

## Beyond 2011 Public Attitudes Research: Report on 2012 Focus

### Group Research

April 2014

#### Background

The Office for National Statistics has taken a fresh look at options for the production of population and small area socio-demographic statistics for England and Wales. The Beyond 2011 Programme carried out research on the options and has recommended the best way forward to meet future user needs.

Improvements in technology and administrative data sources offer opportunities to either modernise the existing census process, or to develop an alternative by re-using existing data already held within government. Since methods for taking the traditional census are already relatively well understood most of the research focussed on how surveys can be supplemented by better re-use of 'administrative' data already collected from the public.

The final recommendation made in 2014, balanced user needs, cost, benefit, statistical quality, and the public acceptability of all the options. The recommendation is for a predominantly online census in 2021 supplemented by use of administrative and survey data. This has implications for population-based statistics in England and Wales and, potentially, for the statistical system as a whole.

#### About this paper

This paper provides the results from a set of focus groups carried out by the Data Collection Methodology branch (DCMCS) of the Office for National Statistics. The research was carried out to explore public attitudes towards data sharing. This work leads on from earlier research carried out in February 2010 by DCMCS which looked public attitudes towards data sharing between government departments and from a quantitative study which was conducted by the Beyond 2011 team in 2009. The aim of the focus groups was to build on previously completed projects and to gauge public opinion on the use of administrative data, the creation of a social statistics database and the creation of a social register. This report will detail the findings of the focus groups with a view to informing future strategies for communicating with the general public.

This document is one of a series of papers being published providing details of the public attitudes research undertaken by the Beyond 2011 Programme.

#### For more information

- Data Sharing between Government Departments: Report on Public Acceptability (November 2009)
- Beyond 2011 Programme Public Attitudes Research: Report on 2010 Focus Group Research
- Beyond 2011 Programme Public Attitudes Research: Report on 2012 Opinions and Lifestyle Survey
- Beyond 2011 Programme Public Attitudes Research: Report on 2013 Opinions and Lifestyle Survey
- Beyond 2011 Programme Public Attitudes Research: Report on 2013 Cognitive Testing by Independent Social Research Limited

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## 1 Executive Summary

In July 2012 Data Collection Methodology (DCMCS) were commissioned to undertake a second wave of qualitative research on behalf of the Beyond 2011 team looking at public attitudes towards data sharing. Three focus groups were conducted across England and Wales with 22 respondents taking part in the exercise.

### Key findings

- Respondents failed to show any understanding when asked what they understood the term administrative data to mean. Rather than addressing the term directly the majority of respondents referred to what they imagined administrative data might encompass. Respondents were noted as using the terms demographic information and administrative data interchangeably and showed no awareness that they were separate concepts. Other respondents suggested that the term was vague whilst the minority of respondents claimed the term meant nothing to them at all.
- There was a great deal more uncertainty when individuals were asked what they understood the term operational data to mean. One respondent suggested that criminal records were operational data whilst another suggested that the term referred to the way that the information was stored. One respondent said that operational data referred to the units of information being used for research, however, the majority reported that they were unable to relate to the term at all. Few respondents over the three focus groups were able to show an understanding of the term and feedback was minimal.
- There was slightly greater clarity with the term statistical data with a larger proportion of the respondents stating that statistical data is data used for analytical purposes. It was also suggested that this data was more likely to be anonymised. One respondent was unsure about the difference between administrative and statistical data thinking they amounted to the same thing. As with operational data, few respondents showed any understanding of the term and it was felt that there would need to be greater clarification.
- When asked about data sharing, many respondents stated that they thought data was already shared between government departments.
- In terms of data sharing, respondents reported that they would not have an issue with information being shared between government departments as long as that information was anonymised and if it was for the purpose of benefitting their local area, e.g., improvements in local schools and health facilities.
- There was a distinct lack of trust with regards to the way in which the government stores individual's private information. Examples of where security had been breached meant that levels of trust had decreased.
- Some respondents were concerned that sharing of data could lead to a 'big brother' state. Others however stated that if you have nothing to hide then you have nothing to be afraid of.
- When asked what types of information might be shared, the majority of respondents reported that basic demographic information would be the most likely thing to be shared.

Some did state that other information such as members within a household, income or in one case, anything you put on a form could be distributed.

- There were levels of acceptability in terms of what information was considered appropriate to share. The majority of individuals were happy to share their basic demographic information, however there was a broad agreement that it would not be appropriate to share health and income related information.
- Respondents felt that they should be informed about what information was being shared, who it was being shared with and why. Controlling the release of private information was a topic which recurred at a variety of points during discussions held across all three groups.
- Trust was also a major issue in terms of data sharing. Respondents were concerned that their personal information could potentially be sold on to external organisations and agencies without their consent and were concerned about who their information could end up with.
- Social media was also noted as having an impact on the concept of data sharing whereby several individuals noted that more personal information was available on networking sites now than ever so controlling who accesses personal information has become more and more difficult.
- The one benefit that respondents stated private industry held over government departments was the inclusion of an opt-out option where personal information is involved. One respondent stated that you had to assume that where information was held with government departments' privacy rules applied.
- There was a wide level of understanding with the term data linkage. It was widely agreed that the term referred to the process whereby an individual's information was grouped together using a common characteristic.
- One respondent did wonder whether linkage was even possible, given the different government departments were likely to use different data platforms.
- Several respondents saw data linking as being a potential Pandora's box. It was suggested that linking an individual's information would lead to government departments being able to monitor people more closely.
- Other respondents did suggest that there were positive aspects to the process stating that it would be a way to ensure political issues such as illegal immigrants are resolved.
- Respondents were predominantly of the opinion that there wasn't so much of an issue with government departments linking information as there was with corporate bodies sharing data. The latter was seen as a money making scheme which would not benefit the respondents.
- There were mixed views when respondents were asked what they thought about the idea of statistics database. When asked what it meant, one respondent said it referred to social status. The majority felt it would contain demographic information. However, other information was proposed such as social aspect e.g., diet, social life.

