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Public Acceptability of Data Sharing Between the Public, Private and Third Sectors for Research Purposes



PUBLIC ACCEPTABILITY OF DATA SHARING BETWEEN THE PUBLIC, PRIVATE AND THIRD SECTORS FOR RESEARCH PURPOSES

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Table of Contents

EXECUTIVE SUMMARY	5
1 INTRODUCTION	12
2 RESEARCH METHODOLOGY	14
3 LITERATURE REVIEW: EXPLORING BENEFIT-SHARING	20
4 LITERATURE REVIEW: EMPOWERING CITIZENS IN DECISION MAKING	40
5 DELIBERATIVE RESEARCH FINDINGS	61
SENSITIVITIES AROUND DATA SHARING BETWEEN THE PUBLIC, PRIVATE AND THIRD SECTORS	61
BENEFIT-SHARING	76
EMPOWERING CITIZENS IN DECISION MAKING	82
6 CONCLUSIONS	88
REFERENCES	92
APPENDIX A: PROFILE OF WORKSHOP PARTICIPANTS	100
APPENDIX B: SUMMARY OF MODELS ACCORDING TO CLASSIFICATION OF PUBLIC ENGAGEMENT APPROACHES	102
APPENDIX C: TOPIC GUIDE	103
APPENDIX D: INTRODUCTORY PRESENTATION ON DATA-SHARING, LINKAGE AND THE STRATEGY FOR IMPROVING DATA ACCESS AND ANALYSIS	107
APPENDIX E: PRESENTATION ON PRIVATE SECTOR INVOLVEMENT IN DATA-SHARING AND BENEFIT SHARING	117
APPENDIX F: PROMPT CARDS CONTAINING EXAMPLES OF ORGANISATIONS, DATA TYPES AND DATA USES	124
APPENDIX G: EXAMPLES OF BENEFIT SHARING MODELS	126
APPENDIX H: VOTING EXERCISE ON FORMS OF PUBLIC INVOLVEMENT	127
APPENDIX I: POST-WORKSHOP QUESTIONNAIRE	128

EXECUTIVE SUMMARY

Introduction

In 2012 the Scottish Government commissioned research to explore the public acceptability of cross-sectoral data linkage for research and statistical purposes to inform the ongoing development of a Scotland-wide Data Linkage Framework. The research indicated that the public was, in principle, broadly supportive of data linkage, particularly for health research, and of the overall objectives of the Data Linkage Framework. However, this support was conditional and a range of ambivalences and concerns were also expressed: there was significant unease about the private sector having access to public sector data and, more specifically, about the scope for commercial gain arising from data linkage (Davidson *et al*, 2012).

In *Joined up data for better decisions: A strategy for improving data access and analysis*, the Scottish Government acknowledged these concerns and outlined a commitment to continue working with members of the public and other stakeholders to explore fully the appropriateness, concerns, benefits and risks of private sector involvement in the use and analysis of data collected and held by public bodies.

Accordingly, in spring 2013 the Government commissioned Ipsos MORI Scotland, along with Dr Mhairi Aitken, Professor Sarah Cunningham-Burley, Professor Graeme Laurie, Dr Claudia Pagliari and Nayha Sethi from the University of Edinburgh, to conduct research to enhance understanding of sensitivities around data sharing between the public, private and third¹ sectors for statistical and research purposes.

Specific objectives of the research were to establish: whether and how attitudes and sensitivities varied depending on the sectors and specific type of organisation involved in data sharing, the type of data being shared and the planned uses of the data; whether the public think about 'public benefit' differently in relation to the private and third sector's use of personal data compared to the public sector's; what methods of benefit-sharing are most acceptable to the public; and what methods could be most effective in empowering citizens in decision making about how their data are used.

Research methodology

The study comprised three elements: a desk-based literature review of international benefit-sharing models arising from the value of data sharing; a similar review of different methods that have been used to empower citizens in decision making about how their data are used; and a series of deliberative events with members of the public. The literature reviews were undertaken before the deliberative research so as to inform the range of issues and examples to be put to participants at the events.

¹ The Scottish Government's Strategy for improving data access and analysis is for the public, private and the third sectors in Scotland. Accordingly, on commissioning of the research, a decision was taken to expand the scope of enquiry to include the third sector.

Review of the literature on benefit-sharing models

Benefit-sharing is a concept that implies that the broadly envisioned advantages or returns from research should be distributed in a fair and equitable manner. Key legal instruments which have called for commitments to benefit-sharing were initially developed within International Law in order to address the distribution of rights to exploit and benefit from natural resources. The concept has begun to be applied in the research context, particularly in relation to biobanking. Benefit-sharing appeals to wider concepts of justice and fairness and is also invoked in the context of promoting trust. Benefit-sharing can mean different things to different people and any broad definition belies complexity in more practical terms; it is an evolving concept and in the context of data sharing, practical application is only just beginning. There have also been some criticisms of benefit-sharing, both as a concept (research outcomes should be considered benefits in themselves and shared de facto and research participation should be based on altruism) and in application (where models of benefit-sharing may legitimise commercialisation with limited attempts at distributive justice).

Six examples of benefit-sharing models in use were elicited from the literature reviewed, three of which were used as examples in the deliberative workshops. The models varied from clearly defined dispersal of net profits across different parties (Generation Scotland), through oversight of benefit-sharing protocols (Newfoundland and Labrador Model) to ensuring better health care through feeding back findings to practitioners (Estonian Genome Project).

Common features have been identified in the practical and conceptual models within the literature. Firstly, collaborative arrangements which attempt to provide positive social, economic and environmental outcomes for local communities by engaging with these communities. Secondly, contract-based models which ensure that the terms of the agreed benefit-sharing are kept, for example, by including points about dispute resolution, verification and incentives. Thirdly, community based partnerships which serve to make stakeholder engagement a core component, usually based on a legally valid agreement around community consultation. Fourthly, a participatory governance shareholder model argues that community consultation is not enough and partnership governance is required whereby donors/participants are treated as shareholders rather than stakeholders.

Despite the scarcity of research and evaluation on benefit-sharing in the context of sharing personal information and sharing data for research and statistical purposes, the literature review does offer some potential ideas for key elements that can be included in a benefit-sharing model. Most of the models included two independent bodies within their governance framework: one with ultimate authority for approving access to resources, and the second, which also scrutinised applications but which appeared independent and geared towards examining applications to ensure appropriate benefit-sharing mechanisms were in place. The independent scrutiny bodies were also employed with an oversight and monitoring function, to ensure that benefit-sharing measures were enforced. Some models have been praised in the literature for having included an element of public consultation or dialogue in their approaches but this has often stopped short of actual inclusion of lay members/donor representatives in any of the decision-making/oversight bodies.

Models which include direct participant representation may offer meaningful inclusion of participants, and provide them with some control in the decision-making process around what happens to collective resources, but issues remain about representation and interests.

Review of the literature on empowering citizens in decision making

Promoting public dialogue is a key component of the policy-making process; benefits include generating an understanding of public attitudes, stimulating greater public participation in civic life, and engendering trust. However, the extent to which public engagement is an empowering and meaningful practice remains a matter of debate. Public engagement comprises a range of goals and purposes; different underpinning orientations may reflect normative, instrumental or substantive positions - normative in the sense that public engagement should be part of our democracy; instrumental in terms of building trust in government; and substantive through including citizens in decision making for improved social outcomes.

Public engagement also comprises a range of activities which can map onto these diverse positions. Although there are different typologies available, these can be assembled into three broad, yet overlapping, arenas of practice: awareness raising, which promotes dissemination of information to apprise and educate; consultation, which seeks to elicit information from the public in order to inform decisions; and empowerment, which promotes citizen control through active participation. Awareness raising can promote public acceptance and includes methods such as a media campaigns or leaflets. Consultation can support the development of socially acceptable policy and may be achieved through surveys or qualitative research. Empowerment can enhance democracy through capacity building and may involve dialogic methods such as citizens' juries or participatory appraisal.

The literature review identified examples of awareness raising, consultation and empowerment and in many cases the studies reviewed can be seen to have aimed at and/or achieved more than one of these goals. Most, however, involved consultation and/or awareness raising. Empowerment was promoted in 12 of the 51 studies reviewed; this was achieved in combination with consultation and awareness raising, demonstrating that activities that inform are important across the range of public engagement activities. These studies can be viewed as empowering participants through devolving control over the engagement processes and outcomes, the development of new skills, greater understanding of issues under discussion and increased confidence to participate. Very few studies explicitly evaluated the engagement process but there was some evidence that participants appreciated the opportunity to take part in these activities and found the experience rewarding. Evaluation against clear criteria is required to assess both the process and outcomes of participatory engagement.

Deliberative research findings

Sensitivities around data sharing between the public, private and third sectors

As in the 2012 research, there was significant concern about the potential for shared personal data to be hacked or otherwise obtained by unauthorised individuals or

groups. This concern was largely informed by past, high profile cases of public officials leaving laptops, data sticks or hard copy documentation in public places. When reminded that data shared for research purposes would be anonymised, most participants appeared to feel reassured that this would mitigate against personal details falling into the wrong hands, though a significant minority were more sceptical.

Still, there was near universal acceptance of public bodies – including the Scottish Government, the NHS, local authorities and the police – having access to anonymised personal data from other organisations (whether public, private or third sector) for research purposes. There were two main factors underpinning this support. Firstly, there was a commonly held view that public sector organisations were concerned with delivering public benefits or promoting the “public good” and that any research they undertook would be similarly oriented. Secondly, and despite concerns about public officials misplacing or losing data, there was an assumption that public bodies had more stringent data protection and security procedures in place than other types of organisation – or at least were more accountable to the public than those other organisations when a breach occurred.

Private sector involvement in data sharing was a more contentious issue and there was strong spontaneous opposition to data being used by the private sector for the sole purpose of profit maximisation. This is not to say that participants were entirely opposed to private sector organisations accessing data, or that no level of profit was acceptable. Rather, the consensus was that private sector access to personal data should only be granted where this is likely to result in some form of public benefit.

Public benefit tended to be conceived of primarily in terms of improvements to local services, local areas or public health, rather than individual-level or direct financial benefits. However, there was some unprompted suggestion that the private sector should be required to pay for access to data and/or to share any profits resulting from research with the relevant data owner(s), so as to generate funds that can be reinvested towards the public good.

Third sector access to data was seen as more acceptable than private sector access but somewhat less so than public sector access. There was a widely held assumption that many third sector organisations, like public bodies, are concerned with promoting the public good. At the same time, there was a perception of the third sector as something of an unknown entity, which prompted feelings of unease about its organisations having access to data. There was a tendency for participants to draw a distinction between charities on the one hand, and pressure groups on the other, with the former generally trusted more than the latter. It was commonly suggested that pressure groups had agendas to advance that may or may not reflect the interests of the general public

When participants were asked about the relative acceptability of different *data types* being linked and shared for research purposes, they tended to begin by saying that it depended on who would be accessing the data and for what purpose, reinforcing the centrality of trust as a determinant of views. Still, they did distinguish between different data types, with three types in particular provoking considerable discussion

and debate across the events: postcode data; sexual orientation data; and commercial data.

There was widespread concern that a focus on postcode data in research could result in areas being negatively labelled – for example as “deprived”, “rough” or low-achieving – and, subsequently, in residents of those areas experiencing stigma or discriminatory treatment. Additionally, there was a view of postcode information as potentially disclosive. This view was most common among people in the more rural locations of Oban and Galashiels several of whom contended that individuals could “quite easily” be identified within a dataset focusing on a small geographic area from a combination of their postcode and other data types.

Data on sexual orientation was most commonly a focus for LGBT participants; most of whom expressed ambivalence on the matter of such information. On the one hand they emphasised a need for better, more accurate data on sexual orientation to increase understanding of LGBT issues and inform improved service provision for these groups. On the other hand, there was trepidation about the potential for such data to fall into the wrong hands and be misused, particularly in the event of its being ‘de-anonymised’, rendering individuals potentially identifiable.

With regard to commercial data, there was general opposition to the idea of banking and other financial information being shared with any third party organisation, whether public, private or third sector. This reflected a view that financial data, even in anonymised form, is very private and should remain so. A similar level of opposition was expressed over the sharing of data held by internet providers and social media companies, with this data too regarded as too personal to be shared.

Benefit-sharing

Benefit-sharing was perceived to be important and necessary, although it was clear that participants thought of benefits differently in relation to the public and third sectors’ use of data compared to private sector use. While they perceived the realisation of benefits as an inevitable goal of research conducted by public and some third sector organisations, the prevailing view was that the main goal of private sector research was ultimately to generate profit and, as a consequence, their access to data should be more strictly controlled. Reflecting these views, benefit-sharing models were commonly seen as more relevant in the case of data sharing involving the private sector compared to the public and third sectors.

Benefit-sharing models were mainly conceived of in terms of *who* should benefit from data sharing and *how* they should benefit, with discussions focusing mainly on data subjects and data users.

In relation to data subjects, a clear distinction was drawn between research requiring their proactive participation and research that draws on routinely collected administrative or statistical data. With regard to the former, the consensus was that data subjects should benefit directly, with suggestions for direct benefits ranging from financial incentives to advice and access to services. With regards to routinely collected data, the prevailing view was that individual data subjects should not necessarily benefit directly and, instead, society in general, or the specific population

to which the data relates, should be the main beneficiaries. 'Societal benefits' were conceived of in terms of primary benefits – outcomes which arose directly from research, such as improved services – and secondary benefits – broader and longer-term benefits, such as better public health.

Discussions pertaining to data users focused primarily on private companies. Despite participants' initial aversion to the idea of companies profiting from research using shared data, the discussion of benefit-sharing led to the emergence of more nuanced views. There was general recognition that profits provided an incentive for private companies to invest in and conduct research, which, in turn, contributed to wider economic benefits. However, participants remained concerned about the potential for private companies to make excessive profits. Consequently, they felt it important that benefit-sharing models incorporated clear provisions to curb the level of profits made from research. Specific suggestions included provisions to ensure that private companies: pay to use data; share profits; provide affordable products and services; or reinvest profits in local communities.

Aside from data subjects and data users, participants identified other countries and future generations as groups that might become beneficiaries of research. There was a view that recognising these groups in benefit-sharing models, particularly in cases where it is difficult to identify an immediate benefit to data subjects or wider society, would go some way towards demonstrating that the research is in the public interest.

Empowering citizens in decision making

There was unanimous agreement that public involvement in decision making on data sharing, including the development of benefit-sharing models, was important and appropriate. In terms of specific forms of involvement, there was a stronger appetite for transparency, feedback and consultation than for more active forms of involvement such as agenda-setting and representation. There seemed to be two main reasons underlying this.

First, while participants felt that the public would be able to contribute to more general discussions about how their data should be used, there was a view that most members of the public did not have the requisite knowledge and expertise to contribute to more specific decisions about the types of research that should be carried out, and other similarly complex issues. Second, it was commonly felt that most people were either unwilling or unable (due to family and work commitments) to devote time to acting as public representatives.

Reflecting participants' views on potential *forms* of public involvement in decision making, three *methods* of involvement were commonly mentioned.

First, there was strong support for the idea of setting up an oversight body, comprising a range of stakeholders, to oversee data sharing. Participants felt that public interests should be represented in the oversight body in an indirect way – there was a specific suggestion for a third party organisation that would regularly consult with the public and feed back to the oversight body accordingly. There was a preference for this consultation to inform general principles around data sharing

(including, rules on what information is made available, who should be able to access it and governance arrangements) rather than to solicit views on specific requests for access to data.

Second, the internet was frequently mentioned as a potentially useful and cost-effective way of engaging the public in decision making around data sharing. A popular suggestion was for a website that could act as a 'one-stop shop' for information on data sharing.

Third, participants, mindful of the limitations of a solely online approach (specifically concerning those without internet access), often felt any such approach should be supplemented with an initial television-based public awareness-raising campaign in the style of a party political broadcast or a public health campaign.

1 INTRODUCTION

Background to the research

- 1.1 Scotland is recognised as an international leader in data linkage for the purposes of research and service analytics, particularly in the health sector where robust mechanisms exist for linking various datasets holding medical records and related sources, such as the Scottish Health Survey. This has helped to generate insights into patterns of health and illness in the population, as well as to examine the impacts of new treatments or policies (see Morris *et al*, 1997; Bhopal *et al*, 2011). Data linkage has also been used successfully in other sectors, such as to demonstrate the impacts of social care on children's education and future crime². However, the technical and regulatory mechanisms for undertaking record linkage studies are somewhat piecemeal and cumbersome and the Scottish Government has recognised the scope for the national research environment and strategic capabilities to be enhanced by facilitating linkage across different public sector databases.
- 1.2 In early 2012 the Government published the consultation document, *A Scotland-wide Data Linkage Framework for Statistics and Research*, which set out aims, benefits and challenges to data linkage, alongside a draft set of 'Guiding Principles' and suggested functions and objectives for infrastructure to support and enhance data sharing and linkage with appropriate regulation and oversight.
- 1.3 A key barrier to data linkage identified in the consultation document was uncertainty, among data custodians, regarding the public acceptability of the process and the legalities of linkage. Up until now, this has led to considerable variation in responses to data linkage requests for research by those who control such access. In order to seek clarity on these issues the Government held meetings and discussions with key stakeholders, sought advice from international experts, written submissions from Scottish stakeholders and commissioned research into the public acceptability of data linkage and the draft 'Guiding Principles' (Davidson *et al*, 2012).
- 1.4 The results of that research – which took the form of a series of public deliberative events across Scotland – indicated that the public is, in principle, broadly supportive of data linkage, particularly for health research, and of the overall objectives of the Data Linkage Framework and its 'Guiding Principles'. However, this support was conditional and a range of ambivalences and concerns were also expressed: there was significant unease about the private sector having access to public sector data and, more specifically, about the scope for commercial gain arising from data linkage (Davidson *et al*, 2012).
- 1.5 In *Joined up data for better decisions: A strategy for improving data access and analysis*, the Scottish Government acknowledged these concerns and reiterated that data linkage activity must be conducted in the public interest and in a manner that is acceptable to the public. Further, it outlined a

² (see the Edinburgh Study of Youth Transitions and Crime <http://www2.law.ed.ac.uk/cls/esytc/>)

commitment to continue working with members of the public and other stakeholders to explore fully the appropriateness, concerns, benefits and risks of private sector involvement in the use and analysis of data collected and held by public bodies.

- 1.6 Reflecting this commitment, in spring 2013 the Government commissioned Ipsos MORI Scotland, along with Dr Mhairi Aitken, Professor Sarah Cunningham-Burley, Professor Graeme Laurie, Dr Claudia Pagliari and Nayha Sethi from the University of Edinburgh, to conduct research to explore the views and deliberations of members of the public on the use of personal data by the public, private and third³ sectors, and in particular the sharing of data between these sectors.

Research aim and objectives

- 1.7 The overarching aim of the project was to build on previous research, existing literature and practical examples to enhance understanding of sensitivities around data sharing between the public, private and third sectors for statistical and research purposes.

- 1.8 Specific objectives of the research were to establish:

- whether and how attitudes and sensitivities varied depending on:
 - the sector (private, public or third) and specific type of organisations that may be involved in data sharing
 - the data types, specifically including personal data on protected-characteristics (sex, age, ethnicity, sexual orientation, religion, disability, pregnancy and maternity), which may make inadvertent statistical disclosure more likely
 - the reasons the data may be shared between the public, private and third sectors for research and statistics
- whether the public think about 'public benefit' differently in relation to the private and third sectors' use of personal data compared to the public sector's, as well as the private sector's use of personal data compared to the third sector's
- what methods of benefit-sharing are most acceptable to the public
- what methods could be most effective and efficient in empowering citizens in decision making about how their data are used

³ The Scottish Government's Strategy for improving data access and analysis is for the public, private *and* the third sectors in Scotland. Accordingly, on commissioning of the research, a decision was taken to expand the scope of enquiry to include the third sector.

2 RESEARCH METHODOLOGY

2.1 The study was conducted using a combination of primary and secondary research methods, comprising:

- a desk-based literature review of international benefit-sharing models arising from the value of data sharing
- a desk-based literature review of different methods that have been used to empower citizens in decision making about how their data are used
- a series of deliberative events with members of the public

Desk-based literature reviews

2.2 The secondary research involved two desk-based literature reviews of published peer-review papers, written in English, and the grey literature. Relevant books/chapters were also included. The following methods were used to access appropriate literature:

- bibliographic searches were conducted through the following databases: ASSIA; IBSS; JSTOR; The Knowledge Network; BioMed Central; EMBASE and Web of Knowledge. Using several databases enabled confidence that all relevant articles were identified
- the titles and abstracts (or summaries) of the initial search results were reviewed in order to eliminate irrelevant references. This led to a refined list of relevant articles. Citation searches for each of these articles were then conducted in Google Scholar in order to identify additional relevant articles. The relevant references from each article were also reviewed
- each article was read in its entirety and analysed qualitatively to identify relevant themes which were integrated into a narrative review.

The desk-based literature reviews were undertaken before the deliberative research and informed the range of issues and examples put to participants.

Deliberative research

2.3 The primary research was conducted using qualitative deliberative techniques. Rather than attempting to identify pre-existing attitudes to data linkage and sharing between sectors, a concept which may not have been immediately relevant to participants nor fully understood, deliberation allowed for the sharing of information and expertise and the development of considered responses across different sessions within the deliberative events.

2.4 In accordance with the objectives outlined in the introduction, the research sought to explore the views of the general public as a whole, while also explicitly seeking the views of members of the public with protected characteristics – defined as sex, age, ethnicity, sexual orientation, religion,

disability, pregnancy and maternity – which may, among other concerns, make inadvertent statistical disclosure more likely and/or more sensitive. To achieve this, the deliberative research comprised:

- four half-day events among a cross-section of the general public. At all of these events, larger equality groupings (women, different age groups, religious communities and people with a disability) were represented broadly proportionate to their representation in the population. Other minority equality groups (minority ethnic communities; Lesbian, Gay, Bisexual and Transgender (LGBT) people; and women who are pregnant or have a child under the age of 1) were over-represented to ensure their inclusion in the study (See Appendix A for a full breakdown of the profile of attendees).
- a separate, smaller scale event among LGBT people. This separate event was held to increase the likelihood of identifying any issues related to sexual identity by creating a forum in which participants might feel freer to talk openly about such issues. All participants were aware of the specific purpose of this event.

2.5 The general public events were held in Oban, Aberdeen, Glasgow and Galashiels between 29 June and 20 July 2013. The LGBT event was held in Edinburgh on 3 August 2013.

Recruitment of participants

- 2.6 The bulk of the recruitment was conducted face-to-face in participants' homes. However, given the relatively low penetration of LGBT people and pregnant women/women with a child under the age of 1 in the population, the face-to-face recruitment was supplemented with more targeted approaches for these groups.
- 2.7 LGBT participants were recruited partly through LGBT community groups and partly using on-street recruitment, with efforts concentrated in areas where there were gay bars and clubs. Women who were pregnant/had a child under the age of 1 were recruited on-street in areas surrounding GP surgeries and health clinics.
- 2.8 All participants were recruited between 17 June and 2 August 2013, using a questionnaire specially designed for this purpose.
- 2.9 To ensure that an appropriate range of people, including those with protected characteristics, were engaged in the research, quotas were set on: sex, age, working status, socio-economic position, ethnicity, disability, parental status and sexual orientation. Participants were also quota sampled based on their responses to a question about trust in public, private and third sector organisations⁴, which previous research shows can be crucial in shaping

⁴ Participants' level of trust in public bodies was established using the following question, included in the recruitment questionnaire: *'I will read you a list of different types of people. For each, would you*

attitudes to data linkage for health research (see Davidson *et al*, 2012 and Aitken, 2011).

2.10 Individuals who worked in market research, media, advertising, PR, statistics/data analysis or for the Scottish Government; and those who had attended a group discussion or event in the previous 12 months were excluded from the research.

2.11 Thirty-two people were recruited to each of the general public events and 14 were recruited to the LGBT event, with the aim of ensuring that around 25 and 10 respectively attended on the day. Table 2.1, below, shows the number of people that attended each event.

Table 2.1: Number of participants attending each event

Location	Date	Number of participants
Oban	29 June	25
Aberdeen	6 July	25
Glasgow	13 July	28
Galashiels	20 July	27
Edinburgh	3 August	12

2.12 Attendees were representative of the broader pool of recruits for each event (Appendix A details the profile of attendees). All received £50 as a ‘thank you’ for their time and to cover any expenses incurred.

Structure of the events

2.13 Table 2.3 shows the structure of the events and summarises the purpose of each stage.

tell me if you generally trust them to tell the truth, or not?’ The Scottish Government; local councils; researchers in universities; the NHS; The Police; private companies; charities.

Table 2.3: Structure of the events

Session	Content/purpose
Plenary session – Welcome & orientation	To welcome participants and outline the scope of the study and key concepts that would be used throughout the day.
Plenary session – Introductory presentation on data sharing, linkage and the strategy for improving data access and analysis, plus Q&A	To provide participants with necessary contextual information, and the opportunity to ask questions.
Break-out groups	To explore <i>unprompted</i> attitudes towards data sharing between the public, private and third sectors, including: immediate reactions; whether attitudes varied depending on the type/role of particular organisations; the reason for sharing data; the type of data being shared.
Lunch break	
Plenary session – Presentation on private sector involvement in data sharing and benefit-sharing, plus Q&A	To provide participants with a fuller understanding of the ways in which, and reasons why, the private and third sectors might be involved in data sharing; the types of organisations concerned; and the types of data that might be shared. The presentation also introduced the concept of benefit-sharing and gave examples of benefit-sharing models.
Break-out groups	To explore reaction to the second presentation, including: types and aspects of data sharing between sectors that participants felt positively/negatively about and why; measures that would mitigate any concerns; attitudes towards benefit-sharing and preferred models of benefit-sharing; and views on empowering citizens in decision making about how their data is used.
Plenary session – Closing remarks	A summing up of the key messages from the event and completion of a post-event questionnaire.

