, descriptive information about individuals).
- 6.3 Participants sought assurances that data would be anonymous and that individuals would not be identifiable through data-linkage.
- 6.4 Whilst not their primary concern, participants also sought assurances that data would be secure within electronic databases and would not be lost or misplaced.
- 6.5 Participants placed considerable emphasis on the uses and purpose of data-linkage. Support for data-linkage was typically conditional on this being demonstrated to be for the benefit of patients, service users or the wider public.
- 6.6 These findings highlight key areas about which members of the public would like further information regarding how their data is used and for what purposes. Providing this information and the necessary assurances may be crucial for ensuring public support.
- 6.7 In sum, the consumer panels (in common with the findings of the SHIP focus groups) have indicated broad, general support for data-collection, sharing and linkage where this is seen to lead to benefits for patients, service-users or broader society. However, this support is conditional on members of the public having confidence that their data is being stored and used responsibly and appropriately. Transparency appears to be an important consideration: As the 'Social care, housing and health data linking project' moves forward it will therefore be important to consider how this transparency can be built into the design of the project (for example, what mechanisms are possible for providing feedback to individuals whose data is used and/or to the wider public).

ANNEX 1: TOPIC GUIDE

BACKGROUND

HEALTH DATA

1. When you use health services what sort of information do you think is recorded about you and the health services you use?
2. What do you think happens with this?
3. Who do you think has access to this information?
Prompts:
 - *Only people directly involved in your healthcare?*
 - *Other people working in the same surgery/hospital?*
 - *Other health care departments?*
 - *Organisations outside of health care?*
 - *The Scottish Government*
4. How do you think this information about you should be used?
Prompts:
 - *Should it only be used in relation to your own health care?*
 - *Should it be shared for management/audit purposes?*
 - *Should it be shared for research purposes?*

SOCIAL CARE/HOUSING (SUPPORT) DATA

1. When you use social care or housing support services what sort of information do you think is recorded about you and the social care/housing support service you use?
2. What do you think happens with this?
3. Who do you think has access to this information?
Prompts:
 - *Only people directly involved in your care/housing?*
 - *Other people working in the same department/agency?*
 - *Other social care departments?*
 - *Organisations outside of social care/housing?*
 - *The Scottish Government*
4. What do you think should happen to this information?
Prompts:
 - *Should it only be used in relation to your own care/housing?*
 - *Should it be shared for management/audit purposes?*
 - *Should it be shared for research purposes?*

Joining information together

<Read background information about data linking>

1. Initial reactions:
 - a. How do you feel about this?
 - b. Do you have any concerns?
2. What sorts of information would you be happy with being joined up?
Prompts:
 - *Social care information only?*
 - *Social care and housing support information?*
 - *Social care, housing support and health information?*
3. For what purposes would you be happy with your information being joined up?
Prompts:
 - *In relation to your own care/housing support?*
 - *For management/audit purposes?*
 - *For research purposes?*
4. Who would you be happy with having access to your joined up information?
Prompts:
 - *Only people directly involved in your healthcare/social care/housing support?*
 - *Other people working in the same department/agency?*
 - *Other social care departments (which you don't currently access)?*
 - *Voluntary sector care organisations?*
 - *Organisations outside of social care/housing?*
 - *The Scottish Government?*
 - *Academics?*

PRIVACY

<Hand out copies of Privacy Notice, and also read out to the group>

1. Initial reactions:
 - a. Is this clear?
 - b. Does anyone have any questions about this?
 - c. Does this address your concerns?
2. Does this reassure you about how your information will be used?
3. What further information would you like?

SUMMARY

1. What are you overall impressions?
 - a. Do you have any concerns?
 - b. Do you have any preferences about how information is joined and/or for what purposes it is used?

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