- Depth of detail was an important factor with many respondents being concerned about the level of personal information that might be stored. Many respondents stated they would want more information on what was being held in such a database. Information regarding health was a particular worry.
- There was concern that information that was held on the system might be out of date or inaccurate and that this might impact upon them negatively, specifically in instances where other government departments accessed their details. One example provided was out of date or incorrect criminal records which could impact upon career options.
- The notion of control was something that came up in all three groups. Respondents suggested that if they were somehow able to verify the information that was held against their name they would be happier.
- Security was also seen as an issue. The notion of a third party being employed was raised as a potential problem. Hackers and inadvertent leaks of information were also raised as issues.
- The idea of a database was seen as being a positive thing were it to be used for the benefit of the local community.
- The risk of it being used as a method of social control was also raised by several respondents.
- Respondents reported that they would be less concerned if the data that was held was anonymised, however, the point was countered by other respondents highlighting that very little effort would be required to identify individuals in a database.
- There was concern that the information the government held would be passed on to private industry for financial gain.
- Respondents showed clear understanding of the terms anonymisation and confidentiality. There was no negative feedback regarding the use of either term.
- When asked about their views on sharing information between different types of organisations respondents were very clear on what they considered to be acceptable.
- Individuals were against the idea of their health information being shared unless prior consent was obtained and it was anonymised.
- They were more responsive to the idea of the council or the authorities as they believed the information held was less personal.
- After recent media speculation individuals within two groups stated that they thought the government was already using information from commercial organisations such as supermarkets and energy suppliers. Most individuals were not comfortable with the idea of their personal information being used in that way, predominantly because they argued that the corporate industries involved had a vested interest.
- Respondents were more negative when asked about the notion that information be obtained from banks and credit reference agencies, stating that they would not be able to trust the companies involved.

- Individuals stated that they would want to know who was contributing to the database and who was able to access it.
- When asked how respondents felt about their information from a year ago being collated the one area that was of concern was income, although this was only highlighted by a couple of respondents.
- Members of all three groups voiced their concern that the data might be used in a manner that might be considered discriminatory, e.g. when assessing candidates for local housing.
- Quality of information stored was an issue and the need to update it to ensure accuracy is maintained.
- Anonymity was again highlighted with several respondents saying they would be more comfortable if they could not be identified. An additional opt-out clause was highlighted.
- When asked about the possibility of a register the majority of respondents said they were comfortable with the idea, mostly because all the information that would be stored in the register was available through other sources.
- One potential benefit of such a register was a possible increase in the levels of accuracy with regards to the information held were data to be obtained through government sources.
- When asked what respondents would be happy to see included in the register characteristics such as name, address, date of birth, household information, national insurance number, national health number, previous addresses, sexual orientation and religion were all highlighted as being information that they would be happy to share.
- When asked whether individuals would be happy with the idea of a 'snapshot' being created on a given date from a variety of sources (akin to the census) the majority of respondents were happy with the idea, particularly if the same rules regarding disclosivity were applied.
- Respondents felt that the creation of a database using this method would lead to a reduction in burden upon themselves, although several individuals stated that having to fill a form in once every ten years was not a burden.
- Accuracy was again raised as an issue and it was proposed by a couple of respondents that there would have to be a way for individuals to be able to verify that their personal information was correct.
- The opinions that respondents held were linked to media reports rather than their own experiences in many instances. One respondent bought newspaper clippings with them to discuss the issue of data sharing pointing out instances where they systems in place had failed to work. Failures included departments failing to protect personal information sufficiently and instances where information was being sold to private companies.

## 2 Introduction

Every ten years, for over 200 years, each household in England and Wales has been required to respond to the census. The statistics it provides underpin the allocation of billions of pounds of public spending each year and are fundamental to decision making, policy formulation and outcome monitoring across government, the commercial sector and the wider community. The Beyond 2011 Programme in the Office for National Statistics has reviewed requirements for population statistics and how they might best be met in future. Improvements in technology and in government data sources offer opportunities to either modernise the existing census process, or to develop an alternative census method that re-uses existing data already held within government. A number of approaches were considered, and each approach was assessed against a published set of evaluation criteria including statistical quality, cost, technical and legal feasibility, public acceptability and public burden. After this work and a consultation carried out in autumn 2013, the following recommendation was made:

- once a decade, like that conducted in 2011, but primarily online supplemented by use of administrative and survey data.

Public acceptability was identified as an important issue when considering making increased use of individuals' personal administrative data within the population statistics system. In April 2009, the Beyond 2011 team used the Office for National Statistics' (ONS) Opinions and Lifestyle Survey to investigate public attitudes towards data sharing and in February 2010 this was followed up by qualitative focus group research:-

- Data Sharing between Government Departments: Report on Public Acceptability (November 2009)
- Beyond 2011 Programme Public Attitudes Research: Report on 2010 Focus Group Research

Leading on from this, in July 2012 Data Collection Methodology (DCMCS) were commissioned to undertake a second wave of qualitative testing looking at public attitudes towards data sharing. The aim of the focus groups was to gauge public opinion on the use of administrative data, the creation of a social statistics database and the creation of a social register. The report will detail the findings of the focus groups with a view to informing future strategies for communicating with the general public.

## 3 Methodology

### 3.1 Sample

#### 3.1.1 Composition

Three focus groups were conducted for this research, involving a total of 30 participants. Ten respondents were invited along to each workshop in order to account for the possibility non-attendance. Each respondent received £40 to cover any transportation costs incurred as well as to reimburse them for their time. Previous research had shown that older females who had lower educational attainment had been more wary of government and the data sharing strategies proposed so it was agreed that the main focus would be to ensure a greater proportion of women aged 36 and over and whose qualifications did not exceed 'A' Level or equivalent. The remainder of the attendees were a mix of age, sex and educational attainment. Participants with a range of ethnicities were represented in the groups, including those who identified as White British, Black African and White Non-British. The sample for each group was divided as shown below. Please note that the figures provided in brackets refer to the target numbers for each group.

- Males 18-35 - Educated to 'A' Level standard or higher (3)
- Females 18-35 - Educated to 'A' Level standard or higher (2)
- Males 36-55 - educational attainment grade D GCSE or below or have no formal qualifications (2)
- Females 36-55 - educational attainment grade D GCSE or below or have no formal qualifications (3)

No geographic restrictions were placed on this wave of testing as this was not considered to be significant in terms of the results obtained in the last phase of testing. However, it was important that devolved governments be considered during the consultation process so it was determined that one focus group should be held in Wales. The focus groups therefore took place in three locations; Cardiff, London and Fareham.

#### 3.1.2 Selection

Purposive sampling techniques were employed during the recruitment period for this study. The sample is designed to pick a small number of cases that will give the most information on the topic of interest (Teddlie and Yu, 2007). Respondents are identified from appropriate sub-populations taking into account characteristics of interest (Willis, 1999). The goal is not to generalise to the population, but to gain insight into 'phenomenon, individuals or events' (Onwuegbuzie and Collins, 2007).

Participants with the desired characteristics were identified in the ONS respondent register. This is a register of respondents who have taken part in the ONS Opinions Survey and have given their permission to be contacted again to take part in other research. Recruitment using the respondent register was augmented by other recruitment techniques, such as using flyers or advertisements.