2.14 For the break-out groups, participants were divided into three groups on the basis of their age to allow for the identification of any variation in views by life stage. At each of the general public events, the intention was to divide participants into uniform age bandings (18 to 34 years, 35 to 49 years and 50 years and over). However, due to differential turnout by age, these bandings were adjusted at some of the events to ensure a roughly equal number of participants per break-out group. Table 2.2 below details the bandings used in each case.

Table 2.2: Age bandings used for breakout groups at the general public events

Location	Youngest	Middle	Oldest
Oban	18-34	35-49	50+
Aberdeen	18-24	25-49	50+
Glasgow	18-34	35-49	50+
Galashiels	18-29	30-43	44+

- 2.15 Participants at the LGBT event in Edinburgh were divided into two broad age groupings. The younger grouping included participants aged from 26 to 33 years and the older grouping included participants aged from 37-59 years.

Event materials

- 2.16 All materials used in the events were designed by the researchers at the University of Edinburgh and Ipsos MORI Scotland. The materials included two PowerPoint presentations with detailed information on topics for discussion, a discussion guide which was used by moderators to facilitate the break-out discussions, stimulus materials to promote discussion around different sectors/organisations, data types and data uses, and a post-event questionnaire (copies of all materials are provided in Appendix F to I).

Analysis

- 2.17 All discussions that took place at the events were recorded and then transcribed with the consent of participants. Group facilitators also compiled summary field notes at the end of each event. In addition to this, the project team held regular meetings, throughout the fieldwork process, in order to discuss findings and emerging themes.
- 2.18 At the end of the fieldwork, the researchers conducted a brainstorming session to identify the top-level findings and implications. The data was analysed using a thematic indexing and charting system often known as 'Framework'. This involved creating a code frame of substantive themes and sub-themes, and adding in key findings within each theme. Transcripts were systematically analysed for key points and illustrative verbatim comments. Any new sub-themes which emerged at this stage were integrated into the code frame.
- 2.19 This method ensured that analysis and reporting of the data was rigorous, balanced and accurate, and that key messages or concepts were brought out. It was also flexible enough to allow for links and connections across different themes or sub-themes to be made, and for moments of interpretive insight and inspiration to be recorded.

Interpretation of qualitative findings

- 2.20 The findings presented in this report were derived using qualitative data collection methods and analysis. Unlike large surveys, qualitative social research does not aim to produce a quantifiable or generalisable summary of population attitudes, but to develop a deeper understanding of the range of factors that shape views as well as identifying key attitudinal tendencies that are likely to be prevalent across society. Qualitative research is particularly useful when exploring complex or hard-to-understand areas, such as cross-sectoral data linkage; single or resolute responses are unlikely but the process of discussing the issues reveal the complexities of opinions and degrees of consensus. The integration of 'deliberative' approaches aids this process, since participants are given the opportunity to explore their feelings towards the topic alongside considering information provided to them. This

process reveals a more nuanced and informed set of considerations and the influences underlying them, which can be useful for informing policy-making.

3 LITERATURE REVIEW: EXPLORING BENEFIT-SHARING

- 3.1 This chapter considers key issues related to benefit-sharing in the context of data sharing for research and planning purposes. It describes key findings from a desk-based literature review examining key concepts and methods of benefit-sharing.
- 3.2 The evidence base for this chapter has been developed primarily from a literature review of relevant legal and sociological materials, including published peer-reviewed papers written in English, the grey literature (including official reports, primary and secondary legislation) and relevant books.
- 3.3 Scotland and, more generally, the wider-UK have developed an impressive international reputation for conducting research on electronic records. Such records can be used for diverse purposes, including administrative planning, quality assurance and for conducting health, social and economic research. The increasing number of initiatives dedicated to electronic-record based research demonstrates the perceived value of such data.
- 3.4 Alongside the potential benefits of using these records are associated risks. For example, matters become complicated where the outcomes of the research can lead to commercial profit, particularly where research conducted within the private sector is based on data which emerges from the public sector. The question of how such benefits can and should be shared between stakeholders (including citizens and those who store and use the data) must be considered.
- 3.5 This chapter builds on previous interdisciplinary work carried out in the field by: conducting a cross-sectoral survey of relevant benefit-sharing models, drawing on lessons learned, and making recommendations about how issues around 'benefit-sharing' might be approached in the context of data sharing.
- 3.6 The chapter details the results of a literature review, conducted in order to survey the extent of proliferation of (real and theoretical) benefit-sharing models in the field of data sharing, and to uncover evidence of any evaluations of their effectiveness that have been conducted to date. It provides a synthesis of common features of viable benefit-sharing models, and includes a commentary on these features and their potential impact on the design and delivery of benefit-sharing.
- 3.7 More specifically, the chapter considers how a working definition of benefit-sharing might be constructed, noting that it includes but is not restricted to wealth, health and social benefits. It also offers key exemplar areas of benefit-sharing. The report focuses on known pressure points of concern which previous research has highlighted (including the relevance of the public/private nature of the funding and use of data resources).
- 3.8 This chapter is organised in three parts:

Firstly, it introduces the concept of benefit-sharing and its origins in order to set the context of the discussion on how this concept relates to the research setting. The literature review considers the concept of benefit-sharing as has been discussed in other sectors (of most relevance for this research, in the context of biobanks). However, it has to date remained relatively under-explored in relation to sharing electronic patient records and regardless of context, little concrete evidence exists around what benefit-sharing models look like in practice.

Secondly, it offers an overview of actual and theoretical/conceptual benefit-sharing models which have been advanced, considering their key features, strengths and limitations in the context of how they might be translated to the data-sharing context.

Thirdly, it includes a discussion of the key considerations which must be factored in to any benefit-sharing approaches which might be adopted. The chapter concludes by offering key considerations for the Scottish Government moving forward, and by suggesting key themes for exploration in the deliberative work.

Introduction to Benefit-sharing

- 3.9 There is increasing recognition of the potential value that can arise out of research based on large-scale datasets. Much of the data used in research originates from the public sector, and the benefits that can arise from research are diverse, including economical and societal gains such as improved planning and wellbeing. Ensuring that we are making the most that we can out of this type of research is becoming a priority. For example, within the health sector, the Academy of Medical Sciences (2011: 57) has stated that it is 'crucial' that data is accessible across the population in order to maximise the potential benefits of health research. Indeed, the recent Caldicott 2 Report (2013: 21) has introduced a new principle which explicitly stresses to those responsible for granting access to patient data that 'the duty to share information can be as important as the duty to protect confidentiality'.
- 3.10 The value of such research stretches far beyond the health sector too. In addition to the Scotland-wide Data Linkage Framework aimed at maximising the potential of statistical data, the Administrative Data Taskforce (2012) has recently recommended the establishment of four UK-wide Administrative Data Research Centres in order to better facilitate research based on administrative data.
- 3.11 An important issue related to research is benefit-sharing. Benefit-sharing is a concept which, broadly stated, implies that the benefits (and burdens) of research should be 'universally shared' in a fair and equitable manner (Sheremata and Knoppers 2007: 160).
- 3.12 Key legal instruments and guidance which have called for commitments to benefit-sharing were initially developed within International Law (Sheremata and Knoppers 2003) in order to address 'how to distribute rights to exploit and benefit from natural resources' (Hayden 2007: 734). It has been argued that

having a fair agreement of benefit-sharing in place can avoid exploitation of individuals (and their resources) (e.g. the Convention on Biological Diversity 1992, Bonn Guidelines 2002 and Human Genome Organisation 1996).

- 3.13 Additional rationales in favour of benefit-sharing have been advanced within the literature; it is argued that sharing benefits arising out of collective resources addresses notions of justice and fairness. Trust is also seen as a rationale for benefit-sharing (Laurie and Hunter 2004, Knoppers 2000). It is also thought that benefit-sharing itself can lead to 'increased medical interventions to improve health [and] increased knowledge about health' which can be made available to citizens, can lead to job creation (particularly in pharmaceuticals, and research more generally), and to profits for commercially oriented research companies (Schroeder and Gefenas 2012: 20).
- 3.14 When we turn, however, to consider what benefit-sharing actually means in practical terms, things become more complex. First, the concept of benefit-sharing is constantly evolving (Knoppers 2000) because different benefits and burdens can arise depending on the type of research under discussion. For example, the potential benefits and risks associated with clinical testing of medications on humans will be different to those from research related to using information from public sector datasets.
- 3.15 Second, 'benefit-sharing' can mean different things to different people. Some definitions are particularly broad: one definition describes it as sharing the benefits of whatever results from using 'biological resources, community knowledge, technologies, innovations or practices' (Organisation of African Unity: 2000). As a technical term, benefit-sharing 'describes an exchange between those who grant access to a particular resource and those who provide compensation or rewards for its use' (Schroeder 2007: 205). This technical definition also illustrates how broadly benefit-sharing can be defined, and the importance of articulating not only what 'benefit' means, but also who stands to receive and provide benefits.
- 3.16 We consider working definitions of benefit-sharing in section 4 below, but when reading this chapter, it is important to keep in mind that BS is a broad and evolving concept and arriving at consensus on what constitutes a fair agreement is not a straightforward undertaking, let alone arriving at a consensus on *how* different contributors might benefit and in what way.
- 3.17 In the data-sharing context, the key question which arises is how to ensure that the benefits (and burdens) of research are fairly and equitably shared between the users and the contributors/managers of the data. This is particularly important where private sector organisations stand to benefit from the use of personal information contributed by citizens (and particularly where benefit is in the form of commercial profit) and maintained by the public sector. On the other hand, unrealistic expectations can be made about benefits, particularly when considering the extent to which companies actually profit from data-based research – not every research study will result in 'positive' outcomes, let alone considerable, if any, financial gain.

- 3.18 Although little discussion has taken place around benefit-sharing in the specific context of sharing electronic records for research, some lessons can be learned from previous approaches and experiences in other sectors. Benefit-sharing has been discussed in other settings including forestry partnerships, corporate social responsibility and biobanks. As we will see, discussion tends to be very aspirational and there is a lack of guidance on how benefit-sharing looks in practice.
- 3.19 Benefit-sharing raises many important questions which must be considered before determining which approaches might be best suited for this particular context. First and foremost, we must consider which benefits will be identified and offered. Further questions then arise including (but not exclusively) the following:
- who decides what constitutes a benefit?
 - how would benefits be distributed?
 - would benefit-sharing take place according to the number of people who contribute to the project, how much effort participation involves, and/or some other factor? (Millum 2012)
 - how will contributions be weighed? : For example, will contributions be made by individuals about whom the data is based, those who collect the data, those (organisations) that manage the data resource, the scientists who analyse the data, 'the institutions that trained the scientists, and the distribution of benefits?
- 3.20 Benefit-sharing approaches which have been adopted and considered in the case of human genetic databases or biobanks may offer the most in terms of guidance around how it should be approached when sharing electronic patient records. However, given the novel nature of constructing benefit-sharing mechanisms in this particular setting, additional (and potentially separate) concerns unique to data-linkage may arise. For example, individuals may view sharing genetic information in a different light to sharing non-genetic information.

Arguments against benefit-sharing

- 3.21 The aim of this review is to explore the issues involved with benefit-sharing rather than to assess whether benefit-sharing is in itself an appropriate mechanism. However, before proceeding, it is worth noting that there is some scepticism and criticism of benefit-sharing. For example, Chadwick and Berg (2001: 321) note that where an emphasis on benefit-sharing is made, this may be with the intent to 'buy people off' rather than to strive for distributive justice.
- 3.22 For others (particularly when considering human genetic research), the outcomes of research should be considered as benefits in themselves. Some consider that altruism should be the guiding principle for contributors to research (Schroeder 2007, Kadri 2007). An altruistic approach implies that we act in the interest of others without expecting personal benefits.
- 3.23 Some have viewed benefit-sharing as a way of trying to legitimise commercialisation and profit, arguing that financial or other benefits should

not compete against ‘overarching values like human health and quality of life’ (Kadri 2007: 5). Barr et al (2006:110) also warn of the risks of inadequate arrangements for sharing of benefits, with communities signing away their rights. This can happen where information sharing and consultations are inadequate. This flags up the importance for the Scottish Government in ensuring that all stakeholders are involved in consultations and that appropriate information sharing procedures are put in place. It is also important to remember that benefit-sharing does not negate the need for informed consent to research where the law requires this (Chadwick and Berg 2001).

- 3.24 Another overarching concern is that benefit-sharing can give rise to elite capture – that is, where resources which are meant to benefit the larger population are actually only used by a few individuals or groups in power. Again, including all stakeholders in the consultation process in a meaningful way, as well as ensuring careful and transparent oversight of research can serve to lower risks of elite capture.
- 3.25 All of the risks mentioned above are not recounted in order to imply that benefit-sharing should be avoided, but rather, they serve to stress that we should be aware of the potential failures which can arise where inappropriate models or approaches to benefit-sharing are adopted. Given the potential importance of the role of benefit-sharing in research and the increasing number of initiatives dedicated to maximising the potential benefits of research arising out of data-linkage, it is paramount that questions around benefit-sharing are explored now in a robust, open, transparent and inclusive manner.
- 3.26 Governments can play a positive role in facilitating benefit-sharing agreements where they have in place mechanisms and policies for fostering partnership, dialogue and negotiation. There is a real opportunity for the Scottish Government to shape an effective and efficient approach to benefit-sharing which reflects the concerns of the public.

Benefit-sharing models

- 3.27 This section outlines some benefit-sharing models discussed within the literature. There is a particular (but not exclusive) focus on models discussed in the context of large-scale DNA databases/biobanks because those discussions are most likely to raise issues which are also relevant to the use of large-scale electronic datasets for research and planning purposes.
- 3.28 The review below includes an overview of key elements and structures incorporated (or proposed for inclusion) within each model, and comments on the associated strengths and limitations of the models. Special consideration is given to how well each model (or its key elements) could be transplanted to the data-sharing setting.
- 3.29 The literature review incorporated sources including published peer-reviewed papers written in English, the grey literature (including official reports, primary and secondary legislation) and relevant books.

- 3.30 The methods used in this literature review are described in chapter 2. Bibliographic searching focussed on the last 10 years (although some sources which extended beyond this timeframe were of relevance), including international literature. Key words identified for searching included: benefit-sharing, profit share, access, commercialisation, and evaluation. Reference lists were reviewed in order to ascertain further articles not identified through searches. The titles and abstracts of the resultant literature were reviewed in order to distinguish relevant and less relevant articles. In the end 26 journal articles were included in addition to reports, a doctoral thesis, primary and secondary legislation, and websites. Academic colleagues with experience on the concept of benefit-sharing were also consulted, and sources which they recommended were included.
- 3.31 In order to identify, assess and note the most useful elements and considerations contained in different models (and the wider literature), a bespoke template was constructed and each source was tested against the template. The criteria included reflect key considerations which must be factored-in to benefit-sharing approaches. The criteria are:
- the model being discussed (and context) and where applicable, the type of data being shared
 - key features of the model
 - any working-definitions of benefit-sharing which were offered
 - examples of benefit to include wealth, health, social, cultural and others;
 - nuances between public/private access to/uses of data
 - points of concern (including the relevance of: the public/private nature of funding of data resources; purposes for which data are used; and commercial objectives in access and use)
 - a note of or discussion on net contributors/beneficiaries in the model;
 - whether or not public dialogue was developed in the construction of the model and if so, to what extent and
 - any additional comments/observations
- 3.32 The analysis begins with an overview of concrete models which have been implemented in practice, beginning with national and subsequently international examples. These practical examples serve to help the reader develop a more concrete idea of how benefit-sharing has been implemented in practice, and to indicate the challenges and limitations of BS models.

Actual models of benefit-sharing

Generation Scotland

- 3.33 Generation Scotland (GS) is a collection of human biological samples from over 30,000 participants, which are made available for medical research. It involves a partnership between Scottish University Medical Schools, NHS Scotland and research participants. It receives core funding from the Scottish Government and through collaborative research (Generation Scotland 2013).
- 3.34 GS initially had 2 oversight bodies:

- a Scientific Committee which consists of members of all participating institutions including doctors, scientists and project managers. The committee has overall decision-making authority for overseeing access to and uses of GS resources.
 - the Advisory Board was appointed by the Scottish Executive. It consisted of experts in genetics, law and ethics and would oversee the work of the Scientific Committee advising on conformance with the Governance framework, ensuring that Generation Scotland resources are used in the best interests of the public and advising on ethical issues that may arise during the study for genetic and health related research.
- 3.35 In its policy on access and publications, GS stressed that participants or their heirs would not receive payment for any profits made from use of their samples, nor would individual patient contributions be acknowledged. Participants would not receive direct benefits apart from basic health advice (feedback to the patient and, with permission, their GP, on basic clinical information, for example, height, weight, BMI, blood pressure, serum cholesterol, glucose, and smoking status).
- 3.36 In terms of sharing any income that would arise out of projects, the GS policy set out that any net profit (once patents and legal costs were paid) from commercial exploitation would be divided between the parties as follows: 25% to the University parties; 25% to the NHS parties; 25% to the party/parties which own the rights to the commercial projects, and 25% to Generation Scotland.
- 3.37 GS had a sustained programme of public engagement which explored public reaction to a wide range of issues relevant to the use of genetics in healthcare. Focus groups indicated that they would prefer an independent public body to govern the database; different review committees (scientific and ethical) were suggested in order to maintain trust. Feedback from specialists also stressed the need for 'independent management and governance and for openness and accountability' (Haddow et al 2008: 146).
- 3.38 GS offers a helpful example of how a BS model might be constructed. It offered explicit expressions on how benefits would be shared (and in order to manage expectations, clarification about the limitations of feedback that participants would receive about their health). It had two oversight bodies to provide for independence and to monitor accesses to, and uses of, participant information. However, there was no lay-representation on either the Scientific Committee or the Advisory Board and, despite engaging in the consultation process, GS has been criticised for not involving donors or publics in how the resource functions.

Newfoundland and Labrador Model (Pullman and Latus: 2003)

- 3.39 This model was developed in response to increased interest in carrying out research on the inhabitants of the Canadian province of Newfoundland and Labrador. The province was particularly attractive for genetic researchers given the relative homogeneity of the population. A benefit-sharing protocol was developed; this assesses individual genetic studies on a case by case basis.
- 3.40 The model had two oversight bodies:
- a Standing Committee on Human Genetic Research (SCHGR) that would operate alongside but at arm's-length to;
 - the Provincial Health Research Ethics Board (PHREB), in order to ensure appropriate benefit-sharing arrangements were made.
- 3.41 A benefit-sharing proposal with supporting rationale must be submitted to the SCHGR which would either approve this or make necessary changes. In order to preserve independence, the PHREB would make its decision independently, however approval would necessitate a satisfactory report from the SCHGR.
- 3.42 The establishment of a PHREB helps to maintain local control over access to health records and to ensure its own research infrastructure is developed and expanded. However, as with Generation Scotland, the Canadian model has been criticised for not providing the actual donors with control over how resources which they have helped to create are used. Winckoff (2008:11) argues that by excluding the donors from the decision-making process, 'expert decision-making becomes less legitimate'.

UK Biobank

- 3.43 UK Biobank is a major national health resource and a registered charity. It recruited 500,000 people aged between 40-69 years from across the UK. Donors have undergone measures, provided blood, urine and saliva samples for future analysis, provided detailed information about themselves and agreed to have their health followed. Commercial companies are allowed to profit from their research provided the proposal that they submit falls within UK Biobank purposes and is compliant with its scientific and ethical requirements.
- 3.44 The Ethics and Governance Framework (EGF) sets up standards for UK Biobank to adhere to, and to ensure that samples and data from the biobank are only used for research that is scientifically and ethically approved (UK Biobank). The UK Biobank Board of Directors have final decision-making authority on access and use of samples (or these may be delegated to access committees). An independent Ethics and Governance Council (EGC) is responsible for ensuring that UK Biobank operates in accordance with the EGF and that it acts in accordance with the participant and public interests. Selection of members of the EGC is in accordance with the Nolan Principles on Public Life (1995).

- 3.45 UK Biobank has been commended for the extensive public engagement programme that it has conducted; however, it has also been criticised as being biased, ignoring public concerns, and for having excluded important issues such as health strategies and the science behind the project (Goddard 2004, Wallace 2005, Winickoff 2008).

Iceland Health Sector database and deCODE

- 3.46 Iceland authorised deCODE Genetics, a private for-profit company, to access publicly available health records of the entire Icelandic population, including genetic and genealogical data (Greely 2000). DeCODE created a health database and was granted an exclusive license which gave it the right to use the database for 12 years for a license fee. The sub-license agreement provided that all Icelanders could access any products that resulted from the research (free of charge for the patent term). Additionally, deCODE agreed to pay 6% of profits annually to the Ministry of Health (Arnason 2007).
- 3.47 DeCODE was met with significant controversy – this may also be to do with the involvement of a private company and the presumed consent and privacy problems that were associated with the organisation. In terms of benefit-sharing, it has been argued that the Icelandic model exploited the Icelandic population and that they were not fully aware of the importance or extent of what was being given away, and the fact that the directors of deCODE were responsible to the stakeholders rather than the population at large was ethically troublesome (McInnis 1999). Further, the offer of free drugs to the Icelandic population was perceived, by some, as a harm (to health) rather than a benefit in that new drugs posed more risk (than older well-established drugs) due to the lack of knowledge on side effects (Arnason 2007).

Estonian Genome Project (EGP)

- 3.48 This is a public-private partnership developed by scientists under the not-for-profit Estonian Genome Foundation. The Human Genome Regulation Act Estonia 2001 provides that the database can only be used for scientific research, medical treatment, public health research and statistical purposes. In order to facilitate the delivery of pharmaceutical and health related products, a for-profit US entity, EGeen, was granted commercial access to all data emerging from the EGP; however, the Estonian Genome Foundation holds a financial stake in the company. The EGP also created an advisory ethics committee.
- 3.49 Unlike some other models, under the EGP, all information generated from the initiative is fed back to practitioners ‘in the hope of providing better healthcare (Knoppers 2003: 100). However, public-private endeavours can also be problematic, giving rise to different expectations around the outcomes (and thus benefits) of a project. Some (private) funders may be more concerned with immediate (financial) benefit rather than long-term population benefits (Metspalu 2004).

Convention on Biological Diversity (CBD)

- 3.50 This is a regulatory instrument rather than a benefit-sharing model, but it has formed the basis for many benefit-sharing models and it is worthwhile noting the principles that underpin it. The CBD stresses that stakeholder engagement is essential in order to ensure that access and benefit-sharing arrangements are adequately developed and implemented. It demands that member states set up national authorities that are responsible for granting access to genetic resources. Responsibilities of such authorities can include: negotiating terms for access e.g. requiring prior informed consent; monitoring benefit-sharing agreements and their enforcement; and providing mechanisms for ensuring effective stakeholder participation.
- 3.51 The principles in the CBD (1992) (and related Bonn Guidelines) are flexible enough to be extended to the human genetic setting (Sheremeta and Knoppers 2007).

Theoretical models of benefit-sharing

- 3.52 This part of the chapter looks at some conceptual approaches to benefit-sharing that have often been proposed in an attempt to tend to the failures and limitations of previous benefit-sharing models which have been implemented. One of the key challenges with considering theoretical models is that they tend to be abstract and aspirational in nature. This makes it difficult to identify in sufficient detail how such ideas can be translated from theory into practice.
- 3.53 Despite the challenges that come with considering conceptual models, there is still value in discussing proposed ideas for benefit-sharing models. In particular, models propose solutions for problems previously encountered in practice. Rather than look at specific models, this section considers the common features which have emerged within the literature on theoretical models of benefit-sharing.

Collaborative arrangements

- 3.54 *Features* - Collaborative arrangements attempt to provide positive social, economic and environmental outcomes for local communities by engaging with these communities effectively. These arrangements can include contract-based models and community-based partnerships (Lewis, Freeman and Borreill 2008). Partnerships and collaborative agreements are set up between many stakeholders, including participants, those responsible for managing the resource, and, potentially, governments, research agencies, non-governmental organisations and other relevant groups.
- 3.55 *Example* - The World Bank Agricultural and Rural Development Department (Barr et al 2007: 33) carried out extensive research in order to understand how forest partnerships could be forged between local communities, forestry industries and other key actors. The research suggested that the most important factors to be included in any collaborative arrangements are:

- legal validity
- full bargaining (identifying each issue and interests in these issues)
- mutual respect
- common expectations about the project and what it means to keep agreements
- self-determination – each individual should feel like they are making a choice
- trust
- practicality
- verifiability
- communication and
- recognition of, and sensitivity to, past history

3.56 Amongst the factors outlined above, four factors were almost universally important according to the study: trust, practicality, mutual respect and communication (*ibid.* 33).

Contract-based models

3.57 *Features* – Contract-based models include legally valid contracts (expressed in plain English). The contracts include points on ensuring that the terms of the BS are kept. In particular, contracts can include information on how disputes will be handled, details on practicalities, communication, verification and incentives, and consideration of common issues that have previously led to disagreements.