### 3.2 Research technique and procedure

DCMCS performed this research using a series of focus groups. Focus groups allow participants to interact with each other; they can discuss their own thoughts and opinions, and also consider those of others. Listening to the experience of others in the group allows participants to reconsider and refine their own views, further stimulating the discussion. As Ritchie and Lewis (2003) explain, 'as



the discussion progresses (backwards and forwards, round and round the group), individual response becomes sharpened and refined, and moves to a deeper and more considered level’.

Each focus group was conducted using a script which provides the basis for discussion during session. This not only ensured that relevant issues identified in advance were covered but also allowed discussion of other related issues that arose. The use of a script also provides consistency where more than one moderator is contributing to the work, as was the case for this research. The protocol covered three main areas; awareness of data sharing, preferences for data sharing, and views on a single population database. The protocol used for the focus groups can be found in Appendix A.

### 3.3 Analysis

After completion of each focus group, a written summary was prepared by the assistant moderator. These summaries were based on the assistant moderator’s notes that were taken during the focus group, and were shared with the groups at the end of each session to ensure that the main messages were captured. The recordings were then transcribed by an external transcription company.

A thematic approach was used for the analysis which was carried out jointly by DCMCS members. The transcriptions formed the basis for the analysis which commenced with a stage of familiarisation with the data. This familiarisation involved careful reading and re-reading of the transcriptions, followed by organisation of the text into themes, ideas, concepts, anomalies, similarities or inconsistencies. These findings are drawn together into the results presented later in this report. Verbatim statements by participants are presented in italics.

It should be noted that qualitative analysis does not allow the researcher to draw quantitative conclusions so statistical reliability cannot be inferred from the results obtained. Additionally, whilst the respondents are representative of the sampling criteria one cannot discount the possibility that some responses are unique and therefore cannot be extrapolated to the wider population. That said, where opinions recur through the data it is possible to suggest that the responses obtained are more likely to be representative of the wider population than not.

### 3.4 Confidentiality and ethical issues

DCMCS followed the Royal Statistical Society (RSS) Code of Conduct and principles set out in the UK Statistics Authority Code of Practice while carrying out this research. In line with ethical guidelines the participants were informed at the beginning of each focus group about the purpose of the focus groups; that their participation was voluntary; that they could withdraw from the study at any time; and that the information they provided would be kept confidential to the research team, and reported thematically along with information provided by other participants. Additional measures such as encrypting files, separation of personal data and use of secure storage were also employed to protect the confidentiality of the participants and the data.

## 4 Understanding of the main concepts behind data sharing

One of the main purposes of this research was to investigate whether respondents understood the terminology used in the public consultations on the Beyond 2011 project. Failure to understand the terminology is likely to have a number of negative impact on the feedback received in a variety of ways: respondents may be intimidated by their lack of understanding and may opt not to contribute their opinion; respondents may misunderstand the terminology and as a result their feedback may not accurately reflect the purpose of the consultation process; respondents may opt out of participating altogether. The main three terms which were investigated were administrative, operational and statistical data. The feedback from the focus group attendees is outlined below.

### 4.1 Administrative/operational/statistical data use

The first concept respondents were asked to discuss was administrative data. Respondents were asked what they thought the term meant and how they thought it might relate to them. Respondents showed minimal ability in their understanding of the term administrative data. Feedback showed that their were unable to explain the concept, but at the same time some were able to outline the types of information might be incorporated within the field of administrative data. The majority of respondents felt that the term referred to demographic information, although opinion was mixed as to the level of data included.

*“Just basic data, nothing personal, but names, addresses, contact numbers, like local...”*  
Males, 13-35, London.

*“Maybe just the basic stuff; name address, date of birth, that kind of basic information.”*  
Female, 36-55, Cardiff.

*“Is it a nice way of saying personal data, because if you would say personal data it makes people feel a little anxious, what of my personal data are you going to have?”*  
Female, 36-55, Fareham.

Other participants were unable to provide a definition and stated that the term was vague and required further definition. A minority of respondents claimed the term meant nothing to them at all, whilst one suggested that it was to do with the way that the information was handled and who had access to it rather than it being about a specific type of data.

*“It’s something that I can’t figure out now. I’ve got to think”*  
Female, 36-55, London

*“Yeah, the term doesn’t actually mean a great deal to me.”*  
Male, 18-35, Cardiff

*“For me the keyword is administrative so it makes me think that it’s data which can only be accessed by a certain group of people in an organisation.”*  
Male, 18-35, Cardiff

The mixed reaction to the term lead to the same respondents being suspicious of what might be included with such a concept and the potential implications for them. Respondents said they would require further clarification before they could fully understand and therefore be able to make informed decisions on the use of administrative data. It was stated that factors such as what’s going to happen to it, how it’s going be stored and what is it being used for were all important when considering how to reach an informed opinion.

*“Everyone knows what administrative is and everyone knows what data is, but put the two together and there’s no definition that I’m aware of; it could cover a multitude of sins and that makes me suspicious.”*

*Male, 36-55, Fareham.*

There was a great deal more uncertainty when individuals were asked what they understood the term operational data to mean. A few respondents over the three focus groups attempted to show an understanding of the term and feedback was minimal. Only a couple of individuals were able to propose a definition, both of which were inaccurate.

*“It’s the data that you’re actually focusing on that you’re collecting, so it’s what you’re going to build up into your stats so to speak.”*

*Male, 18-35, Cardiff.*

*“I guess they can keep a log on you. If you’re moving house obviously your details get changed, children I guess, that can all be flagged up and changed on your data.”*

*Male, 18-35, London.*

Most respondents reported that they were unsure of the term and as a result had no idea what it meant for them as individuals.

*“Haven’t got a clue!”*

*Female, 36-55, Cardiff*

One respondent used the Police and the information they held in order to provide an example of both administrative and operational, stating that operational data was a broad spectrum of information such as criminal records, i.e., only information that the Police would have at their disposal. Administrative data on the other hand would again be held by the police but access would not be limited to the Police.

When respondents were asked about statistical data a larger proportion of the respondents that attended the focus groups were able to provide a definition although it was still not a concept that was familiar to all those that attended. Those that did provide a definition suggested that statistical data was a source of information used for analytical purposes. It was also suggested that this data was more likely to be anonymised.

*“I think the way you compile your stats if you like without sounding too simple. The way you’re going to set out the data you’re collecting.”*

*Female, 18-35, Cardiff*

*“That’s probably your age and the amount of children you’ve got.”*

*Male, 18-35, London*

*“It can be large, you’ve got the national census and things like that but then you’ve also got things like this, that you’re doing now.”*

*Male, 36-55, London*

*“It’s probably anonymous as well; it can’t be linked back to you, the statistical stuff.”*

*Female, 18-35, London*

One respondent was unsure about the difference between administrative and statistical data.

*“Aren’t they [administrative and statistical data] one and the same thing? Just different words for the same concept?”*

*Male, 36-55, Fareham.*

As with operational data, the majority of those that attended the focus groups failed to show any understanding of the term statistical data.

## 4.2 Data sharing

When asked about data sharing, all respondents were confident in defining what the process meant. They were also of the opinion that this was a process that was already routinely undertaken between departments. There was some confusion between government departments sharing information and the practices of corporate organisations where databases of personal information are sold to third parties.

*“Sharing between different offices or different parts of government really.”*

*Female, 35-55, Cardiff.*

*“Pretty much different departments of government actually talking to each other and sharing information.”*

*Male, 18-35, Cardiff.*

*“Well, isn’t it already shared? I mean for instance councils sell information to...”*

*Male, 36-55, Fareham.*

*“You have to opt out, that’s a bit different, but opting out is not quite the same as it is, because they do it unless you opt out. Well, a lot of people don’t know.”*

*Female, 36-55, Fareham.*

In addition to the definitions that they offered respondents were also happy to discuss that they thought the term meant to them in a variety of contexts. Respondents reported that they would not have an issue with information being shared between government departments as long as that information was anonymised and if it was for the purpose of benefitting their local area, e.g., improvements in local schools and health facilities.

*“Statistical data definitely needs to be shared. I think that’s something that, it’s anonymous so it doesn’t harm anyone directly but it’s also beneficial that it needs to be shared.”*

*Male, 18-35, London.*

*“Yeah, if children are being born people need to know school places, and so I guess in the future they can plan so yeah it’s got to be shared between departments.”*

*Male, 36-55, London.*

There was a distinct lack of trust with regards to the way in which the government stores individuals’ private information. Examples where security had been breached meant that levels of trust had decreased.

Some respondents were concerned that sharing of data could lead to a ‘big brother’ state. Others stated that if you have nothing to hide then you have nothing to be afraid of.

*“Where the government is concerned you’ve got to consider the Orwellian situation, you know, the balance between security and liberty. Because if the government was to have databases*

*that were compatible with each other, or integrated into one large one, you could get into an Orwellian situation very easily, where if you coughed, somebody knew..."*

*Male, 36-55, Fareham.*

*"It crosses over into the boundary of privacy so I think that's where personally and people who I've spoken to have an issue with data sharing. It's about privacy... Things like statistical data that's more beneficial... whereas personal data such as your personal life, whatever it be, how you live, what job you might have, things like this you might not want to share."*

*Male, 18-35, London.*

*"There might be certain things that you want to share with one department that you don't want to share with another department."*

*Female, 36-55, Cardiff.*

When asked what types of information might be shared, the majority of respondents reported that basic demographic information would be the most likely thing to be shared. Some did state that other information such as members within a household, income or in one case, anything you put on a form could be distributed. There were levels of acceptability in terms of what information was considered appropriate to share. The majority of individuals were happy to share their basic demographic information, however there was a broad agreement that it would not be appropriate to share health and income related information.

Respondents also felt that they should be informed about what information was being shared, who it was being shared with and why. Controlling the release of private information was a topic which recurred at a variety of points during discussions held across all three groups. There was again a difference between government organisations and private industry. It was felt that sharing between government departments was OK if it were for the greater good, however, respondents were not keen to have their information shared where they considered it to be for financial gain.

*"I think people get more worried about data being shared...when they don't necessarily know what the data is that's being shared, whether it's anonymous data or whether it can be linked back to you."*

*Female, 18-35, London.*

*"It crosses over between maybe government and private, corporate information and how does that get shared because maybe ones beneficial, but ones for profit, so again..."*

*Male, 18-35, London.*

*"It's not a bad thing [if you agree to it], but if you don't agree to it, you should be asked shouldn't you? They really haven't got the right to sell mine [information]"*

*Female, 36-55, Cardiff*

Trust was a major issue in terms of data sharing. Respondents were concerned that their personal information could potentially be sold on to external organisations and agencies without their consent and were concerned about who their information could end up with. Accountability was also considered to be important. It was felt that government departments very rarely admitted liability and that as a result this undermined trust further.

*"I'm very conscious about the data security, it's my job. HMRC lost 25 million records not so long ago, my daughter was a child then. She's now 20 and I'm waiting for her, something to happen to her credit profile because somebody out there has got all her data."*

*Female, 36-55, Fareham.*

*"Security is also very important. I mean the government's record of loss of laptops and computer discs is dreadful."*

*Male, 36-55, Fareham.*

*"It's ensuring that there is some kind of, what's the word I'm looking for, that they are answerable to people and that we'd never see if they're audited."*

*Male, 36-55, London.*

Social media was also noted as having an impact on the concept of data sharing. Several individuals noted that more personal information was available on networking sites now than ever before so controlling who accesses personal information has become more and more difficult.

*"Nowadays, with Facebook and Twitter and everything, people are so easy, they give their information to the wide world, so you know, you're giving that information. Anyone can pick it up."*

*Female, 18-35, Fareham.*

In terms of information being shared, the one benefit that respondents stated private industry held over government departments was the inclusion of an opt-in/out option where personal information is involved. One respondent stated that you had to assume that where information was held with government departments privacy rules applied. As a result were that rule to change it would seem appropriate that an opt out option be offered as it is in private industry.

*"I think I would like more of an opt-in option because it's easier to be given the choice than to be forced in any way..."*

*Female, 18-35, London.*

*"I'd...like to be given the choice whether they share that information or not..."*

*Male, 36-55, Fareham.*

### **4.3 Data linking**

There was a wide level of understanding of the term data linkage. It was widely agreed that the term referred to the process whereby an individual's information was grouped together using a common characteristic. However, respondent's perceptions of the process were such that they often reported that the information would be used as more of a surveillance measure rather than for the research purposes it is actually intended.

*"Well, with the two that you gave us there, so NHS and DWP, they're both going to be holding records on you so it's how that data ties together. So for instance, so DWP they'd have your national insurance payments, they'd keep track of that."*

*Male, 18-35, Cardiff.*

One respondent did wonder whether linkage was even possible, given the different government departments were likely to use different data platforms. It was assumed that different government bodies used different systems. This was considered detrimental where data could not be shared efficiently but at the same time beneficial in as much as it would reduce the risk of universal hacking were different packages to be used in different departments.