3.58 *Comments* – Entering a written document such as a contract can have the effect of emphasising to all parties concerned that they are making a ‘true commitment’ to upholding their responsibilities (Barr et al 2006: 23) This type of formal document can also allow all stakeholders to consider the different risks involved and the roles and responsibilities of each of the stakeholders. A contract can also serve the purpose of informing potential outside investors/other parties of the agreement.

3.59 One risk with contract-based models is that they can be open to abuse and ‘elite capture’ (*ibid.*: 40), that is, where resources which are meant to benefit the larger population are actually only used by a few individuals or groups in power. An example of elite capture might be where a contract does not include any provisions for a company which profits financially from using the resources to contribute a percentage of its profit back into the resource.

Community-based partnerships

3.60 *Features* – Community-based partnerships serve to make stakeholder engagement part of the ‘core business strategy’ (*ibid.*: 7). These would normally be in the form of a legally valid (but not overly complicated) agreement; again, it would ideal if this was set out in plain English. The agreement would include appropriate and effective community consultation in order to identify community needs and build trust. A community-based partnership would also serve to increase transparency about how resources

are managed, setting measurable goals and reporting on progress. A workable governance structure that would allow further development to respond to unexpected trends/event can be incorporated.

- 3.61 *Comments* – Community-based partnerships can offer the opportunity for issues to be debated in a fair and open manner. Such partnerships openly acknowledge that there is room for disagreement and make sure that fair and practical governance structures are in place. Expectations can be managed by defining roles and responsibilities from the outset.

Participatory Governance Shareholder Model

- 3.62 *Features* – This is a theoretical model for benefit-sharing (based on a corporate shareholder model) which has been advanced by Winickoff, who argues that community consultation alone is not enough. He argues that legitimate group representation is a key component to benefit-sharing, and that this can be achieved through partnership governance. Partnership governance views donors as shareholders (rather than stakeholders) and implements ‘control rights at the level of the research participation collective’ (Winickoff 2008: 12).
- 3.63 Winickoff’s model would grant a participant group a legal stake in the decision-making process and a formal governance role. Using UK Biobank as an example, he proposes that when providing consent, individuals can volunteer to participate in a donor association. This association would then elect leaders/representatives to subsequently sit on the UK Biobank Board of Directors and on the Ethics and Governance Committee.
- 3.64 *Comments* – As we have noted above, many models have been criticised for excluding participants from making decisions about how resources which they have helped to create are used. Giving participants a formal role in the governance structure can offer an element of control which, it has been argued, is important for participants (Winickoff 2008; Haddow et al 2008).
- 3.65 Although on its face, a shareholder model appears to offer control to participants, it faces significant operational challenges, and it is questionable whether the idea of having shareholders is appropriate when data resources are managed by a registered charity or a not-for-profit company. For example, Hunter argues that the idea of shareholders goes against the notion of a company like UK Biobank and asks whether donor representation would best serve the aims and objectives of the company ‘which is aimed at benefiting the wider community or society’ (Hunter 2011: 232).

Interim Summary

- 3.66 Given the scarcity of research which has been carried out on benefit-sharing in the context of sharing personal information, and the relative novelty of secondary data usage for research, no perfect model has been advanced to date and certainly none for the specific purposes of sharing electronic health records for research. However, the literature does offer us some potential ideas for key elements that can be included in a benefit-sharing model.
- 3.67 Most of the models included two independent bodies within their governance framework: (1) one body with ultimate authority for approving access to resources, and (2) one (normally independent) body which also scrutinised applications (such as ethics committees) but which appeared independent and geared towards scrutinizing applications on behalf of the public (interest), i.e. to ensure appropriate benefit-sharing mechanisms were in place.
- 3.68 The independent scrutiny bodies were also employed with an oversight and monitoring function, to ensure that benefit-sharing measures were enforced. In a study around UK Biobank, survey participants showed strong support in favour of the Ethics and Governance Council having an advisory role to UK Biobank on matters around access to the resources (Webster et al 2008).
- 3.69 Some models have been praised in the literature for having included an element of public consultation or dialogue in their approaches (often in line with CBD emphasis on stakeholder engagement), but this has often stopped short of actual inclusion of lay members/donor representatives in any of the decision-making/oversight bodies.
- 3.70 Models which include direct participant representation may offer meaningful inclusion of participants, and provide them with some control in the decision-making process around what happens to collective resources. Such arrangements may, however, raise important practical considerations. For example, how many representatives should be included? The risk of having too many representatives may arise. Some representatives might have their own vested interests (especially when representatives volunteer themselves rather than being voted for by all participants). There is also the problem of determining where representatives would sit and the powers they might have (or lack) – would they sit on a board and, if so, would this be purely advisory or one with real weight in decision-making?
- 3.71 It appears common practice to have a formal document in place. These documents set out standards and procedures adopted by organisations or managers of resources. These can be in the form of framework documents, legal contracts or access policies and protocols. These documents are often explicit in communicating which benefits will not be shared with participants, and procedures for third party access (and the distribution of benefits resulting from such research); however, some organisations have been accused of lacking openness and transparency in these matters.

Discussion

- 3.72 This section outlines key findings from the literature review through discussion of key considerations which should be factored in to assessing or selecting an appropriate benefit-sharing model. In particular this section highlights issues which were identified after applying the template (discussed at 3.5 above) to the concrete and theoretical benefit-sharing models discussed in the previous section.
- 3.73 As we have already noted, the literature included in the review discusses benefit-sharing in different contexts but not in the specific context of sharing electronic records. For this reason we must extrapolate findings and apply these to the data-sharing setting where relevant.

Working definition of 'benefits'

- 3.74 The literature shows that 'benefits' can be construed widely rather than in a restricted sense. Benefit can be imaginative and, in any benefit-sharing model, it is important to ask what potential benefits are being offered and excluded. It is also crucial to understand who is providing (or withholding) benefits, and to whom these benefits are provided (or withheld from). It is also important to clarify how benefits would be shared, and the circumstances for benefit-sharing to take place.
- 3.75 Key international provisions on benefit-sharing tend to define benefit in a broad and inclusive sense. For example, the UN refers to the right of everyone to enjoy the benefits of scientific progress (The United Nations International Convention on Economic, Social and Cultural Rights 1976). The HUGO Statement on Benefit-Sharing (2000) differentiates between benefit and a financial profit. In situations where benefit is restricted to a percentage of profit, how BS may be conceptualised is limited, particularly given that only a small proportion of research studies will lead to significant commercialization (Sheremata and Knoppers 2007: 173).
- 3.76 As Sheremata and Knoppers note (2007: 161), 'What constitutes a benefit for a particular individual or community will depend on the circumstance, the needs, the values, and the cultural priorities and expectations of that individual or that community'.
- 3.77 Due to the fact that benefits can be defined so broadly, diverse examples of benefit (not restricted to monetary benefit) are offered and there is evidence in the literature that publics do not necessarily expect immediate benefit. For example, in Generation Scotland consultations, participants considered benefits to include the scope for earlier diagnosis, better quality of life, cures for cancer and mental health, and more research in general (Haddow et al 2008).
- 3.78 How benefits are defined is important, i.e. whether these are agreed before research commences without room for negotiation, or are linked to the outcome of the research. It has been argued that merely including participants in consultations could actually be a benefit in itself (HUGO 2000).The

Convention on Biological Diversity (1992) states that informed consent processes must include: information about benefit-sharing arrangements in place, about the agreement in place between research partners, and have specific provisions which address benefit-sharing and information about benefit-sharing arrangements in place including the details about agreements which have been made between different research partners.

Examples of benefit

- 3.79 Kadri (2007: 13) notes that often it is not about 'handing out benefits' but, rather, enabling access to products and technologies that have resulted from the research. Some population-scale database organisations specifically stress that they will not provide feedback or direct benefit to donors/participants, emphasising that the fruits of research will be directed towards future generations (e.g. UK Biobank). A survey conducted in Australia found that participants strongly agreed that treatments resulting from research should be accessible to donors (Nicol and Critchley 2009).
- 3.80 In some cases, however, feedback/health benefits are offered. For example, Generation Scotland offered (limited) feedback regarding health statistics to individuals and with permission, GPs. In Iceland, deCode offered access to health products resulting from research for the duration of the patent, however, for some (including a previous owner of the organisation), provision of new drugs was a harm to the health of patients, in that these carried more risks due to the lack of knowledge of adverse effects (Arnason 2007).
- 3.81 Where monetary benefits are offered, these might include 'payment of access fees, royalties, license fees, research funding, joint ventures of intellectual property rights, sharing of information, research collaboration, contribution in education, technology transfer, capacity building, social recognition and joint ownership of intellectual property rights (Sheremeta and Knoppers 2007: 161).
- 3.82 Benefits can also be identified as research facilities and jobs (Pullman and Latus 2003), as well as research cooperation and training of local researchers, i.e. capacity building.
- 3.83 The HUGO Ethics Committee also includes improved environment and increased human respect within benefit and suggests that, at the very least, participants should receive a 'thank you' and information on the overall outcome of the project (presented in a way that is straight-forward to understand). 'A thank-you does not trivialize benefit-sharing. It is a sign of respect for persons and their basic intelligence and altruism' (HUGO 2000).
- 3.84 The notion of solidarity was also encountered in the literature. Solidarity implies a realistic approach about benefits, acceptance that trade-offs will be made and that endeavours such as those involving data sharing/research can be packaged in a manner that speak to collective overall gain. This solidarity-based approach appears to be a more European construct and one which would appeal in the Scottish context.

- 3.85 Individual, community, national or international levels of benefit-sharing exist. The following table developed by Kadri (2007: 17) outlines key (non-exhaustive) benefits at different levels.

Table 1: Types of Benefits (Kadri 2007)

	Health benefits	Commercial/economic benefits	Scientific benefits
Individual level	Designer drugs and other individual aspects of “personalised medicine”	Profits to the investors	Non-instrumental knowledge: development of science and gaining of new information as a value in itself, regardless of whether it is useful to humans
Communal level		Non-medical benefits to communities; capability-building	
National, state level	Efficient health care services, policy planning, etc.	Development of biotech and related sectors, new jobs etc; capability-building	
Global level	Eradication of diseases, etc.		

Public/private nuances

- 3.86 One important consideration is whether attitudes to benefit-sharing differ depending on whether there is involvement from the public or private sector. One survey conducted in Australia on biobank participants revealed that participants thought that the biobanks should receive payment from those accessing the resources, and especially when commercial companies were accessing the resources (Nicol and Critchley 2009).
- 3.87 On the other hand, there is a risk of overstating any difference between public and private sector research, for example, research that might begin in the public sector may eventually lead to products that are sold commercially in the private sector (Pullman and Latus: 2003). For this reason, some argue that communities should be wary of signing away economic benefits simply because a research initiative starts out in the public sector.
- 3.88 Some have stressed that as governmental and non-profit organisations also partially sponsor some research, these are less likely to be motivated by profit-potential and ‘attention should be paid to the differing capabilities’ of organisations to provide benefits (Kadri 2007: 8).
- 3.89 Sheremeta and Knoppers (2007: 167) have suggested that some biobank-related concerns may be specific to the private realm, in particular there may be concerns ‘about the ability of commercial biobanks to adequately protect biobank participants and to return any meaningful information’.
- 3.90 In the case of deCODE, it could be argued that the private nature of the endeavour was, to some extent, harmful to research (beyond that carried out by the organisation): ‘deCODE has been given exclusive rights to the medical information contained in the database. No one can use that information for

scientific research without permission from deCODE, and it is explicitly stated that a permission will be given only if the proposed research is not perceived to conflict with deCODE's business interests.' (Arnason 2007: 14).

Pressure points of concern

False expectations/promises

- 3.91 Expectations on the benefits of research can be unrealistic, and, similarly, perceived risks associated with research can also be exaggerated, particularly in the context of human genetics (Kadri 2005). For example, promises of access to treatments and products arising through database use during the patent period can be empty given that it is not possible to foresee how many, if any, drugs will result directly from the DNA data used (Greely 2000).
- 3.92 In addition to the difficulty in predicting what types of medicines and therapies might arise out of research, it is also important to note the inherent difficulty in predicting what commercial benefit might accrue from studies. Things are further complicated when forced to consider whether or not these would be long or medium term benefits and, if so, how they might be shared.
- 3.93 Despite the inclusion of explicit statements in access policies stating that feedback will not be provided, there may still be an expectation from participants that they will receive some form of feedback. There may also be an expectation that if the individual is identified as being at risk, the researchers will contact them. On the other hand, not all individuals see feedback as a positive benefit and it may give rise to unnecessary anxiety (Melas et al 2010).
- 3.94 It is worthwhile considering whether unrealistic expectations of benefit and risk might also be associated with research using large-scale databases which give rise to even more unpredictability in terms of potential research outcomes. It is crucial that any benefit-sharing agreements offer explicit and clear information around benefit-sharing so as not to raise unrealistic or false expectations.

Profit and commercialisation

- 3.95 Concerns around exploitation have been made where for-profit companies stand to make significant commercial profits as a result of accessing resources. This is particularly concerning where commercial sectors do not offer adequate compensation for using the resources. There is also a fear that commercialisation will make research outcomes inaccessible, especially where these are patented and the wider scientific community is excluded from the knowledge which was generated (Chadwick and Berg 2001, Kadri 2007).
- 3.96 Whilst the potential negative consequences of commercialisation should be taken into account, it is also important to understand that different studies will have very different potentials for generating economic benefit; many studies do not lead to discoveries or products that can be patented and marketed. Further, many projects are expensive and time-consuming to carry out,

especially epidemiological studies – for which large-scale databases could be used (Pullman and Latus 2003). Public consultation on benefit-sharing has indicated that the public feels that where commercial organisations are involved in using resources, the biobanks should also receive a share (Nicol and Critchley 2009). Others also raise the point that commercial/private interests are to some extent a ‘necessary evil’ in the research setting (Haddow et al 2007: 276).

Ownership and access

- 3.97 Ownership has been raised as an important issue in some sectors (particularly where the resources involve community land) but is more problematic when discussing electronic records and particularly where this is stored in large-scale databases. Some have questioned whether a property-ownership model could be adopted in the benefit-sharing setting (Kadri 2007); however, it is difficult to see how this would be implemented in practice, particularly where databases would contain population-level datasets. In the context of biobanks, one approach has been to consider the managers of biobanks as custodians or stewards rather than owners of the data. In Scotland, ISD NHS NSS acts as custodian for a vast range of datasets.
- 3.98 With regard to accessing information, various factors must be considered. For example, whether or not users should be charged for access. One study found that charging fees for access was considered acceptable by participants, so long as the practical considerations of how profit would be shared had been discussed (Webster et al 2008).
- 3.99 Another important consideration around access is based on who can access the information. In the Generation Scotland consultation, participants suggested that access to information they regarded as private should only be granted to medical personnel, academics or research scientists who had obligations of confidentiality. In the case of UK Biobank, some participants raised concerns over international researcher access to the resources (Webster et al 2008). Further, access by insurance companies was flagged as inappropriate and potentially leading to non-participation. Concerns were also raised over access by employers and banks. Involvement of pharmaceutical companies was also generally perceived negatively, for some it was considered a necessary evil, as were commercial/private interests.
- 3.100 This suggests that there is not a one-size-fits-all approach to how resources should be accessed and that there are sensitivities around certain groups accessing information, particularly depending upon whether they might stand to profit significantly. It also suggests that the public might be more comfortable when their information is used by individuals/groups that are bound by obligations of confidentiality.

Contributors/beneficiaries

- 3.101 Benefit-sharing pertains to the distribution of benefits but also, often implicitly, to the burdens arising from research and beneficiaries are not limited to those who partake in studies, but also ‘those from the same community or the wider

population where the research is undertaken' (Kadri 2007: 3). In the Universal Declaration on Bioethics and Human Rights (2005), UNESCO stresses that benefits derived should be shared with 'society as a whole and the international community' (Article 15).

- 3.102 It is important to acknowledge that how discussions around BS (and justifying BS) take place, and who is involved in these discussions will exclude or include specific communities. For example, if we consider benefit-sharing as compensation for voluntary risk, then it is only fair that benefits are restricted to those who have participated. If, however, we consider our information common property, then the benefits are to be extended across humanity.

Involvement in public dialogue

- 3.103 Whilst the joint literature review on citizen empowerment will look more closely at methods to engage the public, here we consider approaches which have been taken specifically in the context of constructing benefit-sharing models.
- 3.104 Involvement in public dialogue did take place in actual benefit-sharing models (e.g. Generation Scotland and UK Biobank) however this dialogue was/is not always sustained throughout the course of the data use. This is problematic because the very nature of large scale research (and research more generally) dictates that the uses of data can change over time, as can the involvement of different (public and private) stakeholders. Public consultation and dialogue is also criticised as being overly tokenistic.
- 3.105 Upstream consultation, i.e. where the public is consulted before benefit-sharing models are in place has also gained support in the literature (Haddow et al 2008), and one study indicated that participants were highly in favour of knowing what benefit-sharing arrangements were in place before deciding to participate in a project (Nicol and Critchley 2006). It is important to note, however, the difference between approving to uses on behalf of the wider community and providing consent for use of information where this is required (the community cannot consent on behalf of individuals).
- 3.106 An interesting nuance noted by Hunter is that HUGO places the onus on researchers to consult with the public, but other approaches have traditionally placed this responsibility with those managing biobanks as opposed to those who will be using the resource, because managers of biobanks are perceived to be in a relationship of trust with the participants (Hunter 2011). It has also been argued that engagement of the scientific community in planning and conducting genetic research has been inadequate (Berg and Chadwick 2001). It is worthwhile considering whether including researchers in the consultation process could serve to help engender a relationship of trust with the public.

Solidarity

- 3.107 In addition to notions of justice, fairness and equity, some authors have considered whether the ethical principle of solidarity should be appealed to when discussing benefits (e.g. Kadri 2007, Prainsack and Buyx 2011). This

approach would imply that benefits arising from research would be shared based on principles of social justice. The notion of solidarity is increasingly being discussed within bioethics literature, it is 'linked to ideas about how societies function, and about how and where the boundary between individual, familial, communal and societal spheres of responsibilities should be drawn' (Prainsack and Buyx 2011: 1). More generally, solidarity emphasises the relationships between members of a community and responsibilities that might arise out of that relationship. A solidarity-based approach in the context of data sharing and research might imply that the overall aims of research should be to assist others rather than to prioritise financial gain.

- 3.108 The HUGO Statement on Benefit-sharing (2000) includes references to the principles of solidarity; HUGO insists that affluent nations and commercial entities 'foster health for all humanity'. This broadens the scope of benefit to humanity rather than restricting it in a group, and it does not necessitate direct BS. For example, Kadri (2007: 14) notes that 'fostering health' could include increasing the research focus on diseases that are prevalent in poorer countries, so that the whole of humanity can benefit from the technology and know-how'. This might be as an alternative to increasing the complexity of informed consent and the amount of information that is given to participants (Chadwick and Berg 2001).
- 3.109 One problem with basing benefit-sharing on the solidarity principle is that tensions will arise between the principle and taking a compensatory approach to benefit-sharing. This would be particularly significant in the context of data-linkage as 'the larger the number of participants in research, the more significant the concept of solidarity becomes in benefit-sharing' (Kadri 2007: 13). Further, benefit-sharing 'in the form of personal gains may undermine the solidarity notion and, thus, decrease enrolment of those who participate based on altruistic motives (Melas et al 2010: 94). Broadly used, altruism refers to 'acts and practices of people to benefit others without: (a) being obliged to do so due to a legal norm; and (b) without receiving, or even expecting, anything in return' (Prainsack and Buyx 2011: xiii).

Summary and Implications

- 3.110 It is clear from the literature review that there is a lack of evidence of benefit-sharing models that move beyond the rhetoric (in general, and more specifically in relation to data sharing) and of actually delivering effective models and solutions in practice. To attempt to offer a prescriptive model of benefit-sharing would be both premature and, arguably, lack legitimacy without prior public consultation.

4 LITERATURE REVIEW: EMPOWERING CITIZENS IN DECISION MAKING

Introduction

- 4.1 This chapter presents the findings of the desk-based literature review of methods of empowering citizens in decision-making processes, particularly relating to uses of data for research purposes. This informed the design and development of the deliberative public workshops.
- 4.2 The chapter is structured around three main sections: Firstly, it begins by presenting a literature review on public engagement and empowerment. This provides some background about the ways in which public engagement emerged as a central theme within policy-making in the UK (particularly relating to science and technology). This section will then go on to discuss key motivations for undertaking public engagement, the benefits that can arise from public engagement and some of the various ways in which public engagement can be undertaken. It will present a tripartite typology of public engagement approaches (awareness raising, consultation and empowerment) and discuss some of the ways that citizens can be empowered through public engagement processes.
- 4.3 The subsequent section of this chapter will then present the findings of a literature review relating to the different methods that have been used to empower citizens in decision-making about how their data are used in research. This review classifies the various approaches to public involvement according to our typology of public engagement. It outlines how the various studies have undertaken awareness raising, consultation and empowerment activities, paying particular attention to the ways in which empowerment has been pursued and achieved.
- 4.4 Finally, the chapter will identify key messages from this review relating to the ways in which members of the public might be empowered in decision-making relating to the sharing of data between the public and private sector.

Public engagement and empowerment

Background

- 4.5 In 2000, the UK House of Lords Science and Technology Committee (2000) stated that there was a 'crisis of trust' in science. This landmark statement coincided with a widespread change of thinking regarding the relationships between science, technology and the public (Pieczka & Escobar 2013). Whereas previously there had been an emphasis on improving public understanding of science through awareness raising in order to increase public confidence and acceptance of science (e.g. Gregory & Miller 1998, Jasanoff 2005, Wakeford 2010), this gave way to an emphasis on two-way, dialogical forms of public engagement.

- 4.6 In the wake of high profile scientific controversies (such as BSE) there were calls for 'greater acknowledgement of doubt and uncertainty in scientific research and for a change in the culture of science communication and decision-making [...] A new consensus emerged in the early 2000s which suggested that science would gain legitimate authority only if citizens were given a voice' (Wakeford 2010: 88). This also reflects a wider belief that 'new relationships between citizens and institutions of governance must emerge if a crisis of democratic legitimacy and accountability is to be averted' (Coleman & Gotze 2010: 4). Pieczka and Escobar (2013: 113) observed that: 'The demand for direct citizen participation in policy-making has grown steadily, underpinned by the idea that a more participatory democracy can complement and strengthen representative institutions, as well as reduce the democratic deficits caused by technocratic governance'.
- 4.7 Rowe et al (2005: 331) have observed that within 'contemporary democratic societies [there is a] growth in enthusiasm within policy circles for public "engagement" or "participation" as a means of approaching certain difficult issues like the management of risks'. Wilsdon and Willis (2004: 18) note that the 'science community has embraced dialogue and engagement, if not always with enthusiasm, then at least out of a recognition that BSE, GM and other controversies have made it a non-negotiable clause of their "license to operate"'.

Criticisms of Commitments to Public Engagement

- 4.8 Nevertheless, despite widespread and increasingly routine commitments to public engagement, recent critical work has argued that this has not gone far enough (e.g. Irwin 2006, Wakeford 2010, Wilsdon & Willis 2004, Wynne 2006). For example, Wynne has raised concerns that public engagement and dialogue are employed instrumentally in order to secure public trust. He contends that: 'it is a contradiction in terms to instrumentalize a relationship which is supposed to be based on trust' (Wynne 2006: 219). Trust may be earned through openness and transparency and through the creation of meaningful opportunities for participation. However, sponsors of public engagement exercises should not expect participants 'to trust oneself, if one's assumed objective is to manage and control [their] response' (ibid.: 219-220).
- 4.9 For Wilsdon and Willis (2004: 16) the emphasis on public engagement with science represents a wider pattern whereby the 'standard response' of government to public ambivalence or hostility towards technological, social or political innovation is 'a promise to listen harder'. However, such promises do not lead inevitably to meaningful forms of public engagement. Previous public engagement initiatives have limited the opportunities for, or scope of engagement. For example, they have tended 'to be restricted to particular questions, posed at particular stages in the cycle of research, development and exploitation. Possible risks are endlessly debated, while deeper questions about the values, visions and vested interests that motivate scientific endeavour often remain unasked or unanswered [...] when these larger issues force themselves on to the table, the public may discover that it is too late to alter the developmental trajectories of a technology' (ibid.: 18).

- 4.10 Similarly, Irwin (2006: 309) has observed that recent policy announcements have included both commitments to public engagement and openness as well as to 'longer-established notions of sound science [...] typically, one part of a document adopts the language of re-building trust while another is committed to an established economic and technical agenda'. While it is clear that there is a growing policy emphasis on public engagement relating to science issues Irwin questions the meaning and implication of this commitment. In his examination of the UK Government's public dialogue relating to genetically modified (GM) agriculture, he noted that 'the UK Government offered no guarantee during the exercise that it would act upon the report' (Irwin 2006: 313). Furthermore, it was noted that this public dialogue was part of a broader debate about GM which also involved (though not exactly simultaneously) economic and scientific strands of debate. 'It would appear that the construction of public debate, economic and scientific reviews as three separate strands inhibited the possibility of transparent public engagement in 'technical' analysis or of public discussion openly reflecting upon technical issues raised by the other streams' (ibid: 313).