*“Where we’ve got separate working platforms it’s much harder for a hacker to infiltrate that personal information through all the doors he’s got to get through where one door and he gets full access to everybody’s information, date of birth and he robs you of all your identity.”*

*Male, 36-55, Cardiff*

Several respondents saw data linking as being a potential Pandora’s box. It was suggested that linking an individual’s information would lead to government departments being able to monitor people more closely.

*“See what about the Health Service, what about the data they’ve got, I mean, that could be quite serious if another government department got hold of something, you know, say mental health or something. It’s supposed to be confidential but they got hold of it... you know, it could be used against you by another department. I mean I don’t trust any of them quite frankly.”*

*Male, 36-65, Fareham.*

Other respondents did suggest that there were positive aspects to the process stating that it would be a way to ensure political issues such as illegal immigrants are resolved.

Respondents were predominantly of the opinion that there wasn’t so much of an issue with government departments linking information as there was with corporate bodies sharing data. The latter was seen as a money making scheme which would not benefit the respondents.

*“It seems to be there’s a corporate money making opportunity within it and that’s when it starts to scare me. Whereas government’s different organisations, that doesn’t worry me as much.”*

*Female, 18-35, London.*

Respondents also saw there being a positive side to information linking, particularly where individuals were breaking the law or where the outcome was beneficial to the individual.

*“But if people are claiming benefits and shouldn’t be, and earnings, I’m like, well absolutely, let’s stop this, because that money would free up and sort out our NHS.”*

*Female, 36-55, Fareham.*

*“So my GP does not have a general overview of my condition because....my accident happened in West Wales...and the information has not been linked to my record which I think is a bit wrong really. There should be a standard platform.”*

*Male, 36-55, Cardiff.*

#### 4.4 Social statistics database

There were mixed views when respondents were asked what they thought about the idea of statistics database. When asked what it meant, one respondent said it referred to social status. When asked what participants thought might be included in the database, respondents suggested that basic demographic information would need to be held on the system, e.g. name, address, sex and date of birth. The provision of this information was thought to be acceptable. There was some uncertainty as to what else might be added to the database. There was variation in the type of information that participants were comfortable with, for example, it was proposed that other information such as social aspect e.g., diet, social life might be included. Many respondents stated they would want more information on what was being held in such a database. Information regarding health was a particular worry. Participants also mentioned data that might be deemed more sensitive such as criminal records and income as information that they would not want to be distributed between government departments.

One reason for this concern was that there was the risk that the information held on the system might be out of date or inaccurate and that this might impact upon them negatively, specifically in instances where other government departments accessed their details. One example provided was out of date or incorrect criminal records which could impact upon career options.

The notion of control was something that came up in all three groups. Respondents suggested that if they were somehow able to verify the information that was held against their name they would be happier.

*“Centralised and owned by who, or who’s in control of it I guess, yes, that’s the question, and then maybe you’re going, oh, what do they want that information for and then you can make more of an opinion on it.”*

*Male, 18-35, London.*

*“And just who else can access it? I would want to know specifically.”*

*Female, 18-35, London*

Security was also seen as an issue. The notion of a third party being employed was raised as a potential problem. Hackers and inadvertent leaks of information were also raised as issues.

*“Is it going to be outsourced to a private company, like the census, because that’s cheaper? And do you trust the company?”*

*Male, 18-35, London.*

*“The only worry I have is who could get their hands on that database, but I guess they can get hold of it now if they want to. People forage in bins to get personal details...”*

*Male, 18-35, Fareham.*

The idea of a database was seen as being a positive thing were it to be used for the benefit of the local community, so it was accepted in much the same way that the idea of data sharing was. The risk of it being used as a method of social control however was also raised by several respondents.

*“I can see the pluses though...I saw that there’s 275,000 migrants that haven’t left the country. Well if they ran that database and got that information...ran it against the benefits database, there could be a big government saving...”*



*Male, 36-55, Fareham.*

*"I think if it's used to provide statistical information that's not so bad, or isn't bad. I don't know, say it was all linked together and there was a huge DNA database, those people that have a gene for Alzheimer's and well let's identify those people and in some way control them, that wouldn't be a good thing. That's not so far away."*

*Male, 36-55, Fareham.*

Respondents reported that they would be less concerned if the data that was held was anonymised, however, the point was countered by other respondents highlighting that very little effort would be required to identify individuals in a database.

*"...you've only got to link two surveys together and you've got the information there. And if somebody was Tsarist enough to do that, they could, so in that sense I can't see how you could maintain and ensure that it remains anonymous."*

*Male, 18-35, Fareham.*

There was also concern that the information the government held would be passed on to private industry for financial gain. Again, it would seem that respondents were unable to distinguish between corporate industry selling and purchasing consumer information and the use of data for research purposes by government departments.

#### **4.5 Confidentiality and anonymisation**

Respondents showed clear understanding of the terms anonymisation and confidentiality. The definitions that were provided within each of the groups were highly similar. There was no negative feedback regarding the use of either term.

## 5 Views towards sharing information with different types of organisations

One possible method for collecting information in the future is to utilise data that is already available via third parties. Focus group attendees were asked how they felt about a variety of sources and whether they felt they were appropriate candidates for data sharing. They were also asked how they felt about ONS accessing information from the same sources. When respondents were asked about their views on ONS obtaining information from different types of organisations respondents were very clear on what they considered to be acceptable. The following question was broken down into three separate categories: public authorities, commercial organisations and financial organisations.

### 5.1 Public authorities

Focus group members were not averse to the idea of ONS having access to data held by councils or public authorities as they believed the information held was less personal. There was also a belief that the information held by local councils was mostly at a lower level of disclosure and therefore posed less of a threat than for example information held about an individual by HMRC or by banks or other private commercial organisations. It was assumed by many of the respondents that information held by local authorities would most likely to be used to inform decision making in the local community. This practice was deemed acceptable as it did not require personal information and would benefit the community as a whole.

There was also a line between local government feeding into a database that other government departments have access to and feeding into a database which is accessible by the corporate community.

*“I don’t mind if it’s the council or the authorities they get some of my information but I wouldn’t like to give my information to other companies without any understanding or reason...”*

*Female, 36-55, London.*

*“If it’s within government, whether local or national, I would agree with that, but again private companies, I might not.”*

*Male, London, 18-35.*

### 5.2 Commercial organisations

After recent media speculation where it was suggested that organisations such as ONS were already in the process of using information obtained from supermarket loyalty cards, individuals were already of the opinion that information from commercial organisations such as supermarkets and energy suppliers was being used for research purposes. Most individuals were not comfortable with the idea of their personal information being used in that way, predominantly because they argued that the corporate industries involved had a vested interest. Respondents perceived the process of using commercial information as being a potential ‘tracking device’ rather than it being a source of statistical information. Others could not see the rationale.