'Lay Expertise'

- 4.11 Yet, much persuasive literature exists to argue that members of the public very often have their own expertise which can be of great value and relevance in decision-making regarding science and technology. For example, in a study of the public's understanding of new genetics, Kerr et al (1998) concluded that due to their various forms of 'lay expertise' it is more useful to think of lay people as being expert in, as opposed to ignorant of, the potential impacts of genetics on their lives. Similarly, Rowe and Wright (2001), in an evaluation of empirical studies into expert and lay judgements of risk, concluded that there was no proof to suggest that experts' judgements were more accurate or significantly different from those of the public. As Wakeford (1998: 12) notes; 'citizens have shown themselves to be highly capable of understanding complex scientific and technical information'.
- 4.12 Acknowledging the value of public (lay) knowledge highlights the important and varied roles which public engagement might play. However, in order for this engagement to be meaningful a number of considerations have to be addressed. For example: who is in control of the issues that are discussed? Who decides what constitutes a valid – and relevant – fact? And if dialogue is a two-way process, what assurance do participants have that decision-makers take on board their insights and priorities? (Wakeford 2010).

Benefits of Public Engagement

- 4.13 Public engagement has an important role to play in democratic societies, as the Wellcome Trust (2005: 2) observe: 'Most agree that decision-making in a democratic society should take account of public attitudes, and that elections alone can be a poor way of gauging the public's views on a range of issues'. Moreover, for some, public engagement is viewed as a remedy for many problems in current democratic societies such as 'falling voter turnout; lower levels of public participation in civic life; public cynicism towards political institutions and parties; and a collapse in once-strong political loyalties and

attachments' (Coleman & Gotze 2010: 4). The OECD (2001) contends that public engagement can lead to better public policy, greater trust in government and stronger democracy. In this context public engagement is presented as a mechanism for strengthening democratic institutions (Pieczka & Escobar 2013).

- 4.14 Much has been written about public engagement in the development studies literature. Here it is widely acknowledged that appropriate policies and developments are best achieved through consultation and participation (Agrawal & Gibson 1999, Brown 2003, Holmes & Scoones 2000, Kothari 2001). 'Participatory approaches [...] are justified in terms of sustainability, relevance and empowerment' (Cooke & Kothari 2001: 5). It is seen that by involving local people in decision-making processes the outcomes will better reflect their interests and needs and will therefore be met with greater support or acceptance by those affected, which in turn leads to more sustainable policy outcomes (Kothari 2001).
- 4.15 Participatory techniques are also regarded to serve an educational role. It is considered that participants will benefit from sharing their own knowledge and perspectives whilst also engaging with 'expert knowledge' - hence gaining a better understanding of the issues in question. Equally, 'experts' involved in the process will learn from public (local/lay) knowledge, which, in many cases, may be substantial and relevant. This, Brown (2003) argues, leads to the creation of 'fusion knowledge' which could potentially be of great value. 'Transformational changes potentially occur to participating publics, stakeholders, organisations and institutions in the ways they frame and think about such issues, their acknowledgement of each other's understandings, visions and concerns, and their responses to the social (and other) implications of science' (Chilvers 2010: 33).

Why Engage the Public?

- 4.16 Wilsdon and Willis (2004: 39) summarise three main positions underpinning public engagement:
- *a normative position* suggests that 'such processes should take place because they are the right thing to do: dialogue is an important ingredient of a healthy democracy'
 - *an instrumental position* holds that 'engagement processes are carried out because they serve particular interests'. For example: 'Governments may want to engage in order to build trust in science and manage their reputation for competence'
 - *a substantive perspective* suggests that the goal of public engagement 'is to improve social outcomes in a deeper sense [...] From this point of view, citizens are seen as subjects, not objects, of the process. They work actively to shape decisions, rather than having their views canvassed by other actors to inform decisions that are then taken'.
- 4.17 Related, INVOLVE (2004) (a non-profit organisation specialising in public participation) present a number of reasons for engaging with the public:

- public participants can provide different and valuable perspectives
 - people who use services can help to ensure that the issues prioritised are important to them
 - public involvement can help to ensure that money and resources are not wasted on research that has little or no relevance
 - service-users can ensure that research doesn't simply measure outcomes deemed important by professionals
 - service users can help with recruitment of peers (especially from marginalised groups)
 - service users can help disseminate the results of research and ensure that changes are implemented
 - involvement in research, done well, can help empower people who use services
 - involvement of the public is becoming an increasing political priority
- 4.18 It is widely accepted that there can be practical benefits for organisations from creating opportunities for public engagement. Simultaneously, it is considered that engagement has benefits for wider society and for democratic institutions. For example, the National Consumer Council (NCC 2008) suggests that deliberative forms of public engagement can improve the quality of decisions and policy solutions whilst simultaneously enhancing representative democracy. INVOLVE (2005: 18) contend that a distinction can be made between mechanistic views which 'see participation as a very practical exercise of getting people's input on something' and humanistic views which see 'the main point of participation [as being] the expansion of people's horizons, social contracts and sense of their own power and ability' (this is similar to the distinction made between instrumental and substantive approaches to public engagement outlined above).
- 4.19 INVOLVE (2005: 20) summarise four main objectives of participatory activities within current public policy circles as being:
- 'GOVERNANCE: e.g. strengthening democratic legitimacy, accountability, stimulating active citizenship
 - SOCIAL COHESION AND SOCIAL JUSTICE: e.g. building relationships, ownership and social capital, equity, empowerment
 - IMPROVED QUALITY OF SERVICES: more efficient and better services, especially public services that meet real needs and reflect community values
 - CAPACITY BUILDING AND LEARNING: for individuals and organisations, to provide a basis for future growth and development and, especially, to help build stronger communities.'

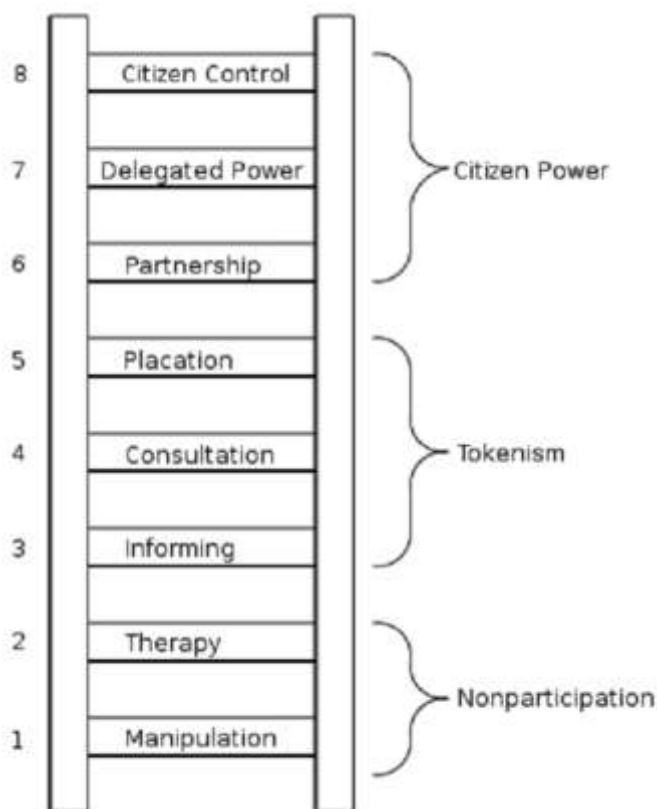
Forms of Public Engagement

- 4.20 There are many different ways in which public engagement can be conducted. Rowe and Frewer (2005) argue that although there is an international trend towards increased public involvement in policy areas, this is understood as meaning a variety of different things and in turn is used to describe a variety of different approaches and projects: 'involvement as widely understood (and

imprecisely defined) can take many forms, in many different situations (contexts), with many different types of participants, requirements, and aims (and so on), for which different mechanisms may be required to maximize effectiveness (howsoever this is defined)' (Rowe and Frewer 2005: 252). The form and methods of public engagement adopted largely reflect the objectives or purpose of the exercise; therefore, public engagement can take many different forms in serving many different purposes.

- 4.21 Much of the literature refers to different levels of engagement. References are frequently made to Arnstein's (1969) ladder of public participation (see figure 2.1). Arnstein's model set out eight levels of participation which were broadly summarised as representing 'Non-Participation', 'Tokenism' and 'Citizen Power'. On the bottom rungs on the ladder (Non-Participation) public engagement is viewed as an opportunity to educate the public and/or engineer support. In the middle of the ladder, tokenistic forms of participation include informing and consulting members of the public. Arnstein suggested that both of these can be valuable first steps towards participation but that they are limited by the lack of influence which participants have. Consultation is described as being a 'window-dressing ritual'. A third form of tokenistic participation described by Arnstein is placation whereby 'a few hand-picked "worthy" poor' are placed on boards but given that 'the traditional power elite hold the majority of seats, the have-nots can be easily outvoted and outfoxed'. The top rungs of the ladder therefore require redistribution of power to members of the public.

Figure 2.1: Arnstein's (1969) Model of Public Participation



- 4.22 Arnstein's model has been adapted by various individuals and organisations writing on the topic of public engagement. For example, Wilcox (1994) simplifies Arnstein's model to arrive at five levels of participation: Information; Consultation; Deciding Together; Acting Together; and Supporting Independent Community Interests. A guidance document produced by Fife Council refers to three broad purposes of public consultation: Informing; Seeking Views; and Participation and Partnership. The International Association for Public Participation's (IAP2) (2007) 'spectrum' of public participation has five levels: Inform; Consult; Involve; Collaborate; and Empower. Rowe and Frewer (2005) have developed a typology of public engagement mechanisms which is structured around three main forms: Public Communication; Public Consultation; and Public Participation. These are just a few examples of many existing typologies or classifications of approaches to public engagement.
- 4.23 Although these models of public engagement use different terminology and different numbers of levels it is possible to identify common patterns and themes within them. Each starts with a 'bottom' layer of engagement which is essentially concerned with information provision. They then have one (or more) layer(s) with limited forms of public feedback into decision-making processes, and finally they each have a 'top' layer with more participatory forms of public engagement which give greater control to participants. In order to summarise these patterns three principle layers have been categorised by the broad aims of: Awareness Raising; Consultation and; Empowerment. Appendix B sets out which 'levels' from various models have been included under each heading.
- 4.24 The following is a summary of each of these main purposes and what they imply for the conduct of public engagement.

Awareness Raising

- 4.25 This category of public engagement is essentially concerned with the dissemination of information. Wilcox (1994: 10) describes this as 'a "take it or leave it" approach' which is used when there is little flexibility about what the outcomes will be and where the purpose is simply to inform the public. INVOLVE (2005: 18) suggest that this form of public engagement aims to 'provide the public with balanced and objective information to assist them in understanding the problem, alternatives and/or solutions'. Rowe and Frewer (2005: 255) note that at this level 'Information flow is one-way: there is no involvement of the public per se in the sense that public feedback is not required or specifically sought'. For some the one-way nature of Awareness Raising approaches mean that they should not be considered public engagement, unless they are combined with other approaches (such as consultation) (e.g. Dialogue by Design 2008).
- 4.26 As the most basic form of public engagement awareness raising is also the most limited in what it can achieve. In summary, awareness raising approaches involve one-way, top-down flows of information and are aimed at increasing awareness or understanding of particular issues.

Consultation

- 4.27 This form of public engagement seeks to elicit information from the public in order to inform decisions. It can involve (to varying degrees) two-way flows of information. Wilcox (1994: 11) contends that: 'Consultation is appropriate when you can offer some choices on what you are going to do – but not the opportunity [for the public] to develop their own ideas or participate in putting plans into action'. Through consultation, public views are sought and taken into consideration; however, there is no obligation that these views will necessarily be acted on (Dialogue by Design 2008, INVOLVE 2004).
- 4.28 Depending on how consultation is facilitated it could be either a one-way or two-way process. Rowe and Frewer (2005) contend that it is conducted as a one-way process since public opinion is sought on topics or questions which are chosen and/or designed by the sponsors and these do not necessarily reflect which topics members of the public consider most relevant. The OECD (2001: 16) suggest that, where participants are providing feedback on information previously provided to them by sponsors/facilitators, a 'limited two-way relationship' can occur. However, participants do not have power in or over the process since facilitators/sponsors define 'whose views are sought on what issue' (OECD 2001: 16).
- 4.29 It is frequently acknowledged that public engagement can be most effective and best-received by public participants when it is seen to be meaningful and influential (Dialogue by Design 2008, INVOLVE 2004, Wilsdon & Willis 2004). Wilcox (1994: 5) notes that public engagement processes (and their outcomes) are more likely to be successful if people 'feel they can achieve something' and that they 'are most likely to be committed to carry something through if they have a stake in the idea'. As such consultation is likely to be better received when it can be demonstrated that it will have meaningful outcomes and that public participants' contributions will be valued. Therefore, Sciencewise (2009: 6) advise that it is important to: 'Ensure that participants' views are taken into account, with clear and transparent mechanisms to show how these views have been taken into account in policy and decision-making'.
- 4.30 In summary, consultation approaches can involve either one-way or two-way flows of information. They enable public perspectives, opinions or values to be fed into decision-making processes. However, control over how the processes are set up and run and how the information gathered is used remains with the facilitators and/or sponsors. Consultation can be a valuable mechanism for reflecting public interests, but can also lead to disappointment and frustrations if participants feel that their views are not being taken seriously or that the exercise is used to legitimise decisions that have already been made.

Empowerment

- 4.31 Public engagement approaches classified under the heading of empowerment are those which would be positioned at the top of Arnstein's (1969) ladder of participation. These approaches involve giving control to public participants and aim to create benefits not simply for the decisions and/or projects under consideration, but also for the participants and broader society.

- 4.32 Empowerment can occur to varying degrees and is facilitated through a range of mechanisms. For example, this category includes the OECD's model of 'Active Participation' which is described as 'an advanced two-way relation [...] based on the principle of partnership' (2001: 16). It also includes INVOLVE's (2004: 9) model of collaboration comprising 'active, on-going partnership with members of the public in the R&D process. For example, people who use services might take part in a steering committee for a research project, or collaborate with researchers to design, undertake and/or disseminate the results of a research project'. INVOLVE (2004) note several advantages and disadvantages associated with collaboration. Advantages include increasing relevance of outcomes, benefits in terms of recruitment of research participants, help with interpreting and understanding data and an increased sense of ownership of projects and results on the part of service-users. Disadvantages are higher costs of collaborative research (both in terms of time and resources), the need for extra skills relating to facilitation and negotiation and the loss of power/control on the part of researchers. Collaboration 'involves an active commitment from the researcher to collaborate, which means that control over research will be shared rather than being controlled only by research professionals' (ibid: 9).
- 4.33 Empowerment also includes Wilcox's (1994) category of 'Acting Together' in which 'different interests [not only] decide together what is best, but they form a partnership to carry it out' (Wilcox 1994: 8). This approach can involve 'short-term collaboration or forming more permanent partnerships with other interests' (ibid: 12). This requires 'a common language, a shared vision of what you want, and the means to carry it out' (ibid: 12).
- 4.34 Rowe and Frewer's (2005) typology includes the category of 'Public Participation' which can be seen to reflect aims of empowerment. In this model, 'information is exchanged between members of the public and the sponsors. That is, there is some degree of dialogue in the process that takes place (usually in a group setting), which may involve representatives of both parties in different proportions (depending on the mechanism concerned) or, indeed, only representatives of the public who receive additional information from the sponsors prior to responding' (Rowe & Frewer 2005: 255).
- 4.35 At a higher level of empowerment this category involves 'Supporting Independent Community Interests' (Wilcox 1994) which is a more hands-off approach on the part of facilitators whose role it is to help 'others develop and carry out their own plans [...] this is the most "empowering" stance – provided people want to do things for themselves' (ibid: 13).
- 4.36 Empowerment is best illustrated through approaches which involve a high degree of participant control over the processes and outcomes. This reflects INVOLVE's (2004) category of User Control. They describe this as being 'broadly interpreted as research where the locus of power, initiative and subsequent decision making is with service users rather than with the professional researchers. It does not mean that service users undertake every stage of research, or that 'professional' researchers are necessarily excluded from the process altogether' (INVOLVE 2004:10).

4.37 Advantages of user controlled research noted by INVOLVE (2004: 11) include that:

- 'the research is likely to address questions which may not have been considered by researchers'
- 'innovative user-driven approaches can often reveal evidence otherwise missed by 'professional' researchers'
- 'service-users will be committed to 'disseminate the results of research to influence change in practice'
- 'both professional and public participants are likely to gain new skills'
- 'involvement in user-controlled research can be an empowering experience for service users who are often marginalised'

4.38 Identified disadvantages are:

- user control 'requires researchers to hand over 'ownership' of a project to people who use services. Some researchers (and funders) find this difficult or unacceptable'
- there is 'Potential for 'bias'
- 'the research may not be perceived as independent'
- cost and time implications associated with necessary training

4.39 In summary, approaches to public engagement characterised by the objective of empowerment involve giving a high degree of control (over both processes and outcomes) to public participants. It involves considerable flexibility about what is to be included since, ultimately, participants must be able to determine what is relevant. These approaches have enormous potential to produce outcomes which are appropriate in terms of reflecting public interests/concerns/opinions whilst simultaneously building capacity among participants and having spill-over positive impacts on wider society and democratic institutions. These forms of public engagement can be viewed as an essential component of building social capital (INVOLVE 2005).

Summary of Methods

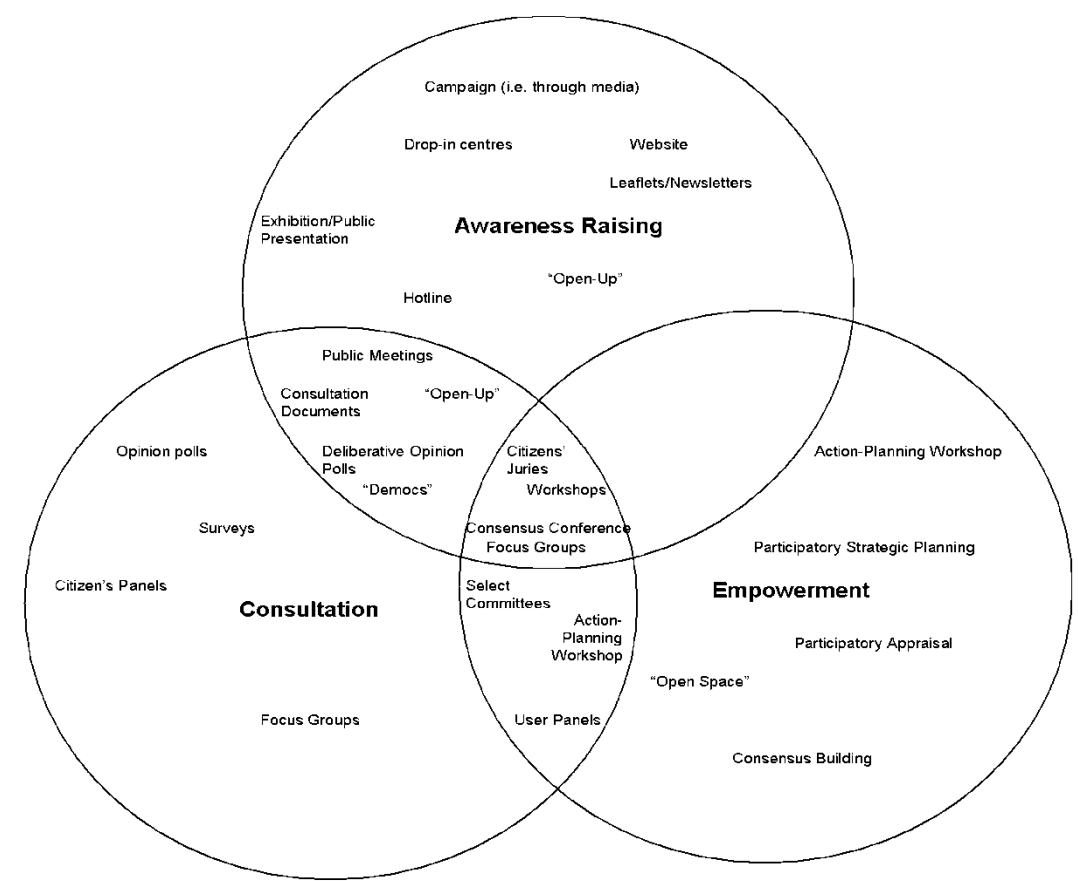
4.40 Table 2.1 summarises these three broad categories of public engagement approaches. Importantly, these should not be viewed as mutually exclusive, but rather; 'they should be regarded as a spectrum of participatory strategies' (Coleman & Gotze 2010: 14). As The Wellcome Trust (2005: 11) have noted, 'serious efforts at public engagement are likely to employ a mixed strategy'. In practice public engagement exercises may use a range of methods reflecting different approaches and motivations. For example, public engagement can be carried out in order to raise awareness whilst simultaneously consulting the public on their views. Similarly, consultation can be done in ways which have empowering effects on participants (for example through capacity building). Ultimately, it is not possible to rank engagement approaches in terms of their merits since: 'Different levels are appropriate at different times to meet the expectations of different interests' (Wilcox 1994: 4). Figure 2.2 illustrates the range of public engagement methods that can be used to reflect different, and multiple approaches/motivations.

Table 2.1: Summary of Categories of Public Engagement

	Purpose	Desired Outcome	Potential Methods
Awareness Raising	Information provision and public education.	Greater public acceptance or legitimacy for policy/project.	Media campaign. Public exhibition/ presentations. Leaflets.
Consultation	To gain insight into public opinion/views.	Creation of appropriate/socially acceptable policy/project.	Surveys. Focus groups.
Empowerment	To work with the public enabling them to play key roles in decision-making.	Greater social capital. Capacity building. Enhanced democracy.	User panels. Citizens' juries.

4.41 It should also be noted that public engagement can take place in both formal and informal ways and is not necessarily always invited. Chilvers (2010: 11) notes that the 'distinction between invited and uninvited engagements is based on who is responsible for organising public dialogues. Uninvited engagements are initiated and organised by citizens mobilising themselves independently of formal decision institutions'. Uninvited public engagement is generally not formally structured but can be valuable in 'open[ing] up alternative framings and perspectives on science-related issues' (ibid.: 11).

Figure 2.2: Potential Methods for Each Category of Public Engagement



Public Involvement and Research Use of Personal Data

4.42 This section will present the findings of a desk-based literature review which explored the different methods that have been used to involve members of the public in research and/or decision making relating to the ways that their data are used. The principal objectives of the review were:

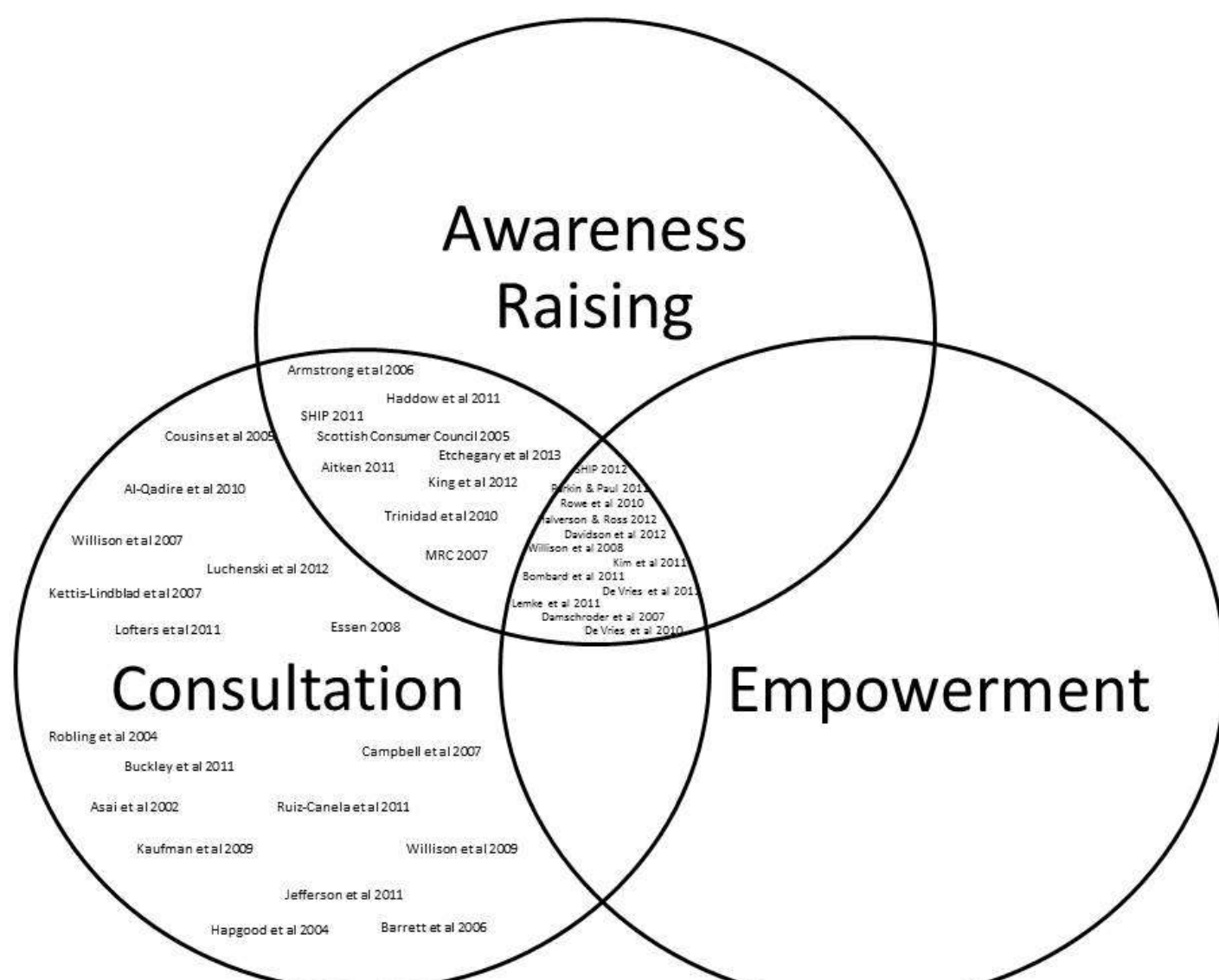
- to survey the range of public engagement methods that have been utilised in relation to the research and statistical use of personal data and data sharing
- to identify those methods that utilise an empowerment approach and assess how effective and efficient they have been, including what effect they have had on participants
- to develop recommendations for the most appropriate methods of involving citizens in decision making about how their data are used

4.43 The methods used in this review were described in chapter 2. A total of 51 papers and reports were included in the final review for this study. Each of these articles were read in their entirety and analysed in accordance with the typology of public engagement outlined above (i.e. to identify instances of awareness raising, consultation and empowerment).

Overview of Studies

4.44 Of the 51 papers and reports included in this review 38 reported results of studies or programmes involving public engagement activities (the remainder presented secondary analysis). The studies related to a range of national contexts including the UK, US, Canada, Australia, Japan, Spain, Saudi Arabia and Sweden. The studies which involved public engagement activities employed a variety of approaches including surveys and questionnaires; focus groups and deliberative workshops or events. There were examples of awareness raising, consultation and empowerment within the studies – and in many cases the studies can be seen to have aimed at and/or achieved more than one of these goals. Figure 3.1 represents a summary of the analysis of the studies in relation to these goals; this will be discussed in more detail below.

Figure 3.1: Classification of Studies



- 4.45 The studies included in this review discuss a range of subjects. Whilst there are some examples of studies engaging members of the public in relation to data sharing or data-linkage for research purposes, this is a new area and the literature is, as yet, limited. Accordingly, it was decided that it would be relevant and necessary for this review to include studies of public engagement in relation to other forms of data (e.g. genomic and genetic data) and consider public participation in a broader range of research approaches (e.g. biobanks). As such, this review draws on a broader, relevant body of literature and aims to point to lessons which can be learnt from more established fields.

Awareness Raising

- 4.46 There were no examples of studies which were aimed solely at awareness raising identified within the review. This is most likely due to the nature of the

studies which were largely focussed on reporting public opinions and/or attitudes towards uses of data and, therefore, included consultative elements.

- 4.47 However, the majority of the studies included in this review (21) involved at least some element of awareness raising. This was evident in studies taking a qualitative approach to consultation (e.g. through focus groups or deliberative events) where information was provided in order to inform discussions or prompt responses. For example, Etchegary et al (2013) describe conducting 'hybrid information-consultation sessions' in order to explore public expectations and attitudes about genetics research. Similarly, deliberative workshops (reported by SHIP 2012; Davidson et al 2012; Halverson & Ross 2012; Parkin & Paul 2011; Bombard et al 2011; de Vries et al 2011 and 2010; Kim et al 2011; Lemke et al 2011; Rowe et al 2010; Willison et al 2008; MRC 2007; Damschroder et al 2007; and Armstrong et al 2006) involved presentations and/or written information materials circulated either before or during the events. In some cases participants had opportunities to prepare particular questions or set discussion topics for the events, or request particular further information. In these instances, awareness raising can be seen to be more than simply one-way flows of information, but rather forms part of a two-way dialogic process.
- 4.48 There were examples of studies where awareness raising was reported to lead to greater public acceptance of research uses of data (e.g. SHIP 2012, Kim et al 2011, Parkin & Paul 2011, MRC 2007) or reduced concern (King et al 2012, Lemke et al 2011). It was also reported that awareness raising was beneficial in engendering informed discussions which, in turn, led to considered responses to consultation (e.g. Lemke et al 2011, Bombard et al 2010, de Vries et al 2011). Further, it was reported that awareness raising activities were valued by participants who appreciated the opportunity to learn more about the subject under discussion (e.g. Etchegary et al 2013, SHIP 2012, de Vries et al 2011).

Consultation

- 4.49 All 38 of the studies reporting on public engagement activities involved consultation as a key (and in most cases primary) aim. The subject of the consultations varied a great deal. They included, for example: the acceptability of linking personal data for statistical and research purposes (Davidson et al 2012); privacy in healthcare (King et al 2012); attitudinal changes regarding biobank research governance (Halverson & Ross 2012); and incentives and barriers to participating in Alzheimer's disease clinical research (Jefferson et al 2011).
- 4.50 The methods used ranged in the extent to which they involved one-way or two-way flows of information and in the degree of control participants had within/over the process. For example, studies using quantitative methods such as questionnaires or surveys took a highly structured approach and captured participants' responses to particular pre-defined and fixed questions (e.g. Luchenski et al 2012, Ruiz-Canela et al 2011, Lofters et al 2011, Al-Qadire et al 2010, Kaufman et al 2009). Conversely, a number of studies used focus groups which represented a more flexible form of consultation where

public opinions were explored through open-ended discussion which, whilst guided by facilitators, allowed participants to raise particular topics of interest and (re)direct the discussion (e.g. Aitken 2011, Haddow et al 2011, SHIP 2011, Trinidad et al 2010, Scottish Consumer Council 2005). This approach is more dialogic and involves two- or multi-way flows of information between participants and facilitators. There were also a number of studies which involved lengthier deliberative processes to explore public opinions whilst devolving greater control to participants (for example, in relation to the topics discussed, the format of the events or information that was provided). These more deliberative forms of engagement served the purpose of consultation but also provided opportunities for greater interaction between participants and facilitators (and in some cases relevant experts) and their content was determined in large part by the participants (e.g. SHIP 2012, Halverson & Ross 2012, Parkin & Paul 2011, Bombard et al 2011, de Vries et al 2011, Lemke et al 2011). As such, whilst all the studies had consultation as a key, if not primary, aim this was pursued and achieved in a number of different ways.

4.51 Key themes emerging from the review of these consultations were:

- **privacy and confidentiality** – addressing privacy concerns was widely reported to be crucial for fostering public support for research uses of personal data (e.g. King et al 2012, SHIP 2012 & 2011, Davidson et al 2012, Lofters et al 2011, Trinidad et al 2010, Kaufman et al 2009, MRC 2007, Asai et al 2002).
- **control and consent** – it was widely reported that members of the public wanted to be in control of how their data was used for research and often had a preference for consent-based governance models (e.g. King et al 2012, SHIP 2012 & 2011, Buckley et al 2011, MRC 2007, Willison et al 2007, Scottish Consumer Council 2005, Robling et al 2004). However, what this meant in practice was understood in a variety of ways (e.g. King et al 2012, SHIP 2011, Willison et al 2009, Willison et al 2008, Kettis-Linblad et al 2007).
- **the public good** – public participants were generally reported to acknowledge the value of research using personal data and/or the value of data-linkage for research or service-planning in the public interest (e.g. SHIP 2012, Davidson et al 2012, Aitken 2011, Parkin & Paul 2011, Trinidad et al 2010, Barrett et al 2006, Cousins et al 2005, Scottish Consumer Council 2005, Robling et al 2004).
- **calls for greater public engagement and transparency** – a number of studies reported that public participants had indicated a need for greater transparency relating to use of data in research and greater public engagement in order to engender public trust and acceptance (e.g. Etchegary et al 2013, Davidson et al 2012, SHIP 2012 & 2011, Armstrong et al 2006).

Empowerment

- 4.52 Twelve studies were classified as taking an empowerment approach. These are studies which devolve power to participants over the engagement process and outcomes and include deliberative workshops (SHIP 2012, Davidson et al

2012, Halverson & Ross 2012, Lemke et al 2011, Rowe et al 2010, Damschroder et al 2007), a citizens' jury (Parkin & Paul 2011), a citizens' panel (Bombard et al 2011), deliberative democracy sessions (de Vries et al 2011 & 2010, Kim et al 2011), and public dialogues (Willison et al 2008). Table 3.1 summarises the key features of these methods.

Table 3.1: Key features of empowerment approaches

Method	Format	Participants	Outcomes
Deliberative Workshops	These were generally half-day events where members of the public listened to presentations, took part in small group discussions and in some cases voted on key issues or completed questionnaires.	Invited members of the public. Typically around 30 participants per workshop. Some studies aimed for a representative sample while others aimed to include a diversity of views.	The workshops aimed to facilitate informed discussions. Participants' views were captured via recorded and/or noted group discussions, electronic voting and questionnaires. Participants were reported to value the opportunity to learn more about the subject, to listen to and meet experts and to discuss the subjects in depth. In some – but not all – cases participants' attitudes were reported to have changed over the course of the workshops.
Citizens' Jury	These run over a period of several days. They are overseen by a steering group of relevant stakeholders who set the questions for the jury to consider and select experts and jurors for participation. Participants listen to and question experts. They deliberate as a group and at the close present their verdict – usually a set of recommendations.	Around 12 participants. Selected by the steering group to be representative of the wider population.	Parkin & Paul (2011: 152) reported that their citizen jury unanimously decided 'that researchers contracted by a public body should [in specific circumstances and subject to safeguards] be permitted to use medical information about identifiable people, without their consent [...] Six jurors reported that their views on the question had changed during the jury hearing. The reasons cited were the information provided by the expert witnesses, learning that there were systems (legal and ethical) in place to oversee the use of medical information, and having the opportunity to discuss these matters with their fellow jurors. Two others reported feeling more confident about their original views (both supported the use of medical information)'
Citizens' Panel	Citizens' Panel members are engaged in informed, facilitated discussion over a period of time. In Bombard et al's (2011) study this took place over five 1-day structured deliberation sessions. Material on each deliberation topic and a set of discussion questions were circulated one week in advance of each meeting. Each meeting involved	Bombard et al's panel consisted of 14 members, selected through a stratified random sampling method in order to be representative of the wider public.	Bombard et al (2011: 140) concluded that: 'Public engagement offers an informed and participatory approach to eliciting ethical and social values in [Health Technology Assessment]. Deliberation about the use and diffusion of new health technology fostered a process of making public values explicit. This participatory process allowed members to find common ground around trade-offs and collectively articulate values to guide decision-making. Our results demonstrate that participatory

	discussions, summary presentations by the facilitator or guest presenter, Q&A sessions and either externally-facilitated or self-facilitated discussion around pre-circulated questions in large and small groups. Questionnaires were also completed before and after the process.		approaches, which employ sustained deliberations, are a feasible method to elicit a core set of ethical and social values inherent in health technology assessment.'
Deliberative Democracy Sessions	Day-long deliberative events. Participants take part in small group discussions, listen to plenary talks and deliberate in small groups on particular dilemmas or topics.	Invited members of the public, identified to represent particular groups. (Could also be conducted with a representative sample).	<p>Participants deliberate on particular questions based on the information they have heard and the discussions they have taken part in throughout the day.</p> <p>De Vries et al (2011) have contended that it is important to build evaluation into the design of deliberative democracy sessions in order to develop a best practice model. Kim et al (2009) contend that the important features to pay attention to in designing deliberative democracy sessions are ensuring access to accurate, balanced, and understandable materials, knowledgeable experts, well-trained facilitators, and adequate facilities and resources.</p>
Public Dialogues	Day-long deliberative events. Participants receive background information in advance. The events consist of plenary presentations and small group discussions. Questionnaires are administered before and after in order to assess impact on participants' opinions.	Between 15 and 20 participants per event. Willison et al's (2008) events took place across Canada in order to represent regional differences.	Willison et al's (2008) public dialogues relating to consent for access to personal information for health research found that 'broad opt-in consent for use of personal information garnered the greatest support in the abstract. When presented with specific research scenarios, no one approach to consent predominated. When profit was introduced into the scenarios, consent choices shifted toward greater control over use'.

- 4.53 These studies can be viewed as empowering participants through devolving control (to varying degrees) over the engagement processes and outcomes. Additionally, many of these exercises can be seen to empower participants through the development of new skills (e.g. in relation to deliberation or public speaking). However, empowerment can also be achieved in a number of other, often unpredicted (or even unpredictable), ways. For example, participants might be viewed to have been empowered through participation in an engagement process if this resulted in greater understanding of issues relevant to their life or in increased confidence to participate in other

engagement processes or other areas of civic life. Empowerment can be viewed as being served through individual or social capacity building. Accordingly, whilst empowerment may not have been one of their key goals, there are a number of additional studies within our review which might have had impacts which could be classified as empowering. Participants might be empowered through participation in focus groups (e.g. Aitken 2011, Haddow et al 2011, SHIP 2011, Trinidad et al 2010, Scottish Consumer Council 2005), public information-consultation sessions (Etchegary et al 2013) or reconvened discussion groups (Armstrong et al 2006).

- 4.54 It is noteworthy that all of the studies classified as taking an empowerment approach in this review combine awareness raising, consultation and empowerment. Consultation – where this is meaningful in its scope and impact – can be a valuable means of empowering citizens through creating opportunities for public views and/or preferences to inform decision-making. Conversely, consultation which is not meaningful (i.e. where members of the public are asked for their views but these have no impact or are not taken on board within decision-making processes) can have the opposite effect and rather than empowering participants may in fact lead to disillusionment and future disengagement. Awareness raising may be a crucial component of empowerment as it broadens participants' horizons and presents opportunities for learning, hence facilitating more meaningful forms of participation and consultation. As such, including elements of each of these approaches is helpful for pursuing citizen empowerment. However, empowerment requires more than simply awareness raising and consultation, but also devolution of power to participants in engagement processes and/or capacity building. Participants must be at the heart of empowerment approaches.

Evaluation of Empowerment Methods

- 4.55 While studies included in our review typically commented on the value of the consultation elements of their approaches (e.g. in providing insights into public attitudes and values and facilitating informed deliberations), very few of the studies explicitly evaluated how the engagement process was experienced by participants or to what extent/in what ways participants were empowered.
- 4.56 Nevertheless, there was some evidence that participants generally appreciated the opportunity to take part in these activities and found this to be a rewarding process. For example, Parkin and Paul (2011) note that participants in their Citizen Jury in evaluating the process commented on the knowledge they gained. The jurors also demonstrated an enthusiasm for the process in that their final deliberation session ran for some four hours. Similarly, Damschroder et al (2007: 226) commented that participants in their deliberative workshops were 'engaged in the process, showing near-instant camaraderie and high levels of respect for one another'. Participants in the SHIP (2012) deliberative workshops commented that they found the workshops both informative and enjoyable and that they would welcome opportunities to participate in further related engagement opportunities. Moreover, workshop participants felt that 'the public should be involved in

governance processes or should play a role in overseeing uses of personal data in research' (SHIP 2012: 4). As such, public engagement activities have uncovered – and perhaps fostered – an appetite for greater public engagement in relation to uses of data in research.

- 4.57 De Vries et al (2010 & 2011) have highlighted the importance of evaluating deliberative engagement processes in order to develop a best practice model. They propose a framework for evaluating the quality of deliberative processes. This points to key considerations which are summarised under three headings (Process, Information and Reasoning) (De Vries et al 2011: 3-5):

Process

- facilitation – 'Good facilitators keep the discussion moving forward, keep participants on task, encourage participation, and elicit viewpoints from all participants. Good facilitators are also good listeners who avoid inserting their own opinions in the discussion, while managing unanticipated problems and keeping the discussion within the time allotted'
- equality of participation – 'Word counts and "turns taken" by participants are direct and simple measures of participation, but are, of course, qualified by the recognition that perfect equality of contributions is not necessary for good deliberation'
- participant engagement – 'Is there evidence of genuine dialogue and interchange of ideas?'
- respect – 'Positive group dynamics and amicability— even when there are disagreements—are indicators of a respectful process'

Information

- use of on-site experts – 'Do the participants appropriately recognize when more information is needed, and then seek out further information from the on-site experts?'
- use of incorrect information – 'It is important to be alert to instances where incorrect information enters the conversation [...] What impact, if any, did such errors have on the direction of the deliberations?'
- learning new information – 'This can be measured by assessing unprompted remarks in the transcripts, as well as by self-report questionnaires to assess any change in knowledge'
- understanding and application of information – 'In general, it is important to assess whether the deliberators are actually using the information presented'
- impact of information on opinions – 'How does the new information learned affect opinion?'

Reasoning

- justification of opinion – ‘considers how participants justify their positions on the issues discussed. Do they give reasons based on what they have learned? Do they call upon a moral framework?’
- openness to complexity – ‘Deliberative exercises are used to gather public opinion when the policies in question are complicated and in dispute. It is important that participants recognize this complexity and avoid simplistic responses’
- adoption of a societal perspective – ‘Public-spiritedness is critical to the success of public deliberations [...] Evidence of this attitude can be found in the willingness of participants to take the point of view of a policy-maker, rather than looking at the issue only from how it affects their personal situation’

4.58 De Vries et al’s framework provides a useful resource for evaluating the quality of deliberative events. However, in order to evaluate the extent to which, and in what ways, participants are empowered through the process this would need to be supplemented by additional research at some time after the deliberative events. Empowerment effects should endure beyond the lifetime of the engagement process

Summary

4.59 The review has highlighted that a range of public engagement methods have been used to involve members of the public in decision-making processes relating to uses of data in research. The subjects of the engagement processes included in this review are diverse but the experiences reported provide relevant and valuable insights.

4.60 The studies included in this review were predominantly focussed on consultation as a key aim. However, there were many examples of studies combining consultation with awareness raising and empowerment. It is noteworthy that each of the instances which have been classified as taking an empowerment approach included both consultation and awareness raising – this may be a necessary approach to take in developing empowering forms of public engagement in the future.

4.61 The examples of empowerment approaches discussed here typically involved deliberative events through which participants received information about the particular topic, had opportunities to ask questions and took part in group discussions. The outcomes of the processes varied. While evaluations of the extent of empowerment are lacking, it is reasonable to state that where the results of deliberative consultations do not inform decision-making or policy-making processes the empowering effects will be limited. In such instances there is a risk that participants become disillusioned with engagement processes. As such, whilst the review points to examples of relevant methods to be used in empowering approaches, it is important to bear in mind that such an approach requires a meaningful commitment to act on the outcomes of public engagement.

Summary and implications

- 4.62 Public engagement can take many different forms and serve many different purposes. Public engagement can be pursued in instrumental ways – as a mechanism to be used to achieve particular ends such as understanding public opinions or fostering public trust. Conversely, public engagement can be focussed at substantive impacts such as building capacity amongst participants and empowering citizens.
- 4.63 In this literature review we have presented our tripartite classification of public engagement approaches in order to illustrate the three key objectives that public engagement typically pursues – awareness raising; consultation; and empowerment.
- 4.64 In reviewing the different ways that citizens have been involved in decision-making processes relating to uses of data in research we have focussed principally on identifying studies which took an empowerment approach. However, it is noteworthy that each of the studies which are classified as taking an empowerment approach also involved awareness raising and consultation. This highlights that public engagement can serve multiple purposes simultaneously.
- 4.65 The review suggests that including elements of awareness raising and consultation within public engagement activities may be helpful for maximising empowerment of participants. It was reported in a number of studies that participants valued the opportunity to learn more about the subject and to engage with experts. Awareness raising also has valuable roles to play in informing deliberation. However, in empowerment focussed public engagement, awareness raising should be more than one-way communication. Consultation can also be a valuable method for empowering citizens where this meaningfully informs decision-making or policy-making processes.
- 4.66 The examples of empowerment approaches discussed in this review typically involved deliberative events through which participants received information about the particular topic, had opportunities to ask questions and took part in group discussions.
- 4.67 Empowerment can be pursued in a number of ways, and might be achieved through involving citizens in decision-making processes, or through capacity building amongst participants. Whilst the review points to examples of relevant methods to be used in empowering approaches, it is important to bear in mind that such an approach requires a meaningful commitment to act on the outcomes of public engagement. Furthermore, participants must be at the heart of empowerment-focussed methods.

5 DELIBERATIVE RESEARCH FINDINGS

SENSITIVITIES AROUND DATA SHARING BETWEEN THE PUBLIC, PRIVATE AND THIRD SECTORS

- 5.1 This chapter presents the findings from the deliberative events. It begins by exploring participants' perceptions of data sharing between the public, private and third sectors before going on to explore attitudes towards benefit-sharing and empowering citizens in decision-making.
- 5.2 At the outset of each deliberative event, an introductory presentation was given to participants, which provided relevant contextual information on data linkage and sharing for research and statistical purposes (A copy of the presentation is provided in Appendix D). Key themes covered included:
- the scope of data linkage and sharing (including the focus on anonymised data about individuals, as opposed to data about identifiable individuals)
 - a summary of the Scottish Government's Data Linkage Framework and Guiding Principles
 - the emphasis in the Framework on public acceptability and the public interest
 - what is already known about public attitudes to data linkage and sharing from the 2012 research
 - the need for an improved understanding of public attitudes towards data sharing between the public, private and third sectors
- 5.3 Following the presentation, participants were asked for their initial reactions to what they had heard and, subsequently, whether they regarded data sharing (including the sharing of linked data) as more or less acceptable depending on: the sector and specific type of organisation(s) involved in the process; the type of data being shared; and the planned use(s) of the data. Prompt cards containing examples of organisations, data types and data uses were used to facilitate the latter discussions (see Appendix F).

Initial reactions

- 5.4 Initial, unprompted reactions to the presentation centred in the main around the themes of data security and privacy. As in the 2012 research, there was a significant level of concern about the potential for linked and/or shared personal data to be hacked or otherwise obtained by unauthorised individuals or groups. This concern was largely informed by past high profile cases of public officials leaving laptops, data sticks or hard copy documentation in public places, and, to a lesser extent, by incidents such as the Wikileaks and Edward Snowden disclosures.

A couple of years ago, there was a big issue with the Council here shredding information and it was all found; files everywhere.

(Male, oldest age group, Galashiels)

Well, we have heard all the news about DVDs and laptops being left on trains by people working; ministers and that sort of thing, with all your stuff on it, so [it will] maybe get into the wrong hands the information about you.

(Male, middle age group, Glasgow)

- 5.5 When reminded that data shared for research purposes would be anonymised, most participants appeared to feel reassured that this would mitigate against personal details falling into the wrong hands – “*If it’s anonymous, what does it matter*” was a typical remark. However, a significant minority were more sceptical and expressed concern that, even with anonymisation, the potential would remain for personal details to be “leaked” (whether through accident or malice) or obtained through hacking. Such views were again underpinned by consideration of high profile data losses and breaches, but also by the perceived ease with which commercial organisations in particular appear to come into possession of individuals’ details for use in direct marketing campaigns. As in the 2012 research, participants commonly recounted personal experiences of receiving unsolicited but personalised sales calls or emails from a range of companies, particularly insurance firms.

They are saying that [personal details] will no’ be accessible but they’ve got to think. ... It’s scary what they can get hold of.

(Female, oldest age group, Glasgow)

I seem to be getting phone calls from America, how have they got my number, how they got their data? ... It’s obviously through [my] going on an internet website and sign[ing] up for something.

(Female, youngest age group, Glasgow)

- 5.6 Aside from voicing concerns around data security and privacy, initial responses across the events often indicated unease about – or in some cases opposition to – private sector involvement in data sharing for research, as compared with public sector involvement. There was repeated suggestion that the private sector is motivated solely by the pursuit of profit and therefore would likely use data to this end, for example by selling it on to third parties. Public sector organisations, in contrast, were often described as being “for the people” and more inclined to draw on data with the aim of delivering some form of public benefit. (There was very little spontaneous mention of the third sector in these initial discussions). The view that data sharing for research should lead to public benefit was a dominant theme across the events and one that participants returned to time and again.

If the integrity of the whole system was there, then I don’t think there would be many people at this table would have any issues with the likes of the NHS having their data, the police, because they’re there to protect people, and the Scottish Government because it is in everyone’s interest.

(Male, middle age group, Oban)

I would be more wary about the private sector in particular if they are sharing data, even if it's anonymised. It's for their benefit rather than the benefit of society.

(Male, oldest age group, Edinburgh)

- 5.7 Notwithstanding such views, some older participants commented, or alluded to the fact, that the distinction between the public and private sectors is becoming progressively less “clear cut” owing to an increase in the privatisation and contracting out of public services. They regarded this shift as having negative implications for the security of personal data.

You're forever reading in the paper about things that went wrong. In fact we have it the now... I think it was the hospital... they found [information] in a bin and they said: “Oh no, that was the company that did the cleansing; it wasn't the actual members of staff”.

(Male, oldest age group, Galashiels)

- 5.8 When participants were presented with some examples of public, private and third sector organisations, their views on data sharing for research became more nuanced and considered. While they continued to regard private sector involvement as less acceptable overall than public or third sector involvement (for reasons explored in further detail below), they also drew some notable distinctions between different organisations within each of the three sectors. These distinctions were underpinned by consideration of the relative trustworthiness of the organisations and, again, of the extent to which each could be expected to act in the public interest. The concept of the public interest was initially invoked rather than defined, although participants went on to discuss it in terms of specific benefits and disbenefits that might flow from research.