*“I really don’t see what the benefit would be to anyone, knowing what I purchase at [name of large retailer], other than to [name of large retailer]. I guess gas and electricity suppliers could supply certain information about your usage and stuff but surely they could provide that without an anonymous form? I wouldn’t really see what the point was.”*

*Female, 18-35, London.*

*“I think it’s very difficult to stop actually. I think because of the way consumerism is going, whether you volunteer the information with your consent or without it, they still keep it and they still market it.”*

*Male, 36-55, Cardiff.*

### 5.3 Financial organisations

Respondents were more negative when asked about the notion that information be obtained from banks and credit reference agencies, stating that they would not be able to trust the companies involved. This mainly stems from recent banking crises, the effect of which was re-iterated between all three focus groups.

Individuals stated that they would want to know who was contributing to the database and who was able to access it. They were also of the opinion that information collected through financial organisations would have the potential to be biased. In the same way respondents felt that commercial organisations would have their own agenda. This was also true of financial organisations.

*“It would have been a good idea a few years ago but especially now, but yeah they could offer you the best deals knowing, if they know your circumstances. Yeah, it’s whether you trust them anymore.”*

*Male, 18-35, London*

*“I’d like to be informed first.”*

*Female, 36-55, London*

One respondent reported their own negative experiences with reference to the student loan system and the fact that HMRC had continued to extract money from his salary even after his student loan had been paid off. This information led the respondent to reach the conclusion that data quality was not always as good as it could be and that therefore if data such as that obtained by organisations such as HMRC were to be used for research purposes quality checks would have to be in place in order to ensure that the information being used was factually correct. The fact that third party sources such as financial institutions may have incorrect information was also raised by a member of a second focus group.

*“I’d rather it came from me as a source because the third parties may have it wrong. They may have me as 21 when I’m 19 or stuff like that”*

*Male, 18-35, Cardiff.*

The opinions provided above led many respondents within the groups to suggest that there should be a way of verifying information. It was suggested that this would be an opportunity for the respondent to be made aware of what data was being used, how it was being used and who would have access to it, as well as providing the respondent with an opportunity to evaluate the accuracy of the information to be shared.

### 5.4 Provision of information from one year ago

The last question in this section wanted to gauge how respondents felt about certain types of information about themselves from a year ago being placed into a larger database. The items being discussed concerned information such as health information, income information and as

information on housing and address. Given that these areas were considered to be more sensitive than general demographic information earlier in all three groups it was interesting to see how respondents felt about this information being released one year on. A minority of respondents within each focus group reported feeling uneasy with more personal data being shared for wider consumption. However, others appeared to be comfortable with the concept.

*“What would they want it for? Why would they want it? I’d want it to be a damn good reason why they needed this information to want to share it.”*

*Female, 36-55, Cardiff.*

*“If you’ve got nothing to hide I guess that’s fine. It’s only going to improve the local area; they can plan like we said, before they can plan for the future, the amount of hospital places and things like that.”*

*Male, 18-35, London.*

When asked how respondents felt about their information from a year ago being collated the one area that was of particular concern was income, although this was only highlighted by a couple of respondents.

*“Not the income I don’t think. I don’t think that’s got anything to do with anyone in particular.”*

*Male, 36-55, Fareham*

Members of all three groups voiced their concern that the data might be used in a manner that might be considered discriminatory, e.g. when assessing candidates for local housing.

*“If for example you’ve got health information linked to that you could get a situation where somebody’s applied for a house and they’re looking at the data and they go what if we look at health and they’re equal in every other way is that going to be the deciding factor in whether someone gets a home or not. Health information fine for statistics, do I want someone making a decision totally unrelated and having that information in front of them?”*

*Female, 18-35, London.*

*“...discrimination based on a piece of data that actually they didn’t need in the first place but once they’ve seen it, they can’t un-see it”*

*Male, 18-35, London.*

The accuracy of the information and the need to update it to ensure accuracy is maintained was an issue. This also raised the question of who would be responsible for ensuring information that was to be shared was up to date. Respondents were unsure whether they thought it would be their responsibility to maintain the information on the system about them or whether this should be done through a checking exercise to be completed by local authorities.

*“I think as long as it’s updated regularly so the information could change...I work for a local authority and we deal in electoral registration and in order to get credit you have to be on the register...people come in and they’re on the electoral register but credit companies say they’re not. So they’re not updating their systems and it affects people in a negative way...”*

*Female, 18-35, London.*

Anonymity was again highlighted with several respondents saying they would be more comfortable if they could not be identified. There was also concern that there may be certain organisations or authorities that an individual might not want to share their information with. An additional opt-out clause was highlighted.

*“...you might not want certain organisations to find you. You might owe them money or whatever, you might just want to avoid them, or a parking ticket or whatever it is...”*

*Male, 18-35, London.*

*“Yeah, it’s something to think about but at the same time it’s just about privacy and do I want my information to be shared?”*

*Female, 18-35, London.*

Other participants were slightly more accepting of the notion of this level of information being shared as long as guidelines were put in place.

*“With suitable protocols and security, with an independent agency that will depersonalise it I wouldn’t have a problem. I think once you’ve told the information to some government department, to a degree you’ve lost control of that anyway.”*

*Male, 36-55, Fareham.*

## 6 Public perception of the creation of a register

### 6.1 Level of support

When asked about the possibility of a population register the majority of respondents said they were comfortable with the idea, mostly because all the information that would be stored in the register was thought to be available through other sources. Again it was argued that the use of a datastore such as a register could prove to be beneficial for the larger community. The distinction between data obtained for research purposes and data to be used for marketing purposes was also raised.

*“Because it’s only going to help you and your family in the future. There’s nothing I can see that’s not beneficial.”*

*Male, 18-35, London.*

*“It’s nothing they can’t get access to anyway. It’s just basic information isn’t it really? I wouldn’t have a problem with that.”*

*Male, 36-55, Cardiff.*

*“So going back to everything, something that can benefit so my religious, sexual, age, orientation, the size of my family, where I live, not me personally but where someone would live, those things can be beneficial, discrimination and things like this are happening, those things are beneficial. But when it’s personal information solely that is linked to me and that has been used to either contact me or being used for financial gain or things like this then I wouldn’t agree to that, but them collecting my date of birth that may not be necessary, if it’s linked to me and my address, linked to me collecting that from other sources.”*

*Male, 18-35, London.*

*“I think it’s basic information which you have already, to be honest it’s not that difficult to get name and address, date of birth; that’s quite obtainable and so on. It depends how much information it was but if it’s just that basic information then I think there’s no harm in sharing that.”*

*Female, 18-35, London.*

One respondent said that unless more justification was provided they would argue against the idea of a register being created.