The public sector

- 5.9 There was near universal acceptance of public bodies – including the Scottish Government, the NHS, Local Authorities and the police – having access to anonymised data about individuals from other organisations (whether public, private or third sector) for research purposes. There were two main factors underpinning this support.
- 5.10 Firstly, and as already mentioned, there was a commonly held view that public sector organisations were concerned with delivering public benefits or promoting the “public good” and that any research they undertook would be similarly oriented. Further, there was suggestion that by having access to more data and research, public bodies will be better placed to identify and meet the support needs of particular segments of the population – the unemployed, children and people with chronic health conditions received specific mention amongst others– and to deliver improvements to local areas and services. As is discussed further below, a perceived need for better local services was a recurring theme of the discussions and one that, in Galashiels especially, reflected experiences of service cuts and closures over recent years.

- 5.11 Secondly, and despite concerns expressed at the outset of the events about public officials misplacing or losing data, there was a common assumption that public bodies had more stringent data protection and security procedures in place than other types of organisation – or at least were more accountable to the public than those other organisations when a breach occurred. These assumptions tended to be based on personal experiences of working for, or otherwise interacting with, public bodies, particularly the NHS and local authorities.

I don't mind if [data] went to the NHS because you know there usually is a system in place that will protect anonymity. I know when I worked with the city council we had a system: You can't do this, you can't do that. If you disobeyed that you would get sacked. So, I would assume that if your information was going to the NHS they would work under the same restrictions.

(Female, oldest age group, Aberdeen)

At the end of the day, if you're not satisfied with the way the Government is running things, then we have the option of having an effect on that. The Government has to rely on us to keep them in a job.

(Female, oldest age group, Galashiels)

- 5.12 However, participants often expressed reservations about (though rarely outright opposition to) the police having access data from other sources. These reservations seemed to reflect a deeper distrust of the police due to perceived corruption and other forms of malpractice, for example, the inappropriate use of stop and search. There was uncertainty and unease over how the police might use data from other sources and, specifically, over the potential for Big Brother-esque surveillance of the population.
- 5.13 A small number of participants also expressed reservations about the Scottish Government being able to access data from other sources. While they sometimes struggled to articulate the precise reasons for their concern, unease over how the Government might use the data and concerns about the potential for a Big Brother society again appeared to be important considerations. At the same time, a degree of ambivalence in the attitudes of these participants was apparent, with some of them acknowledging the Scottish Government's need for high quality data.

...Too much information is being held by the Government, but at the same time we can't just do like a stab in the dark and hope for the best. [We] have to have some kind of information gathered to direct the right policy or funding to whatever.

(Male, middle age group, Galashiels)

- 5.14 Across the events, there was a view that public bodies in general need to be more transparent about the data sharing that is taking place and/or about how research has contributed to particular outcomes. In some cases, this view was underpinned by a perceived need for the public to be reassured that their data are being used appropriately. In others, it reflected a belief, also evident in the

2012 research, that public bodies do not always do enough with the information they have and ought to be more accountable in this regard.

What are they going to do with the information once they have got it because the Government seem to have a lot of information on you but don't actually do anything with it?

(Male, youngest age group, Aberdeen)

It's okay sharing [but] it's not enough. [The] outcome is more important.

(Male, middle age group, Oban)

The private sector

- 5.15 As already mentioned, private sector involvement in data sharing was a contentious issue. There was a great deal of concern that private companies would sell data to each other for mutual benefit – a practice that was seen as already widespread – although this concern did lessen when participants were reminded that the data would be anonymised so individually targeted sales or marketing campaigns could not be based on such data. More generally, there was strong spontaneous opposition to data being used by the private sector for the sole purpose of profit maximisation. This is not to say that participants were entirely opposed to private sector organisations accessing data, or that no level of profit was acceptable. Rather, the consensus was that private sector access to (anonymised) personal data should only be granted where this is likely to result in some form of public benefit.

I think when it's being done for services; say, social work, to target where you need to do some kind of youth outreach work, that's fine and that sits comfortable with me, but if that then becomes, okay, supermarkets can find out that in this area, there is loads of young families with young children, and end up using that information to do a kind of targeted [campaign] on toys and kids' stuff, that doesn't sit so comfortably with me.

(Male, middle age group, Aberdeen)

I think you maybe get concerned if you think that your information is going to earn somebody else a profit that's not maybe going to benefit society as a whole...I know I am quite willing to give information about me, anonymised, if I thought it would help other people in research but my expectation would be that services to me would be improved because of it.

(Female, older age group, Aberdeen)

- 5.16 As the above comments serve to illustrate, public benefit continued to be conceived of primarily in terms of improvements to local services, local areas or public health, rather than individual-level or direct financial benefits. However, there was some unprompted suggestion that the private sector should be required to pay for access to data and/or to share any profits resulting from research with the relevant data owner(s), so as to generate funds that can be reinvested towards the public good. Invariably, these

suggestions met with strong support from others in the group and laid the foundation for later, prompted discussions of benefit-sharing.

Development is such a huge part of the process of making [a] product; I would say the most important, so if [companies] want to create something that will generate a profit, they need the information, so I think they really should pay for the information.

(Female, oldest age group, Edinburgh)

[Male 1:] *If private companies want access to this information...[they] should have to pay to get access to that information and pay quite a bit.*

[Male 2:] *Then money should go back in*

[Male 1:] *Exactly, yes, feed back into the services.*

(Middle age group, Aberdeen)

There should be some criteria [for] sharing the profit if they are going to make these profits.

(Male, middle age group, Oban)

- 5.17 In terms of the specific types of private sector entity that participants were invited to consider, pharmaceutical companies were the only type that the great majority felt should be able to access data from other sectors. Ultimately, this reflected a view that research by pharmaceutical companies contributed towards improved understanding of diseases and conditions, and to new drugs and treatments. At the same time, several participants expressed unease at the scale of profits made by pharmaceutical companies and it was this unease that prompted the spontaneous suggestions for profit sharing, mentioned above.
- 5.18 In contrast with views on pharmaceutical companies, there was overwhelming opposition to banks, other financial institutions, internet service providers and social media companies being able to access data from other sources. Participants expressed strong distrust of these entities – banks and other financial institutions because of their perceived role in the financial crisis; and internet service and social media companies because of personal or proxy experience of online fraud and a related perception that the online sphere is “impossible to police”. There was a widely held view that personal information, even if anonymised, would not be secure in the hands of these types of company and, as such, ought not to be shared with them.
- 5.19 Two other categories of company; supermarkets and other retailers, and security and surveillance firms, divided opinion at each of the events, although for different reasons.
- 5.20 Supermarkets and other retailers were commonly perceived to be purely profit driven, and this led to many participants rejecting outright the idea of their

being able to access data. At the same time, there was some suggestion that, by having better intelligence about local populations, supermarkets could deliver more tailored products and services, and potentially contribute to public health improvement; for example, through targeted healthy eating campaigns.

Big [companies] like Tesco, Asda, whatever...they're going to go and say: "Oh well, there is a great sale of fags here, there is a great sale of booze, so we will just put all these offers on in that area" and they're going to sell more, they're not in it for the health.

(Female, oldest age group, Galashiels)

It does help with things like having the right stuff in the shops... If you're in an area where there is less money and then they have products that people can afford to buy, rather than everything being Tesco's Finest or something.

(Female, youngest age group, Oban)

If there is a higher rate of heart attacks in an area, [they would know] whether they should promote and sell fruits at a cheaper rate or something, so, in that context, I wouldn't mind them having that information.

(Male, middle age group, Glasgow)

- 5.21 Security and surveillance firms were commonly distrusted owing to the recent high profile G4S failures, as well as personal experiences of perceived heavy-handed or threatening tactics on the part of bailiffs. Nonetheless, there was also some suggestion that these entities need to have access to high quality data in order to guard against terrorist threats and ensure public safety more generally.
- 5.22 It is worth noting that, as well as drawing distinctions between different company types, a small number of participants contrasted companies of a similar or the same type. For example, at the Aberdeen event, a distinction was drawn between Langstane Housing – a social enterprise – and Stewart Milne Homes, with the former trusted more as it was seen to be motivated by social needs. Similarly, at the Galashiels event participants felt that Asda was a more socially responsible company than Tesco on account of its charitable work in the local community. Such views suggest that assessments of the private sector and individual entities are by no means clear cut but reflect the interplay of a range of considerations from general trustworthiness, to local contextual factors and personal experiences.
- 5.23 During the discussions of different company types, participants at times questioned how data owners would know that a company, having been granted access to data, would use the data solely for the original purpose. Transparency was seen as crucial in this regard to mitigate against potential data misuse and to instil public confidence in the process.

The third sector

- 5.24 In general terms, third sector access to data was seen as more acceptable than private sector access but somewhat less so than public sector access. There was a widely held assumption that many third sector organisations, like public bodies, are concerned with promoting the public good and, indeed, often work with those bodies towards shared objectives, such as tackling homelessness or improving services and support, for example for LGBT people. At the same time, there was a perception of the third sector as something of an unknown entity, which prompted feelings of unease about its organisations having access to data. Some participants questioned whether third sector organisations would have robust data protection and security standards in place. Others were concerned that some organisations might be tempted to use data in direct marketing campaigns or sell it to raise funds.

I think there is a lot to gain from these organisations having access to data, because there might be issues that people are unaware of completely...If these [organisations] had access to that sort of information, they could then make a case for funding.

(Male, youngest age group, Edinburgh)

There are companies within the third sector, Barnardos and these companies, that you should trust but have we been suckered into something that we believe has helped children ... Do we actually know what they're doing? Nothing is really ever publicised, there's nothing ever publicised, are they making a profit?

(Male, youngest age group, Glasgow)

- 5.25 There was a tendency for participants to distinguish between charities on the one hand and pressure groups on the other, with the former generally trusted more than the latter. It was commonly suggested that pressure groups, by definition, had “agendas” to advance that may or may not reflect the interests of the general public. Some participants contended that any requests for access to data from pressure groups should be subject to very close scrutiny. Others argued, more strongly, that such requests should be refused as a matter of course.

There is a certain lack of control over groups like that, so for them to have access to data could be damaging because you don't know what their agenda is....I mean, who are those people, how are they controlled, how are they governed, and what are they doing with [the data]?

(Female, oldest age group, Aberdeen)

The English Defence League [is] classed as being a pressure group, so I'd really rather they didn't have any information... you really have to judge case by case, what are the motives of the organisation, what are [they] actually going to use [the data] for and make the decision whether or not they get it.

(Male, middle age group, Aberdeen)

‘Hybrid’ organisations

- 5.26 Participants did not engage to any significant degree with the concept of hybrid organisations. This was partly due to the complexity of some of the issues involved and partly because they often had very little prior awareness of some types of hybrid organisations, particularly university spin-out companies.
- 5.27 To the extent that views were forthcoming, these tended to relate to public-private partnerships (PPPs). For several participants, PPPs raised no new issues in respect of data sharing. They assumed that in any such partnership, the public sector partner would have overall accountability for the operation of the partnership and/or that therefore more stringent data protection and security procedures would apply. There was also some suggestion that PPPs could result in more cost-effective service delivery.
- 5.28 However, other participants were concerned that PPPs widened the scope for unauthorised data sharing between private sector organisations and, consequently, for data misuse. They contended that measures would need to be put in place to ensure that private partners in PPPs used data solely for purposes agreed within the terms of the Partnerships.

[There] could be [a company] that you really trust and then they are obviously in cahoots with another company which is going to take that information and use it and that's not something you want that company to do.

(Male, youngest age group, Galashiels)

How do you control that information – what [the private partner] is doing with it and stuff? There would have to be another external audit to keep an eye on it.

(Female, youngest age group, Edinburgh)

Data types

- 5.29 When participants were asked about the relative acceptability of different data types being shared for research purposes, they tended to begin by saying that it depended on who would be accessing the data and for what purpose, reinforcing the centrality of trust as a determinant of views. They were keen to reiterate that private companies should not be able to use data for purposes aimed solely at profit maximisation, and that access to data should only be granted where this is likely to result in public benefit(s).
- 5.30 Still, they did distinguish between different data types, with three types in particular provoking considerable discussion and debate across the events: postcode data; some socio-demographic data; and commercial data.

Postcode data

- 5.31 There was widespread concern that a focus on postcode data in research could result in areas being negatively labelled – for example as “deprived”,

“rough” or low-achieving – and, subsequently, in residents of those areas experiencing stigma or discriminatory treatment. While this was most commonly discussed with reference to insurance companies blacklisting or setting higher premiums for those living in particular areas, there was a perception that public bodies similarly make assumptions and decisions about people based on where they live (or have lived).

If you've using [Burnfoot] as a statistic area for smoking, for alcohol, for child problems, social work, how many benefits are claimed, it's a bad area. Therefore, anybody accessing that information for likes of insurance purposes is going to go ["no".]

(Female, older age group, Galashiels)

Some universities might feel: “we don't want to involve people from areas of deprivation, because we know they are less likely to finish their course and that's bad for us, for our figures”.

(Male, oldest age group, Edinburgh)

- 5.32 A potential, reverse effect was also identified, with participants expressing concern that their postcode area could lose out on important services or support in the event of not being labelled as deprived or otherwise ‘in need’.

We don't want a postcode lottery again, which happens in schooling sometimes. There needs to be consistency across all areas, instead of just concentrating on a deprived area, there are people who might be deprived within a non-deprived area ... It has to be accurate enough to reflect the society as a whole.

(Male, middle age group, Glasgow)

- 5.33 In addition to concerns about labelling, there was a view that postcode information was potentially disclosive. This view was most common among people in the more rural locations of Oban and Galashiels, several of whom contended that individuals could “quite easily” be identified within a dataset focusing on a small geographic area from a combination of their postcode and other types of data, such as basic socio-demographic characteristics or service usage.

I think, when you live in a big city and nobody knows one another, this is a great idea ... but to people who live in a smaller community, it's not all that good an idea. It's a bit like Big Brother watching you, it's a bit like George Orwell isn't it?

(Female, oldest age group, Galashiels)

Socio-demographic data

- 5.34 Very few participants expressed any concern about the sharing of data on an individual's sex, age, ethnicity, disability and maternity/pregnancy. Data on sexual orientation and, to a lesser extent religion, proved more contentious, however.

- 5.35 As might be expected, data on sexual orientation was most commonly a focus for LGBT participants, most of whom expressed ambivalence on the matter of such information. On the one hand they emphasised a need for better, more accurate data on sexual orientation to increase understanding of LGBT issues and inform improved service provision for these groups.

I think, in general, NHS surveys are quite a good thing, because I think there is a lot of generalisations made about people, especially like around sexuality and gender identity, and I think that there is not really a lot of sort of education within the health service.

(Male, youngest age group, Edinburgh)

Data is valuable...The NHS currently uses the fact that transgender people fail to self-identify in surveys as an excuse not to provide us services.

(Female, oldest age group, Edinburgh)

- 5.36 On the other hand, there was trepidation about the potential for such data to fall into the wrong hands and be misused, particularly in the event of it being 'de-anonymised', rendering individuals potentially identifiable. Among some of the older LGBT participants, this concern was grounded in historic and more recent instances of gay men (as well as other minority groups) being "rounded up" or otherwise persecuted under particular political regimes – there was specific reference to Nazi Germany and the current Putin government in Russia. They contended that such instances could be repeated anywhere at any point in the future and that the ready availability of sexual orientation data could be facilitative in this regard.

It is hugely important to be 'out' at all times if one possibly can, otherwise nobody would know there were LGBT communities... but at the same time, in the old days, it was always taking a big risk... In my lifetime, [things] have improved hugely, so, yes, that's wonderful of course it is, but I'm just worried that although it is wonderful it could all change again.

(Male, oldest age group, Edinburgh)

If this isn't totally anonymised and the same lurch to the right wing happens in Scotland; I'm not saying it would but, theoretically, the same thing could happen. I was sitting in an office in one of the charities I work with and it's like, okay, if we were to take Aberdeen back to the 1930's all of us would be rounded up and that concerns me about any, even [anonymised], data.

(Male, oldest age group, Aberdeen)

- 5.37 Other LGBT participants were more concerned that the sharing of sexual orientation data could lead to an increase in homophobic discrimination, including on the part of public services.

[Male:] *A particular postcode in Edinburgh might be a primarily LGBT neighbourhood, so perhaps a certain homophobic group of police officers may choose not to patrol that area as much.*

[Female:] *Or patrol it far too much.*
(Oldest age group, Edinburgh)

- 5.38 With regard to data on religion, participants at a few of the events felt this was “too personal” to be shared. At the same time, most of them – in common with many other participants – struggled to see the relevance of religion to research, typically posing such questions as: “What has religion got to do with it?” or “Why do they need that?” To some extent this spoke to the way those participants conceived of research, which was primarily in terms of its potential to inform the design and delivery of services.

I understand that [research] needs to be done [but] again I question religion and why that’s particularly relevant to public services.
(Male, oldest age group, Aberdeen)

- 5.39 Such views were not widely held however, with the majority of participants fairly unconcerned about the collection and sharing of data on religion.

Commercial information

- 5.40 Despite participants’ initial assertions that they were happy for public and some third sector organisations to have access to data from private companies for research purposes, it became clear that they regarded some types of commercial data as more acceptable than others.
- 5.41 There was general recognition of the potential value to the public and third sectors of data held by supermarkets and other retailers. Participants were particularly receptive to the idea that loyalty card information could enable the Government and other authorities to develop an improved understanding of people’s eating habits, which in turn could inform public health campaigns. There was a sense in which loyalty card data was seen as much less personal, and therefore less private, than other types of information, especially those held by public sector organisations. Indeed, a few people said that, when they began using a loyalty card, they had fully expected that the information it generated would be used for research and development purposes, and had been comfortable with that.

Public sector information could be much more personal, like your health, your criminal activity, anything like that, whereas what you eat is not that important is it?
(Female, middle age group, Oban)

I think if you sign up for a loyalty card then you're actually giving them permission to use that data.
(Female, oldest age group, Aberdeen)

- 5.42 In contrast with these views, there was general opposition to the idea of banking and other financial information being shared with any third party organisation, whether public, private or third sector. This reflected a view that financial data, even in anonymised form, is very private and should remain so. Some participants were concerned that the sharing of financial data between organisations and sectors would widen the scope for fraud and other types of financial crime.
- 5.43 There was a similar level of opposition to the sharing of data held by internet providers and social media companies. This data was also seen as too private to be passed from one sector (or organisation) to another – although several participants were keen to point out, usually with some disapproval, that the Police already made considerable use of social media channels such as Facebook when conducting investigations.

Data uses

- 5.44 Specific examples of data uses presented to participants (most of which had already been raised and discussed spontaneously albeit to varying degrees earlier in the events) were:
- to develop new drugs or products
 - to plan and improve services
 - to understand the public's behaviour
 - to understand health, illness and disease
 - to inform and test the effect of policy
- 5.45 There was a consensus that all of these uses were potentially positive in the sense that they could result in public benefits. At the same time, there was further reiteration of the view that it would depend on who is using the data and their precise reasons for doing so, with participants once again voicing their objection to the private sector being able to carry out research aimed solely at profit generation.
- 5.46 Accordingly, much of the discussion around the examples of data uses centred on 'research to develop new drugs or products'. Participants reiterated the view that any private sector companies wishing to carry out this type of research using personal data (anonymised) should be required to pay for access to the data or share any resulting profits with the data owners. During these discussions it became clear that fairness was a key consideration underpinning views: across the events there was repeated suggestion that the public sector devotes considerable funds to the collection of data and therefore should be able to recoup some of those funds from other parties wishing to access the data.

I think it is only fair that the public purse gets something back if [the public sector] paid to get statistical information gathered, otherwise [the private company] would use some of its own millions and gather data.

(Female, oldest age group, Aberdeen)

- 5.47 'Research to plan and improve services' also prompted further discussion. While there was general recognition of the importance of this type of research, there was also some debate around how the data might be interpreted. Whereas some participants assumed that the focus would be on identifying areas where additional or better services were required, others – most of whom were at the Galashiels event – reiterated their concerns about possible service closures. Again, these concerns may largely have been a product of recent health service closures in the Borders area.
- 5.48 Beyond the above-mentioned perspectives, very few additional comments were made about data uses that had not already emerged at earlier points in the discussions.

Factors that would mitigate concern

- 5.49 As discussed earlier in this report, and despite the presentation explicitly stating that only anonymised data would be shared, participants continued to raise specific concerns around data security and privacy. A number of actions were identified by participants to mitigate these concerns.
- 5.50 Similar to findings in the 2012 research, the consensus was that anonymisation and guarantees that individuals could not be identified were essential prerequisites for public acceptance of data sharing. Participants felt it vital that anonymity was maintained at all stages of the data-sharing process, by all organisations and individuals involved, to prevent personal details being inadvertently disclosed, sold or misused. Further, it was felt that reassurance over anonymity should be a key facet of information provided to the public about data sharing.

I wouldn't mind any of these [public] services having access to totally anonymised information, but it is never going to be totally anonymised unless the system is really put in place.

(Male, middle age group, Aberdeen)

[The public need] reassurance about anonymity because that's what people worry about.

(Male, older age group, Oban)

- 5.51 Suggested safeguards for ensuring data security were also similar to those identified in the 2012 research and included:
- the establishment of an oversight body to control access to, and use of, data
 - clear procedures and protocols to govern the handling of data, such as ensuring that data are destroyed after use
 - stringent vetting of organisations and individuals who would have access to data
 - the imposition of firm sanctions in the event of organisations or individuals being found guilty of misusing data.

- 5.52 As already indicated, mechanisms for ensuring that public, private and third sector organisations are more transparent about data sharing and its outcomes were also deemed essential. This was perceived to be important, not only in demonstrating to the public that research involving data sharing was producing its intended outcomes, but also in enabling the public to monitor and/or challenge research being conducted. There was a specific focus on ensuring transparency around the level of profit that private companies accrue from research and the extent to which their research is contributing to the public good.

I think it has to be more transparent as to what information the organisation holds and has to be made mandatory for [organisations] to say; "this is the information we hold [and this is how it has been used] for the public benefit".

(Male, middle age group, Glasgow)

It is good to do research and it is beneficial, but is there not anywhere that you can see the current research? There should be a public place that people can actually see what research has been carried out.

(Male, middle age group, Oban)

- 5.53 Some of the above suggestions made by participants to mitigate concerns were developed more fully during later discussions concerning benefit-sharing models and methods for empowering the public in decision making.

BENEFIT-SHARING

- 5.54 As discussed throughout the previous section, participants spontaneously mentioned potential benefits of data sharing. These were predominantly: societal benefits achieved through improved public services and wider knock-on benefits, such as the potential for a healthier society; and the sharing or reinvestment of profits accrued as a result of research based on shared data.
- 5.55 To facilitate more in-depth discussion of such issues, participants were given a second presentation, which introduced the concept of benefit-sharing – including the range of potential benefits arising from research and methods for sharing benefits – and provided specific examples of existing models of benefit-sharing identified in the literature review. The models included those developed as part of the Generation Scotland study⁵; the SHARE database project⁶; and a programme of genetics research in the province of Newfoundland and Labrador in Canada⁷. (A copy of the presentation is provided in Appendix E and a handout for participants summarising the three models is provided in Appendix G).
- 5.56 Following the presentation, there was almost unanimous agreement among participants that benefit-sharing was important and necessary to ensure public acceptance of data sharing. Further, participants felt that the requirement to share benefits should apply to the public, private and third sectors, although it was clear that they thought of benefits differently in relation to the public and third sectors' use of personal data compared to private sector use.
- 5.57 As discussed previously, the promotion of the public good – whether in terms of improving public services or delivering wider societal benefits (for example, improved public health) – was very much seen as the *raison d'être* of public bodies and many third sector organisations, and consequently as an inevitable goal of the research these sectors conduct.

It's in all our interest [for the public sector] to be as efficient as it possibly can be. With more information on how to target resources, they are going to be more efficient, so the benefit is there, it's not complicated. The charities [have] pretty much the same thing, having information will make them more efficient in what they do, so everyone gets the benefit of it.

(Male, middle age group, Aberdeen)

⁵ Generation Scotland is a resource containing biological samples from people across Scotland. These are used by researchers in universities, the NHS and the private sector. Where research using samples results in profit, the income is shared evenly between the organisations involved and the Generation Scotland programme. People who donate samples may receive health advice.

⁶ SHARE is a database of volunteers who have expressed an interest in participating in health research. Volunteers who are suitable for particular research studies are identified from their NHS records and can then be contacted and invited to take part. In some cases they might receive payment for their participation but in most cases they do not.

⁷ In the Province, where a significant amount of genetic research is carried out due to the particular genetic composition of the local population, a local committee was set up to ensure that benefit-sharing arrangements are included in all research proposals. This committee considers proposals on a case-by-case basis and provides local people with control over how their health data is accessed.

- 5.58 In contrast, participants perceived the ultimate goal of private sector organisations – and by extension of the research they undertake – as profit generation (albeit they did recognise that such research can also deliver public benefit). Thus they felt that private sector access to data should be more strictly controlled and subject to pre-agreed conditions.
- 5.59 Accordingly, benefit-sharing models were commonly seen as more relevant in the case of data sharing involving the private sector as compared with the public or third sectors. It was felt that benefit-sharing models would ensure research conducted by private companies was squarely focused on the public interest and that those companies had a duty of care towards data subjects.

Benefit-sharing models

- 5.60 Participants identified both advantages and disadvantages in each of the example models of benefit-sharing, but did not generally regard any of the examples as being ideal for all types of data sharing. Some participants noted that all of the models related to medical research among people who had opted in to the process and, as such, regarded the models as only really relevant in that context. Still, across the events participants did identify desirable features of a benefit-sharing model, sometimes drawing on the examples provided. These features related primarily to who should benefit from data sharing and how they should benefit. The discussions focused mainly on data subjects, data users and groups that might be termed ‘secondary beneficiaries’, namely other countries and future generations.

Data subjects

- 5.61 Participants drew a clear distinction between research requiring the proactive participation of subjects (for example, research involving genetic samples) and research that draws on routinely collected administrative or statistical data (such as health records or census data).
- 5.62 Where research requires proactive participation, the prevailing view was that data subjects should benefit directly. Participants felt this was particularly appropriate in research studies conducted among small and well-defined populations, where administering direct benefits would be relatively straightforward.

It kind of depends on how the research is being done and how much effort is required from the person who is providing the data [that should determine] what benefit the individual should be entitled to.

(Male, middle age group, Aberdeen)

If I was just going to the doctor's surgery for an appointment and they said, can you fill out the questionnaire, and it was to do for something generally, I wouldn't want personally paid for it, but if it was something more specific ... maybe if I had an illness or something and they wanted to use [me] as a guinea pig, and they said we'll give you this...

(Female, oldest age group, Edinburgh)

- 5.63 Direct benefits for data subjects were conceived of in different ways, from financial incentives to advice and access to services. Many participants found the model of benefit-sharing used in the Generation Scotland project – wherein research subjects were provided with health advice through their GP – particularly attractive.
- 5.64 At the same time, a common view was that incentivising or rewarding data subjects, as in the SHARE example, might encourage only particular types of people to take part in research, which, in turn, might have implications for the representativeness of any findings. In support of these views, a few participants discussed personal experiences where they had either been invited to participate in medical research but declined due to the lack of recompense offered, or had friends and colleagues who regularly took part in such research where a substantial financial incentive was offered.
- 5.65 In terms of research that draws solely on routinely collected data, the prevailing view was that individual data subjects should not necessarily benefit directly and, instead, society in general should be the main beneficiary. That said, participants went on to acknowledge that not all research would have relevance to all members of society, which in turn led them to refine their views and suggest that members of the specific population to which the data relates (for example, cancer patients or deprived communities) should be the main beneficiaries.

It depends where [the data] comes from. If [researchers] are getting information [from] the NHS and the government... then it should benefit services we get in the long run, not necessarily the individuals [who provided the data].

(Female, youngest group, Oban)

Every piece of research is not going to affect the whole of society at that particular time, but particular research is going to [benefit] alcoholics, is going to [benefit] the homeless. So, I don't mean everybody at the same time, but I do mean the whole of society depending on their needs.

(Female, middle age group, Glasgow)

- 5.66 'Societal benefits' were conceived of in terms of primary and secondary benefits. Primary benefits were outcomes that arose directly from research and included new and improved products and services – for example, drugs to treat diabetes or more integrated public transport networks. Participants also discussed the potential for products and services to be better targeted at those who need them most, though this view was tempered by concern, discussed previously, about the potential for services to be reduced or removed from particular areas.
- 5.67 Secondary societal benefits were conceived of in terms of broader and longer-term benefits, such as better public health or improved education levels. Some participants referred specifically to Generation Scotland and SHARE as programmes that could lead to a better understanding of health issues. There was a view that such benefits would save the government money in the long

run. For example, improvements to public health would result in reduced pressure on the NHS.

I think [the] government benefits in terms of financial benefits. Health [is] a big portion of the amount of money spent in the country. Therefore, if all these things are working, that should actually reduce the money spent [on health, which could be spent] in a different way.

(Male, oldest age group, Glasgow)

- 5.68 As previously discussed, participants also felt there should be greater transparency around research involving shared data and that data subjects should receive feedback on how their data has been used, regardless of the type of data collected (that is, whether collected routinely or through the proactive participation of subjects). There was a view that such feedback would provide a means of thanking data subjects for providing data and demonstrating to them that the information was being put to good use.

Transparency [is] the key. [By being transparent, organisations are] going to gain more trust in the community and it's going to be a nice circle, building trust and providing more benefit for people.

(Female, youngest age group, Edinburgh)

Data users

- 5.69 Discussions pertaining to data users focused primarily on private companies. Despite participants' initial aversion to the idea of companies profiting from research using shared data, the discussion of benefit-sharing led to the emergence of more nuanced views. There was general recognition that profits provided an incentive for private companies to invest in and conduct research, which, in turn, contributed to wider economic benefits, such as job creation and infrastructure development, as in the Newfoundland and Labrador example. In addition, it was felt that profits would likely be reinvested in future research, which would continue the cycle of product and service improvement whilst safeguarding jobs.

I also want the [researchers] who take the sample from me, to have enough money, so they can go [on to] the next idea.

(Female, oldest age group, Oban)

- 5.70 Despite acknowledging that profit could be beneficial, participants remained concerned about the potential for private companies to make excessive profits. Further, there was a view that, in a bid to maximise profits, private companies may refuse to share profits or make products and services unaffordable.

As long as it's not really excessive profit. We all know how we feel about the banks in terms of the amount of money they make at our cost and it's really angering to think that certain people have actually made that kind of money, profited out of other people's suffering.

(Female, oldest age group, Glasgow)

5.71 Consequently, participants felt it was important that benefit-sharing models incorporated clear provisions to curb the level of profits made from research. Specific suggestions commonly made in this regard included provisions to ensure that private companies:

- **pay to use data** – participants reiterated the view that this would provide recompense to data-holding bodies to cover data collection costs, particularly in cases where it might take years for profits to be generated. Participants continued to argue that private companies, particularly pharmaceutical companies and supermarkets, made vast profits and could afford to pay for access to data. There was also some suggestion that costs for accessing data could vary according to the type of organisation seeking access – for example, public and third sector organisations could be given data for free or at a lower cost than private sector companies
- **share profits** – in line with the Generation Scotland model, participants felt that, where appropriate, benefit-sharing models should include agreements to directly share profits with data holders (for example the NHS) and other research organisations involved (for example universities), thus contributing towards the cost of data collection and providing funds to reinvest in further research. Some participants suggested imposing a limit or cap whereby profits would be shared after reaching a pre-defined level
- **provide affordable products and service** – participants felt that private companies should provide products and services to public bodies and/or data subjects at lower costs. The main example cited in this regard was pharmaceutical companies providing cheaper cancer drugs to the NHS. Some participants suggested this provision could be administered using a sliding scale, whereby costs were reduced proportionate to the level of profit accrued
- **reinvest in communities** – where research focuses on specific communities, participants felt that a proportion of any profits should be reinvested in those communities, for example, to build community centres or provide initiatives for young people

[With profits from] medical research and that kind of [research] the money should be put back into the government for the NHS, because it is something everybody uses and it's about us and it's trying to make things better for us, so we should reap the rewards of it rather than just some pharmaceutical company [making profits].

(Female, youngest age group, Galashiels)

If a company develops a drug and it's through the help of data from different people with a condition, if they are making enormous excessive profit from that drug, the government should be able to bring the price of that drug down.

(Female, oldest age group, Oban)

Secondary beneficiaries

5.72 Aside from data subjects and data users, participants identified two further groups who might become beneficiaries of research, namely:

- **other countries** – there was a view that new or improved products and services resulting from research – cancer drugs received particular mention – could be sold or applied in other countries. Some participants were particularly keen that developing countries where research funding and infrastructure is limited, should benefit
- **future generations** – it was felt that future generations could benefit from research conducted now in much the same way as current generations had benefitted from research conducted in the past

...We wouldn't have the national health service, we wouldn't have drugs, we wouldn't have anything, if it hadn't have been for people being allowed to try things out in the past. So, I suppose, when you look at it like that, it is almost as if you have a moral duty to say, we have benefited, so why shouldn't we contribute for [future generations?]

(Female, oldest age group, Glasgow)

- 5.73 There was a view that recognising these groups in benefit-sharing models, particularly in cases where it is difficult to identify an immediate benefit to data subjects or wider society, would go some way towards demonstrating that the research is in the public interest.
- 5.74 In considering benefit-sharing models, participants not only discussed who should benefit from research and how, but also who should be involved in decision making about the development of these models. As is discussed more fully in the next section, these views invariably reflected, or formed part of, wider discussions about where decision-making power around data sharing in general should lie.

EMPOWERING CITIZENS IN DECISION MAKING

- 5.75 There was unanimous agreement that public involvement in decision making on data sharing, including the development of benefit-sharing models, was important and appropriate. A common view was that, as the data relates to the public, it is important that they are involved in deciding how they are used.

It is such an attractive idea to know about it and to have some kind of control over it.

(Female, oldest age group, Edinburgh)

Well [the public] certainly contributed to the data so why shouldn't they be involved to some degree?

(Male, oldest age group, Aberdeen)

- 5.76 However, participants often struggled to articulate what form public involvement should take or who should be involved. To stimulate discussion of these issues, each group was given a handout outlining five broad forms of involvement identified in the literature review, and asked to consider the relative appeal of these⁸ (A copy of the handout is provided in Appendix H). The five types can be summarised as:

- **Transparency** – the public as recipients of general information about how data are used and shared for research purposes
- **Feedback** – the public as recipients of feedback relating to how their data is used and the outcomes of specific research
- **Agenda-setting** – opportunities for the public to influence the specific types of research that is carried out
- **Informing policy** – mechanisms for public views to be taken on board in policy-making and to shape how data are shared and used
- **Representation** – opportunities for individuals to act as representatives of the wider public in decision making

- 5.77 Whilst views varied across and within the break-out groups, there was a stronger appetite for the transparency, feedback and informing policy forms of involvement than for agenda-setting and representation.

Forms of public involvement: transparency, feedback and informing policy

- 5.78 As discussed previously, there was strong support for mechanisms to ensure *transparency* around how data are used and shared. Participants were keen to have openness and transparency in relation to the following aspects specifically:

- the overall rationale for sharing data
- what data about the public are held and being shared

⁸ Each participant was given 10 'voting' stickers and asked to allocate them to the five forms of involvement according to their preferences; for example, if they felt that each form of involvement was equally important, they would allocate two stickers to each; if they felt one was the over-riding priority, they would allocated all ten stickers to that feature; and so on.

- how data sharing works in practice
- how decisions are made in relation to types of research that are carried out and who is allowed access to data
- which organisations are sharing data
- what research is being carried out.

5.79 In terms of *feedback*, participants were keen to be informed about how research carried out using their data had benefited society; for example, how it had helped to inform the development of a new drug or led to service improvements.

5.80 Significantly, there was a view that transparency and feedback may help foster greater levels of public trust in, and support for, data sharing by:

- providing reassurance that those involved in decision making were competent and acting in the public interest
- pre-empting any negative scare stories about data sharing from unofficial sources
- generating a 'feel good factor' amongst research subjects about the fact that their data has been used in a positive way.

[Transparency is] where you get trust. I don't think anyone would hold back information [if they have been told] what it was being used for and [...] what the outcome would be.

(Female, middle age group, Oban)

5.81 Levels of support for *public involvement in policy-making* were similar to support for transparency and feedback. Participants felt strongly that the public should be involved in setting the rules or guidelines that govern how data are shared, with whom and, less commonly, for what purpose. Crucially, they felt this would enable the public to retain some degree of control over their data. Indeed, during the discussions around different models of benefit-sharing, participants spoke in particularly positive terms about the way in which residents in Newfoundland and Labrador were afforded a degree of control over their data.

[If] the public gets to be involved in setting the standards...then we all know what anybody can pluck out about us and we can reasonably expect, if people are following that, that anything we consider too personal, nobody knows about us unless they directly ask us.

(Female, oldest age group, Edinburgh)

Informing policy, because it just makes you feel like... you actually get asked about it and then your decision is taken into the mix.

(Male, younger age group, Galashiels)

Forms of public involvement: Agenda-setting and representation

- 5.82 The more active forms of public involvement in decision making – agenda-setting and representation – were less popular than transparency, feedback and involvement in policy-making. There seemed to be two main reasons for this.
- 5.83 First, while participants felt that the public would be able to contribute to more general discussions about how their data are used, there was also a view that most members of the public did not have the requisite knowledge and expertise to contribute to more specific decisions concerning the types of research that should be carried out, and other similarly complex issues. It was often said that such decisions should be entrusted to experts – there was specific reference to the Scottish Government, scientists and researchers in this regard. Some participants expressed concern that too great a focus on the public's views may result in the wrong, or less essential, types of research being carried out.

I kind of think to myself, you need more of an expert knowledge on the subject rather than Joe Public. I'm not saying we're all stupid and can't understand things, but some aspects of some processes need more of a government think tank to be working that out [rather] than opening it up to the general public so much.

(Male, middle age group, Galashiels)

I don't think the general public know what research should be done, I think that should be left to the scientists and the professionals. They are the people who know what needs to be researched.

(Female, oldest age group, Glasgow)

- 5.84 Second, it was commonly felt that most people were either unwilling or unable (due to family and work commitments) to devote time to acting as public representatives. A corollary of these views was that people who *do* take up such positions are the “usual suspects” or “busybodies” and thus unrepresentative of the public as a whole. Participants in Glasgow and Edinburgh had particular doubts about the effectiveness of representation in larger, more urban settings, compared with areas such as Newfoundland and Labrador, due to the fact that urban populations are very diverse and therefore cannot be easily reflected in small decision-making forums.
- 5.85 Of the small number of participants who were in favour of public involvement in agenda-setting and public representation on decision-making bodies, most were in the older Galashiels break-out group. This may reflect the group's evident feelings of disempowerment at having not been consulted about a number of important decisions over recent years; particularly local decisions such as the Borders Railway project and the closure of local health services.
- 5.86 Other participants who were in favour of more active forms of public involvement tended to be people who were less trusting of government and/or who had a philosophical belief in public participation.

Governments tend to say something and do the very opposite and they need the public or a body or committee, somebody to keep them in line [and] just to say, "Look this is the way you're supposed to go".

(Male, oldest age group, Galashiels)

Methods of involvement

5.87 Reflecting participants' views on potential forms of public involvement in decision making, commonly suggested methods of involvement were:

- regular consultation work by any body charged with overseeing data sharing
- an online information resource and
- a television-based information campaign

5.88 Views around methods of involvement tended to be framed by consideration of two factors: whether the method would be inclusive of people from different sections of society (particularly in relation to age) and, albeit less commonly, cost-effectiveness.

Regular consultation work by any body charged with overseeing data sharing

5.89 There was strong support for the idea of setting up an oversight body – or a “committee” as participants often referred to it – comprising a range of stakeholders, independent of organisations involved in research, to oversee issues relating to data sharing, including models of benefit-sharing. It was commonly suggested that this oversight body would have no agenda and would ensure that decisions were not made to suit vested interests.

5.90 While participants felt that most members of the public did not have the skills and experience to be part of an oversight body, they nonetheless felt that public interests should be represented in an indirect way. A popular idea was for a third party organisation to regularly consult with the public on key areas of decision making and report back to the oversight body accordingly. Specific forms of consultation suggested included polls/surveys and other types of research, such as the deliberative events in which participants were taking part.

5.91 Reinforcing points made earlier in this section, participants felt that consultation should inform general principles around data sharing (including rules on what information is made available, who should be able to access it and governance arrangements) rather than to solicit views on specific requests for access to data.

5.92 There was also a view that any oversight body should operate an open-door policy, enabling members of the public to seek more information should they wish to do so, or to ask questions or give feedback on latest developments.

Online information source

- 5.93 The internet was frequently suggested as another potentially useful means of engaging the public in developments around data sharing. Internet-based communications were regarded as having two main benefits over other, more traditional methods of engagement.
- 5.94 First, these were widely perceived as being a cost-effective method, particularly when compared with leaflet and television-based communications. A few participants expressed concern that an expensive information campaign would only mean that reduced funds were available for research.
- 5.95 Secondly, a common view was that an online approach would give people the choice over whether and when to seek (more) information. Some people felt strongly that they should not be inundated with unsolicited information (leaflets posted through their door received specific mention in this regard).

Having a website is cost-effective because if people are interested they can go on it and have a look; if they're not then they don't have to. Leaflets and things like that, I think, are expensive and unnecessary because 95 per cent of them will just end up at the bottom of a bird cage.

(Female, oldest age group, Aberdeen)

- 5.96 Consistent with findings from the 2012 research, a popular suggestion was that a website could act as a “one-stop shop” for information on data sharing, of the type described in paragraph 3.79. Others suggested a more interactive website that would allow people to ask questions, feed back their views, and review what data about them is held (in a similar way to reviewing credit history, for example) and whether it has been shared. As an extension of this, a small number of people felt that the website should allow people to set personal preferences around the types of information that is shared, with whom, and for what purpose.
- 5.97 Less commonly, participants suggested that social media could be used to both inform the public about data sharing and to engage them in the process by enabling them to ask questions, comment on posts or start discussions.
- 5.98 However, consistent with views reported in earlier sections, many participants, including those from younger groups, were generally distrustful of social media companies and consequently had doubts as to whether social media sites would be regarded as reliable sources of information on data sharing. There was specific concern about the potential for information on social media sites to “grow arms and legs”, making it difficult for people to distinguish fact from rumour.
- 5.99 More generally, participants were mindful of the limitations of using solely an online approach to disseminate information about data sharing. A common view, particularly among older participants, was that online communication would exclude those who do not routinely use the internet.

- 5.100 Further, a number of participants were keen to point out that people would only access a website about data sharing if they were made aware that such a site existed. There was a clear sense in which the Data Linkage Framework was seen as something that needed to be more proactively brought to the attention of the general public as a first step in promoting engagement with the subject.

A television-based information campaign

- 5.101 Reflecting these views, participants often felt any online resource should be supplemented with an initial public awareness-raising campaign delivered using more traditional methods of communication. Television was felt to be a particularly effective method on the grounds of its perceived inclusivity.

We don't know what is available, don't know where to go what to look for, whereas if it is a big TV campaign, you will see it, the majority of people will see it.

(Female, oldest age group, Galashiels)

- 5.102 It was widely felt that a TV-based information campaign should take the form of a short programme or advertisement rather than a longer documentary that people would be less likely to watch. A popular suggestion was for a programme in the style of a party political broadcast or a public health campaign.

See likes of the campaigns they did for the AIDS campaign and all these kind of things...where they can inform the public very quickly about what's happening.

(Female, oldest age group, Glasgow)

- 5.103 Regardless of the specific method used, participants felt strongly that the public should be communicated with in layman's terms. A number of people criticised communications provided by government departments as often difficult to understand.

It would be good if there was a central point of information that's unbiased and easy to understand, but not in a condescending way.

(Male, oldest age group, Edinburgh)

6 CONCLUSIONS

- 6.1 The purpose of this research was to build on previous research, literature and practical examples from elsewhere to enhance understanding of sensitivities around data sharing between the public, private and third sectors for statistical and research purposes, and to explore options for mitigating concern. Therefore the research also sought to explore public views of benefit-sharing, including which methods of benefit-sharing were most acceptable; and to assess what methods could be most efficient and effective in empowering citizens in decision making about how their data is used.
- 6.2 Across the events and various break-out groups, views were generally consistent, though nuanced, thus providing a reasonably clear and coherent set of findings in respect of the aims and objectives outlined above.

Sensitivities around data sharing between the public, private and third sectors

- 6.3 Concerns and sensitivities around data sharing between the public, private and third sectors clustered around five inter-linked themes:
- 6.4 ***Security and privacy:*** As in the 2012 research, concerns about data security and privacy featured prominently throughout the discussions. Participants continually sought reassurance around how security and privacy would be ensured – not least to prevent their personal details from being shared between commercial actors and used in direct marketing campaigns. While most were content that anonymisation, if rigidly enforced, would go some way towards protecting privacy, even in the event of a data breach, others were significantly more sceptical. Addressing such concern must therefore remain a focus as the Data Linkage Framework is further developed.
- 6.5 ***Data uses and the public interest:*** Participants were unequivocal that research using shared data should only be carried out when it is likely to result in some form of public benefit. Accordingly, they opposed the involvement of private sector organisations that they regarded as predominantly profit driven, or that they otherwise did not trust to act in, or protect, the public interest (this included banks and other financial institutions, as well as internet providers and social media companies). Similarly, there was some opposition to data being accessed by third sector organisations concerned with sectional interests.
- 6.6 ***Labelling:*** As was apparent in the 2012 research, there was clear concern that the sharing of quantitative data across and within sectors could lead to increased negative labelling of individuals and groups, particularly in socio-geographic terms. While this was most commonly discussed in relation to insurance companies blacklisting or setting higher premiums in particular areas, there was a perception that public bodies similarly make important assumptions and decisions about people based on where they live. Efforts on the part of public bodies to make the public more aware of steps they take to look ‘beyond statistics’ and to develop an understanding of individuals’ and

communities' circumstances and needs may go some way towards countering such perceptions.

- 6.7 **Statistical disclosure:** The discussion about data types revealed significant concerns about the potential for individuals to be identifiable from shared datasets. These concerns related mainly to data on postcode and sexual orientation. Postcode data raised particular concerns for participants in Oban and Galashiels, who felt that it would be possible to identify an individual within a database focusing on a small geographic area from a combination of his/her postcode combined with a small number of additional variables. Sexual orientation data was most commonly discussed by LGBT participants, who were concerned about potential data misuses in the event of the information falling into the wrong hands. Such concerns suggest there is a need to inform and reassure people about the contexts in which more personal types of data, like postcode and sexual orientation, might be linked or shared, and mechanisms that will be in place to mitigate (unlawful) disclosure.
- 6.8 **Transparency:** There were significant concerns about how data linkage and sharing will be governed, and specifically about steps that will be taken to ensure that, having been granted access to data, an organisation – whether public, private or third sector – uses that data solely for legitimate, pre-defined purposes.

Conceptions of benefit-sharing

- 6.9 Benefit-sharing was perceived to be important and necessary, although it was clear that participants thought of benefits differently in relation to the public and third sectors' use of data compared to the private sector's. While they felt the realisation of benefits was an inevitable goal of research conducted by public and some third sector organisations, the prevailing view was that the main goal of private sector research was ultimately to generate profit. Consequently, benefit-sharing models were commonly seen as more relevant in the case of research involving the private sector than that involving only the public and/or third sectors.
- 6.10 Benefit-sharing models were mainly conceived of in terms of who should benefit – there was a particular focus on data subjects, data users and secondary beneficiaries – and how. In relation to data subjects, a clear distinction was drawn between research requiring their proactive participation and research that draws on routinely collected administrative or statistical data. With regard to the former, the consensus was that data subjects should receive direct benefits (for example, financial incentives or health advice). With regard to research drawing on routinely collected data, it was felt that data subjects should not necessarily benefit directly and, instead, society in general should be the main beneficiary. Societal benefits were conceived of in terms of primary benefits – outcomes arising directly from research (for example, improved services) – and secondary benefits – broader or longer term benefits (for example, better public health).

- 6.11 Discussions pertaining to data users focused primarily on research involving private companies. Despite participants' initial aversion to companies profiting from research using linked or shared data, the discussion of benefit-sharing led to the development of more nuanced views. There was general recognition that profits provided an incentive for private companies to invest in research, which contributed to wider economic benefits. However, significant concerns remained about the potential for excessive profit-making and participants felt it was important that benefit-sharing models incorporated clear stipulations to curb excessive profits. Specific suggestions commonly made in this regard included stipulations to ensure private companies:
- **pay for using data** – to provide recompense to data-holding bodies to cover data collection costs, particularly in cases where it might take years for profits to be generated;
 - **share profits** – where appropriate, benefit-sharing models should include agreements to directly share profits between organisations involved, thus contributing towards the cost of data collection and providing funds to reinvest in further research;
 - **provide affordable products and services** – participants felt that private companies should provide products and services to public bodies and/or data subjects at lower costs; and
 - **reinvest in communities** – where research involved specific communities, a proportion of profits should be reinvested in those communities.
- 6.12 Participants also identified other countries and future generations as groups who, depending on the nature of the research, might become secondary beneficiaries. There was a view that recognising these groups in benefit-sharing models, particularly in cases where it is difficult to identify an immediate benefit to data subjects or users, would go some way to demonstrating that the research was in the public interest.
- 6.13 Participants felt there should be greater transparency around research involving shared data and that data subjects should receive feedback on how their data has been used. There was a view that such feedback would provide a means of thanking data subjects for providing data and demonstrating to them that the information was being put to good use.

Empowering citizens in decision making

- 6.14 As in the 2012 research, the readiness and ability of participants to engage in discussions about data sharing, along with their positive feedback about the deliberative events, itself provides a strong case for ongoing public engagement in the development of policy and strategy. Further, the findings suggest that the Scottish Government's current approach to involving the public in decision making primarily through consultative work is broadly in line with expectations but this should be supplemented with:

- a) a media-based campaign to raise awareness of the Data Linkage Framework (including the rationale for it, potential benefits and governance arrangements);
- b) mechanisms for keeping the public up-to-date with developments. While the main suggestion made in this regard was for a central online information hub, consideration will need to be given to how best to communicate with members of the public who do not use the internet. One option that might be considered is the provision of a postal address that participants can use to request hard copy information, equivalent to that posted on any website created;
- c) approaching consultation as an on-going process rather than considering it as a one-off strategy to ascertain public attitudes and acceptability; this will enhance citizen engagement and empowerment.