*“The anarchist in me says why should I give you my information anyway, why should I tell you? But you were saying if it’s promoting something for the good of your country tell us about it, sell it to me first because I’m sitting here thinking I don’t want to tell you anything, why should I?”*

*Male, 36-55, Fareham.*

There was mixed feedback with regards to perceived levels of accuracy in the creation of a register. Some respondents saw the register as being beneficial suggesting that could possibly be an increase in accuracy. It was argued that obtaining information from government sources meant there was a greater likelihood that the data used would contain fewer errors.

*“If we’ve given our information to government departments anyway it should be correct so if they’re gathering it from, not from outside companies but from other government departments where you’ve actually given your information to them, then I personally wouldn’t have a problem with that because it should be information I’ve given them anyway, which should be correct.”*

*Female, 18-35, Cardiff*

Other respondents felt that the opposite was the case and were concerned that errors held within the data might have wider implications.

*“How you would know what was on it and if something is incorrect, how would you get it changed, because like you said earlier if there is a mistake somewhere, sometimes it can take forever to get someone to change that on their database and then you don’t know how many other places that wrong bit of information has gone. And if it’s something like your credit status or something like that, if we’re talking about private companies, then that can have a real impact, so if you have a bit of information on that database that’s wrong, would you know and how would you rectify it?”*

*Female, 18-35, London.*

This then brought respondents back to the issue of being able to verify levels of accuracy in the information held.

*“It would be good if you, maybe using your NI number could actually access and see what was on the register about yourself and then you can then inform whoever needs to know if it is wrong.”*

*Male, 36-55, London*

*“Similarly you’ve got that when you look at a credit rating. You can apply and very quickly see what information is there. Secondly who can I contact if there is wrong information or if you want some information removed, is there an option to have that information removed if possible.”*

*Male, 18-35, London.*

## **6.2 What information is appropriate**

When asked what respondents would be happy to see included in the register characteristics such as name, address, list of previous addresses, date of birth, household information, national insurance number, national health number, previous addresses, sexual orientation and religion were all highlighted as being information that they would be happy to share. With regards to basic demographic information it was widely felt that this information was available from a variety of sources anyway and so there was little point in a register being created which contained the same. When considering more personal information respondents were keen to emphasise the importance of confidentiality. In some instances, for example where information such as national health number was provided, respondents also said they would want to know the rationale behind such information being shared. A few respondents also suggested the inclusion of nationality as a source of information.

*“For the most part I’d be okay with that. As you said it’s going to be kept under strict confidentiality rules. Yeah it’d be interesting to know what sort of procedures would be in place when that was breached, so yeah, is it a slap on the wrist or is it booted out the door.”*

*Male, 36-55, Cardiff.*

*“I think it would depend on why you wanted the NHS number for example. If it’s just to have a database where for example if you turn up at A&E somewhere and you don’t know your NHS number and they could call upon that database to get your NHS number quickly, which isn’t always the case if you’re not in your local hospital or somewhere where there’s records of you, then fair enough if that’s what it’s going to be used for. But if it’s going to be used to go, okay this is their NHS number, here’s medical information about them; I think that’s different. So again it’s why it’s there and ultimately be used, whether you would know if the record has been accessed in some way.”*

*Female, 16-35, London.*

*“I think it’s important to put the nationality of the people because that’s the way you find out how many people are from different countries. I think it’s very important because that’s the way, if there’s something happening and they’re looking for an Italian person it’s important to know he’s Italian the person isn’t it or he’s Spanish or English and I think that should be put in anyway without any questions because if you’ve got nothing to hide then you shouldn’t worry.”*

*Female, 36-55, London.*

One respondent expressed concern over the idea that there would initially be a basic register that contained only demographic information with a view to that being extended. Whilst the initial suggestion was acceptable the respondent was suspicious of the implications of the register expanding.

*“If that’s all they’re asking. The thing you said was they may add other things later. That’s the problem. They already know that, the first bit. What are they going to ask later or are they going to add later?”*

*Female, 36-55, Cardiff.*

*“I just think it’s the tip of the iceberg.”*

*Female, 36-55, Fareham.*

This concern was echoed by another attendee at the same focus group who suggested that once the register was in place it would be difficult to argue against new information being added to it. The latter concern would suggest that educational programmes such as those already outlined above would need to be implemented to ensure that the public are made aware of changes in advance and that reassurance is offered where necessary.

### **6.3 Security concerns about the register**

The issue of security was raised when respondents were discussing the creation of a hypothetical register with many participants referring back to security lapses that had been mentioned earlier in the focus groups. The idea that individuals might be able to opt out was proposed in two of the focus groups.



*“I think it’s a good thing, I think it can be a good thing, if created rightly that would help the government manage the country better just thinking about things like immigration status and work employment and who’s receiving benefits and things like that, along with statistical data which I think would probably already be very beneficial. I just think there are dangers that we need to avoid or would like to avoid, especially when outsourcing to brown companies which seem to be, the latest craze anyway, which I’d like to avoid.”*

*Male, 18-35, London.*

#### **6.4 Comparisons between the proposed register and the census**

Given the title of focus groups it was not surprising that conversation eventually turned to the census and what might happen now that the 2011 Census had been completed. Respondents were keen to know whether any of the ideas that had been put forward were going to be actioned in the future as a way of replacing the census. All attendees were informed that the consultation process was still in its early stages and that the feedback that was provided during the focus groups would feed into the research process. This did lead on to further discussion however about the census, the costs of operating such as large project as well as factors such as respondent burden and coverage issues.

One observation with two of the groups was that respondents reported themselves as being fairly comfortable with the idea of data being combined to create a ‘snapshot’ in much the same way that the census is collected. Respondents were given a scenario whereby administrative data was collated from third parties on one day. It was suggested that the data would be compiled into one dataset which would be stored under the same regulations as the census is currently held. Once the data had been collated into a snapshot form the original sources of the information would be deleted so that apart from the newly formed ‘census’ no other information would be stored by ONS.