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APPENDIX A: PROFILE OF WORKSHOP PARTICIPANTS

Table1: General public workshops

	Location				
Criteria	Oban	Aberdeen	Galashiels	Glasgow	Total
Total attended	25	25	27	28	105
Gender					
Men	15	12	11	14	52
Women	10	13	16	14	53
Age					
18-34 years old	8	11	10	9	28
35-49 years old	6	7	10	9	32
50 years and over	11	7	7	10	35
Working status					
Working	13	16	18	20	67
Not working	12	9	9	8	38
Socio-economic status					
Social grades A/B	7	3	4	4	18
Social grades C1/C2	6	11	13	12	42
Social grades D/E	11	11	10	11	43
Religion					
Religious identification	24	15	23	23	85
No religious identification	1	10	4	5	20
Disability					
Disability	6	9	9	12	36
No disability	19	16	18	16	69
Minority equality groups					
Minority ethnic communities	7	7	7	5	26
LGBT people	4	7	5	6	22
Pregnant/child < 1 yr old	1	2	5	5	13

Where numbers do not sum, this is because some participants chose not to provide some information on recruitment

Table 2: LGBT workshop

Criteria	Total
Total attended	12
Gender	
Men	6
Women	6
Age	
18-34 years old	5
35-49 years old	5
50 years and over	2
Working status	
Working	9
Not working	3
Socio-economic status	
Social grades A/B	6
Social grades C1/C2	7
Social grades D/E	1

APPENDIX B: SUMMARY OF MODELS ACCORDING TO CLASSIFICATION OF PUBLIC ENGAGEMENT APPROACHES

SOURCE	LEVEL OF PUBLIC ENGAGEMENT		
	Awareness Raising	Consultation	Empowerment
Arnstein (1969)	<i>Informing</i>	<i>Consultation</i>	<i>Citizen Control/ Delegated Power/ Partnership</i>
COI (2009)	<i>Information-Giving</i>	<i>Information-Gathering/ Consultation/ Involvement</i>	<i>Partnership/ Empowerment (delegated authority)</i>
Dialogue by Design (2008)	<i>Information-Giving</i>	<i>Information-Gathering/ Consultation</i>	<i>Participation/ Collaboration/ Delegated Authority</i>
Fife Council	<i>Informing</i>	<i>Seeking Views</i>	<i>Participation and Partnership</i>
Goss (1999)	<i>Giving Information</i>	<i>Consultation/ Listening Exploring/ Innovating/ Visioning</i>	<i>Judging/ Deciding Together Delegating/ Supporting/ Decision-Making</i>
IAP2 (2007)	<i>Inform</i>	<i>Consult/ Involve</i>	<i>Collaborate/ Empower</i>
INVOLVE (2004)	-	<i>Consultation</i>	<i>Collaboration/ User Control</i>
OECD (2001)	<i>Information</i>	<i>Consultation</i>	<i>Active Participation</i>
Rowe & Frewer (2005)	<i>Public Communication</i>	<i>Public Consultation</i>	<i>Public Participation</i>
Sciencewise (2010)	<i>Communications/ Campaigning</i>	<i>Research</i>	<i>Upstream Dialogue/ 'True Engagement'</i>
Wilcox (1994)	<i>Information</i>	<i>Consultation/ Deciding Together</i>	<i>Acting Together/ Supporting Independent Community Interests</i>

APPENDIX C: TOPIC GUIDE

Topic guide

Deliberative citizen engagement event on

“Public Acceptability of Data Sharing between the Public, Private and Third Sectors”

Topic guide

9.45am – 10am: Arrival

- Registration, provide participants with name badge indicating which of the small groups they will be in
- Workshop facilitators and presenters to mingle
- Poster boards with agenda and purpose of the event
- Teas and coffees

10:00-10:10: Initial Plenary

- Thank respondents for attending
- Introduce Ipsos MORI and University of Edinburgh and the people involved and their roles during the event
- Explain, why they were invited, briefly explain the background to the consultation exercise and emphasise that the focus is on the sharing of data between the public, private and third sectors for research purposes (this could include social research, scientific research or commercial research. Some of this might inform the planning or evaluation of services). Briefly outline agenda for the day.
- Emphasise: confidentiality, no right or wrong answers, give everyone opportunity to speak, important to hear public views and involve public in these issues
- Housekeeping: toilets, fire exits, refreshments, mobile phones switched off

10.10-10:50: Introductory Presentation on Data sharing, Linkage and the Strategy for Improving Data Access and Analysis, plus Q&A (40 minutes)

10:55-12:05: Break Out Groups (70 minutes)

ASK PARTICIPANTS TO INTRODUCE THEMSELVES (NAME, JOB, WHO LIVE WITH, ANY HOBBIES/INTERESTS)

EMPHASISES CONFIDENTIALITY/ANONYMITY OF DISCUSSIONS

OBTAIN PERMISSION TO RECORD DISCUSSION

- How do you feel about public, private and third sector bodies [USE CARDS TO IDENTIFY RANGE OF BODIES] accessing information from other sources about you for research? [RECORD ANSWERS ON FLIP CHART. DIVIDE INTO YES AND NO]

[MODERATOR NOTE: Social enterprises are businesses which exist to tackle social or environmental problems. All of the profits of these businesses are reinvested into the community or back into the business.]

- o **Probe:** Do you think different people might think differently, for example someone who is from an ethnic minority, gay, pregnant/has a young child, has a disability/etc. does this raise any particular concerns for you personally?

- o **Explore** personal knowledge/experience of the different types of organisations and also whether trust is an issue in making judgements
- Do you feel differently about different organisations? [RECORD ON FLIP CHART]
 - o **Probe:** How do you feel about information being shared between different public sector organisations?
 - o **Probe:** How do you feel about information being shared between the public and private sector?
 - o **Probe:** How do you feel about information being shared between the public and third sector?
 - o **Probe:** How do you feel about public sector organisations using data from the private or third sector?

EXPLAIN: There are lots of different types of information which is collected about you which might be interesting for researchers, for example: your gender, age, ethnicity, religion but also details about your education, benefits or past involvement with the criminal justice system.

- Do you feel differently about different types of data? [USE CARDS TO IDENTIFY RANGE OF TYPES OF DATA, RECORD ON FLIP CHART; IDENTIFY ACCEPTABLE/UNACCEPTABLE TYPES OF DATA]
 - o **Probe:** What about data from commercial companies (for example, energy data; club card data?)
 - o **Probe:** How do you think different groups of people will feel about this?

EXPLAIN: data might be accessed for a variety of purposes. For example; research might lead to the development of new products or drugs, better understanding of health and illness, better understanding of behaviour (eating or drinking habits/energy consumption), or it might allow organisations to conduct research to plan and improve the quality of service delivery, it might also inform policies and measure impact of policies, or to learn about the population as in the census

- Do you feel differently about different uses of data? [USE CARDS TO IDENTIFY RANGE OF USES, RECORD ON FLIP CHART; IDENTIFY ACCEPTABLE/UNACCEPTABLE USES] possibly just as an aide memoire
 - o **Probe** types of research and researchers; see if public interest arguments emerge
 - o **Probe:** How do you think different groups of people will feel about this? What about someone with a particular religious or ethnic background?
- Would you expect to benefit in some way from your data being used in this way?
 - o **Probe:** In what way would you expect to benefit?

[USE STICKY WALL– this will enable people to write down their views initially – facilitator can then ‘analyse’ – identify themes]

End session with participants listing issues they’d like further clarification on (we can then attend to that in the presentation and Q and A).

12:05-12:45 Lunch Break (40 min)

12:45-13:15: Presentation on Private Sector Involvement in Data sharing and Benefit Sharing, plus Q&A (30 minutes)

13:15-14:15: Break Out Groups (60 minutes with break)

- How do you feel about what you have heard in this presentation?
 - o **Prompt:** Did anything surprise you?
 - o **Prompt:** Did you think anything was either particularly good or particularly concerning?

- Do you have any concerns about information being shared with private and third sector organisations [RECORD ON FLIP CHART; TRY TO GROUP]?
 - o **Prompt:** What, if anything, would reassure you?
 - o **Probe:** How do you think different groups of people will feel about this? For example, what about someone with a particular religious or ethnic background?
- How do you feel about private sector organisations making a profit as a result of research using your information?

EXPLAIN: In some cases organisations might work across sectors, for example data might be accessed by public-private partnerships or spin-out companies.

- How do you feel about “hybrid” organisations such as this accessing your information for research?

- We heard in the presentation that there are a range of approaches to sharing benefits from research, what do you think about this?
 - o **Prompt:** Do you think benefit-sharing is necessary/appropriate?
 - o **Prompt:** Do you think public sector organisations should share benefits?
 - o **Prompt:** Do you think private sector organisations should share benefits?
 - o **Prompt:** Do you think third sector organisations should share benefits?

DISTRIBUTE BENEFIT SHARING HANDOUT AND EXPLAIN: There are a variety of possible approaches to benefit-sharing. The presentation mentioned three examples:

- Which type of benefit-sharing do you think is most appropriate?
 - o **Prompt:** What do you consider to be its advantages?
 - o **Prompt:** What do you consider to be its disadvantages?
 - o **Prompt:** What would you change about the approaches to benefit-sharing?
- What are the important features to be included in an approach to benefit-sharing [USE FLIP CHART TO LIST FEATURES OF BENEFIT-SHARING MODELS]?
 - o **Prompt:** Who should benefit? Participants, populations, whole of society, future generations, government, public bodies, private companies, third sector organizations
 - o **Prompt:** How should they benefit? Financial, profit, improved products or services, feedback, information
 - o **Prompt:** Who should decide who benefits? Parliament/government, public consultation, quango, oversight body, organization conducting research, organization holding data
- Do you think members of the public should play a role in deciding how data is shared and used for research?
 - o **Prompt:** In relation to which areas of decision-making?
- What are the most important features of public involvement [USE COLOURED SPOTS AND TABLE TO RANK FEATURES OF PUBLIC INVOLVEMENT]?
- How do you think members of the public should be involved [Discuss a RANGE OF METHODS]?
 - o **Prompt:** Leaflets, advertising, website, consultation, research, representation

EXPLAIN: Just to finish up this discussion – thinking about what we have discussed here today, more generally:

- What do you think are the main things that SG can take out of today?
- Would you like to be kept informed about what happens next?

[RECORD ON FLIP CHART]

14:15-14:30: Closing Session (15 min)

- The breakout groups will be brought back together and asked to feedback their views and preferences.
- Summarise key messages from the day and ensure agreements and disagreements noted.
- Thank participants for their input and reiterate next steps.

DISTRIBUTE POST-EVENT QUESTIONNAIRE AND INCENTIVES

APPENDIX D: INTRODUCTORY PRESENTATION ON DATA-SHARING, LINKAGE AND THE STRATEGY FOR IMPROVING DATA ACCESS AND ANALYSIS



WELCOME



Ipsos MORI

Agenda

10:00 – 10:10	Introduction
10:10 – 10:50	Presentation and Q&A session
10:55 – 12:05	Small group discussion
12:05 – 12:45	Lunch
12:45 – 13:15	Presentation and Q&A session
13:15 – 14:15	Small group discussion
14:15 – 14:30	Closing session



Data-Sharing, Linkage and the Strategy for Improving Data Access and Analysis



Purpose of today's consultation

- The Scottish Government has published a strategy for improving data access and analysis for **research**.
- Research using personal but anonymised data about you may be conducted by a variety of organisations in the public, private or third/voluntary sector which means this information may be shared.

Purpose of today's consultation

- The Scottish Government want to know what you think about this and what, if any, concerns you might have
- Understanding what the public thinks will help to inform these plans especially about how to manage data sharing and which organisations may have access under what circumstances or conditions

Key terms

- **Data** – information which is collected about individuals and/or populations (for example, relating to use of services, health records, tax records, social security)
- **Data linkage** - information about individuals collected in different places (for example, education, health care, surveys) being joined together anonymously to create a fuller set of information
- **Data sharing** – the access of this information by other organisations (for example, industry such as pharmaceutical companies, or university researchers)

What information might be shared?

- Development and production of Official Statistics, including the production of aggregate statistical information.
- Production and dissemination of research resources, such as long-term statistical studies like the Scottish Longitudinal Study.
- Ad-hoc research projects, or linkages conducted to answer specific research questions using statistical analyses, such as the West of Scotland Coronary Outcomes Prevention Study.



Who might access these data for research and statistical purposes?

- **Public Sector** e.g. University researchers, NHS, social care services, local authorities, the Scottish Government
 - **Private Sector** e.g. pharmaceutical companies, market research organisations, insurance companies
 - **Third Sector** e.g. charities and voluntary organisations
-

What it is NOT about



- Sharing of information about **named** individuals between agencies to enable **joined-up services**
 - e.g. to assess whether a child is at risk, whether someone is falsely claiming benefits, or to coordinate diabetes care between different health service providers



What it IS about



- The use of information and data for research
 - ❖ Linking across different sources can provide 'rich' data with which to study the population
 - ❖ The data are anonymous/anonymised, so no names and addresses are attached to it.
 - ❖ Sometimes administrative data are linked with information collected in surveys
 - ❖ Survey participants give consent for this to happen

How data might be used?

- The government introduces a new tax credit allowing people on long-term benefits to take low-paid part-time work without risking a loss of income. It links employment, income and benefit records in order to determine whether the new scheme has achieved the desired effect.
- University researchers link records from school, social work, criminal justice and health in order to examine the social determinants of drug abuse.
- A pub chain is considering opening new branches at motorway service stations. They request public sector data on crash histories in the area, compared to elsewhere, along with details of the vehicle occupants (age, gender) in order to demonstrate whether this is likely to be safe.



What are the benefits?

- Better information will help to develop and improve services that meet important needs and to evaluate policies

For example, through research using linked data (e.g. education, social services), we now know that Looked After Children are 8 times more likely to be excluded from school than other children. Support can now be targeted at these children



What are the benefits?

- Produce better statistics

Linking administrative data can help provide more up-to-date information on the population than the ten-yearly Census does.

Linked data can also give a more detailed picture about associations between different things



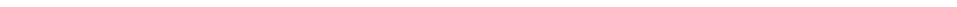
What are the benefits?

- Scotland has a world-wide reputation for its data linkage work in health research

Strengthening data linkage across sectors will make Scotland an excellent place to do research

This should improve our health and well-being

This may bring benefits to Scotland by attracting companies here



Remember this guy?



Balancing public interest
and public good with
individual privacy and
individual needs

What are your views?

“The needs of the many outweigh...
The needs of the few...or the one”

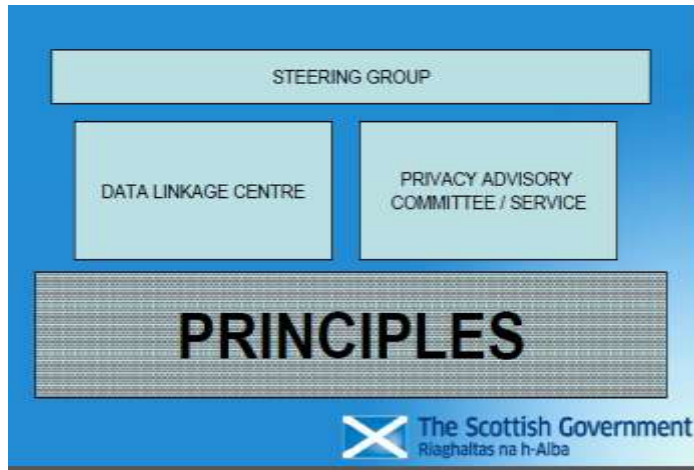
Mr Spock in Star Trek II, The Wrath of Khan, 1982



Public Interest and Public Acceptance

- The Scottish Government is committed to ensuring data are used in ways which are in the public interest
- It is important that data are only used in ways which are publicly acceptable
- The Government’s strategy prioritises transparency and public engagement

The Scottish Government's Data Linkage Framework



What are the principles?

- **Public Interest**
- **Governance and Public Transparency**
- **Privacy**
- **Removal of names and direct identifiers**
- **Consent**
- **Security**
- **Access and Personnel**
- **Data sharing agreements and sanctions**





What we already know about public attitudes

- We know that generally there is public support for research which is in the public interest
 - However, some members of the public are concerned about private companies using their data
 - Some people are concerned about access to linked data, and are worried about the potential for a “big brother society”
 - Safeguards such as ensuring that data is anonymous are important to people
 - Knowing what is going on is also important to people
-



What are your views on this?

- *How do you feel about data-sharing between the public, private and third sectors?*
- *Do you think benefit-sharing is important?*



APPENDIX E: PRESENTATION ON PRIVATE SECTOR INVOLVEMENT IN DATA-SHARING AND BENEFIT SHARING



Private and Third/Voluntary Sector Involvement in Data-Sharing



This afternoon we will discuss in more detail how private and third sector organisations might use data and how benefits which result from this are shared and managed

How might private sector organisations use personal data for research?

Example 1:

A pharmaceutical company might request access to general practice and hospital records in order to assess whether a prescribed drug leads to more side effects in certain people. This helps them to decide whether there is a need for a new drug.

Example 2:

An insurance company might request access to records of criminal activity in different areas order to calculate high risk neighbourhoods.

How might private organisations sector use data?

Example 3 (Private sector conducting research on behalf of public sector):

A private consultancy firm might be commissioned by the Department for Education (DfE) to analyse the National Pupil Database (NPD) and other public sector datasets to examine what it can tell us about educational outcomes.

The consultancy firm could link information about individual pupils (including their age, gender, attainment in national exams, ethnicity and eligibility for free school meals) with data relating to the quality of schools (from Ofsted statistics and reports) and geographic information identifying schools in deprived areas (from Department of Communities and Local Government figures).

The researchers at the firm joined all this data together to make a single dataset which they used to analyse patterns of educational attainment

The public sector also uses private sector data:

Example 1:

A study conducted by the NHS in Scotland combined data from the Information Services Division of NHS Scotland, the NHS General Dentist Service, the British Household Panel Survey and Denplan (a provider of private dental care) to assess use of dentist services across Scotland. They looked at rates of registrations and frequency of visits to dentists as well as additional information available from Denplan which graded individual clients' oral health. This enabled the researchers to identify patterns in registration with and accessing of dentist services in Scotland and the quality of oral health of private and NHS dentist patients. The information provided by the British Household Panel Survey meant that it was possible to study patterns in accessing of dental services in relation to employment status and household income.

The public sector also uses private sector data:

Example 2:

Supermarkets collect information about people's shopping habits, for example this is collected via loyalty cards (such as the Tesco Clubcard or Nectar card). This information contains a lot of detail about individuals' patterns of consumption. This could be useful for researchers in the Scottish Government who are interested in people's spending or lifestyle habits. For example, this information might be relevant for understanding rates of alcohol or cigarette consumption which might help to inform healthy living campaigns and policies.

The public sector also uses *third* sector data and the other way round:

Example:

Charities working with homeless people collect information about those individuals. This information might include their age, gender, ethnicity and also details relating to alcohol or drug addiction or health problems. Local councils also keep records of homelessness based on local housing records. These local councils may want to access data from the charities in order to conduct statistical research and verify their own figures. This may be useful for planning or improving services in the community.



“Hybrid” organisations

In some cases organisations might work across sectors, for example data might be accessed by public-private partnerships or spin-out companies. This is a growing area where such partnerships may develop ‘analytics’ – ways of interpreting data – which can then be used by others (e.g. pharmaceutical companies or hospitals)



How might we define benefits?

Public good – better services, quality of life etc

Economic benefit – more jobs, new companies forming

Social/cultural benefit – more interest in data, research and research outcomes

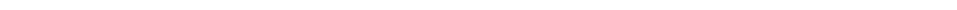
Public involvement

Profits



What about profits?

- Private sector organisations using data might make a profit as a result of the research they carry out.
- For example, a pharmaceutical company may use patient data from the NHS to conduct research which leads to the development of a new drug, which they then sell for a profit. Or a spin-out company uses data to develop new tools for analysis; the software can be licenced with a fee for using it.
- *How do you feel about this?*
- *Should benefits from research be shared?*





Models of Benefit-Sharing

Example 1:

Generation Scotland is a resource containing biological samples from more than 30,000 people across Scotland. These samples are used by a variety of researchers in universities, the NHS and the private sector. In some cases research conducted using these samples might result in a profit for the research organisation. In these cases, the income is shared evenly between the universities, the NHS and commercial partners as well as with the Generation Scotland programme. People who donate samples to Generation Scotland do not receive financial benefits, however they may receive health advice at the time they participate.



Models of Benefit-Sharing

Example 2:

In Newfoundland and Labrador, in Canada, where a significant amount of genetic research is carried out due to the particular genetic make up of the local population, a local committee was set up to ensure that benefit-sharing arrangements were included in all research proposals. This committee considers research proposals on a case by case basis. This means that local people have control over how their health data is accessed and also means that local research facilities and employment opportunities are developed and expanded.



Models of Benefit-Sharing

Example 3:

SHARE is a database of volunteers coordinated by the NHS in Scotland. The volunteers are people who have expressed an interest in participating in health research and who agree to allow SHARE to use information from their NHS computer records to check whether they might be suitable for particular research studies. The volunteers can then be contacted and invited to take part in particular studies. In some cases they might receive payment for their participation but in most cases they do not. The benefits of taking part are the potential improvements in health or healthcare in Scotland.



What are your views on this?

- *How do you feel about data-sharing between the public, private and third sectors?*
- *Do you think benefit-sharing is important?*



APPENDIX F: PROMPT CARDS CONTAINING EXAMPLES OF ORGANISATIONS, DATA TYPES AND DATA USES

Examples of organisations (each shown on a separate card)

Public sector:

Scottish Government

NHS
Police

Local councils

Social work services

Private sector:

Pharmaceutical companies and private health & social care

Supermarkets and other shops/ retailers
Banking and financial Services

Security & surveillance companies

(e.g. G4S) & private law firms

Internet service providers and social media

Third sector:

Health & social care charities

Homelessness & housing charities
Children's charities

Social enterprises (e.g. the Big Issue)

Pressure groups/ non-governmental organisations
(e.g. Greenpeace/British Medical Association)

Examples of data types (each displayed on a separate card)

Health records

Education

Police & criminal justice records

Benefits claimed

Social work records

Housing

Personal characteristics (e.g. age, sex, ethnicity religion)

Postcode & type of area you live

Examples of data uses (each displayed on a separate card)

To develop new drugs or products

To plan & improve services (e.g. the number/types of hospitals needed in an area)

To understand the public's behaviour (e.g. diet and exercise, use of public transport)

Understand health, illness and disease

Learn about the population (e.g. whether or not the population is ageing)

To inform and test the effect of policy (e.g. whether free school meals help to improve children's health)

APPENDIX G: EXAMPLES OF BENEFIT SHARING MODELS

Example 1

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Example 3

SHARE is a database of volunteers coordinated by the NHS in Scotland. The volunteers are people who have expressed an interest in participating in health research and who agree to allow SHARE to use information from their NHS computer records to check whether they might be suitable for particular research studies. The volunteers can then be contacted and invited to take part in particular studies. In some cases they might receive payment for their participation but in most cases they do not. The benefits of taking part are the potential improvements in health or healthcare in Scotland

APPENDIX H: VOTING EXERCISE ON FORMS OF PUBLIC INVOLVEMENT

Transparency Open communication about how data are used and shared for research purposes generally for example through a website, public information campaign	Feedback Members of the public receive feedback relating to how their data are used and what the outcomes of this are, for example through letters or leaflets	Agenda-Setting Members of public can influence what sort of research is carried out, for example through discussion events with government or scientists	Informing Policy Members of the public's views are taken on board in policy-making processes shaping how data is used and shared	Representation People who are representative of the wider public are involved in decision making; for example, through membership of committees

APPENDIX I: POST-WORKSHOP QUESTIONNAIRE

Data Linkage Discussion Event Feedback Form

We are interested in your opinion of today's event. Please take a few minutes to complete this short questionnaire.

Q1 How far do you agree or disagree with the following statements?

PLEASE TICK ☐ ONE BOX ONLY FOR EACH ROW

		Strongly agree	Agree	Neither agree nor disagree	Disagre e	Strongly disagree
a)	I found the event enjoyable.....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b)	The presentations were informative and interesting.....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c)	The opportunity to ask questions was useful.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
d)	Overall I feel better informed about the material discussed	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
e)	The design of the event was stimulating.....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
f)	There was enough time to hear the views of others	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
g)	There was enough time to share my views with others.....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Q2 What, if anything, did you enjoy most about the event?

PLEASE WRITE IN BELOW

Q3 What, if anything, did you enjoy least about the event?

PLEASE WRITE IN BELOW

Q4 What, if anything, would have made the event better?

PLEASE WRITE IN BELOW

PLEASE TURN OVER

Q5

Is there anything you would have liked to have said but didn't?

PLEASE WRITE IN BELOW

Q6

Did this event change your views about any aspect of data sharing between public, private and third sector organisations?

PLEASE TICK ☐ ONE BOX ONLY

Yes

☐

No

☐

If **yes**, please tell us how your views have changed? **PLEASE WRITE IN BELOW**

Q7

Thinking about everything that has been discussed today, what do you think are the most important issues to consider or resolve regarding the sharing of data between public, private and third sector organisations?

PLEASE WRITE IN BELOW

Q8

Did you find today's venue suitable or not suitable?

PLEASE TICK ☐ ONE BOX ONLY

Suitable

☐

Not suitable

☐

Don't know

☐

If you found the venue unsuitable, why do you think it was not suitable? **PLEASE WRITE IN BELOW**

If you would like a copy of the final report, please write your email address or, if you don't have an email address, your postal address in the box below:

*Thank you very much for the feedback.
Please hand your completed form to one of the moderators.*

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