*“Well it certainly sounds more acceptable. If the information is there anyway and it means that we don’t, we’re not going to get this visit and then this huge form to fill in, because you can gather the information in any case, I mean that to me seems fairly acceptable. Just a snapshot one day of what, you know, and you’re going to do it anyway aren’t you whatever, whichever method you’re going to use you’re going to carry on collecting all this information. And the fact that it’s already there anyway, you might just as well do that. I don’t know, I’d have to think about it a bit more but I mean it seems to me at the moment...why haven’t they done it before?”*

*Female, 36-55, Fareham.*

*“I haven’t really got a problem with it. Your information’s already out there anyway.”*

*Female, 16-35, Cardiff.*

*“Well the 100 year rule itself is generally not a problem because most people are then dead! ...So yeah I haven’t got a problem with that being shared.”*

*Male, 36-55, Cardiff.*

*“If it meant saving money that they could put into schools and hospitals then I’d be all for it.”*

*Female, 36-55, Cardiff.*

Some respondents didn't consider the filling in of the census to be a burden given that individuals are only required to fill it in once every ten years. It was suggested that perhaps people were more content to fill it in at the moment because the census had only been run in the previous 12 months and so it was going to be a while before it came round again. Others suggested that there was at present a 'Jubilee effect', whereby everyone was proud to be British and filling in the census came along with that sense of identity.

It was suggested that promoting the benefits of the census would be a way to encourage completion with respondents suggesting that they had no idea as to how the census had benefitted them individually.

*"It would be good to know what the census, how it's helped us as a nation, maybe we need to publicise that a little bit more to understand why we do have to do it."*

*Female, 18-35, Fareham.*

Respondents suggested that there was a variety of ways in which the data could be verified. One respondent suggested an internet-based system where individuals could be given a unique code for their household which they could access and then edit or verify the information attached to their address as appropriate. Another respondent suggested that paperwork similar to that distributed for the electoral roll be used although there were security concerns regarding the level of data that would be despatched and the fact that postal delivery might not be the most secure method of transferring the information.

The transient nature of society was another issue that was raised:

*"The problem is we move a lot don't we and students even move more than general, so what happens there, what's going to happen, you know, the same thing's going to happen. You'll still have to somehow find out where these people are at that given day and time."*

*Female, 36-55, Cardiff.*

*"It'll also be the issue of disabled and elderly people who are maybe housebound and not computer literate, not being able to access a computer in the library."*

*Female, 36-55, Cardiff*

## 7 Conclusions

This report has illustrated that the terms administrative, operational and statistical data require clearly defining and further testing to ensure that respondents are fully able to understand the concepts being discussed. There is a risk that using the phrases as tested will have a negative impact on the public's perception of the overall Beyond 2011 project. One possibility is to offer further guidance where these terms are employed or to provide examples of the types of data that the terms refer to.

In all three focus groups it was apparent that some of the attendees were suspicious of the concepts that were presented to them. Some of this suspicion was based on previous media coverage of security breaches. Respondents were also guarded as a result of the impact that corporate industry has on their perception of privacy, particularly surrounding the practice of information being sold on to third parties. In terms of data sharing it would seem that a lot of the negative reaction to the concept stems from the fact that respondents are not fully aware of the reasons why the information is being shared, how it is being used and the limitations placed on the types of information being collated i.e. only collecting basic demographic information. There also seemed to be the assumption that very few restrictions would be placed on the number of departments that would have access to the information. DCMCS would suggest that including basic information on the above aspects of the data sharing process would greatly enhance respondents' understanding of the overall concept and that, as a result, the concept might be received in a more positive light.

Responses to the questions raised in this section of the report were in keeping with those that had been asked previously. Without additional guidance to suggest otherwise, participants were unable to make the distinction between the collection of data for statistical purposes and the collection of data as either a form of social control or financial gain. As stated in previous sections DCMCS would suggest that educating the general public with regards to the rationale behind data sharing is vital if the public are to be able to make real and informed decisions.

Having looked at the reactions of the three focus groups when considering which sources of information are suitable for data sharing it is apparent that mistrust of commercial and financial organisations means that they would not be seen as a suitable source of personal information. The attendees at the groups were more accepting of the idea that local authorities might share information with ONS, mostly because this information was considered to be more high level but also because it was suggested that sharing information would be beneficial for the community.

Anonymity is something that has arisen throughout the course of the focus groups and this is predominantly linked to those areas which are considered to be highly personal e.g. income and health. As with the recommendation above, DCMCS would recommend that the public be made aware of the types of information that would be stored in such a database so that they are able to have an informed debate. It would seem that it is lack of background information which causes respondents to extrapolate their reasoning out to incorporate a 'worst case scenario', in this instance social monitoring, discrimination and the potential for fraudulent activities against themselves.

Accuracy of data also appears to be an issue for respondents. Some participants were concerned about quality of data stored about them with some detailing their own negative experiences. In order to improve public perception of data sharing it might be necessary to include some kind of verification process.

Opinions regarding the creation of a population register did not differ greatly from those obtained when respondents were asked about a social database. The respondents were broadly in favour where they felt that it would be beneficial to the community but were suspicious that corporate involvement would only be detrimental. It was widely believed that security would be an issue, especially where sensitive information on individuals was stored within one database potentially making respondents vulnerable to hackers. The opportunity to opt-out was seen as important for many respondents who felt uncomfortable at the idea of information being shared on a register without their permission.

As with previous topics respondents often tended to look towards a 'worst case scenario', predominantly because little information had been provided on any of the circumstances presented before them. Security measures are particularly important in terms of issues that need to be addressed. Media reports were seen to have contributed to an overall negative perception of the way that the government handles personal information and this is something that would need to be addressed to ensure that the public are supportive of the creation of any database or register.

The opinions expressed regarding the Census are beyond the remit of the proposed script. However, because respondents were keen to discuss the implications for the Census it was deemed appropriate that their views be recorded. The topic was discussed across all three groups and it seemed that respondents were broadly in favour of there being a different method of collecting data for a census and were quick to highlight the potential benefits, one of the major ones being cost. As with all of the topics discussed, security was an issue. In terms of anonymity some respondents acknowledged the fact that this would be far more difficult in a census type database but given the 100 year rule<sup>1</sup>, this was not seen as such a big issue. It was suggested that the 100 year rule be extended given progressing longevity of life however this issue only arose in one group.

Respondents reported that they would want to be fully informed as to the type of information that would be held about them on such a register.

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<sup>1</sup> Census records are kept confidential for 100 years before being made available to the public.

## Appendix A: Beyond 2011 Public User Consultation Focus Groups Script

### Introduction

Firstly, thank you to all of you for coming along to this focus group discussion this evening; we really value your help and your input.

I'm ... and this is ..., and we work for the Office for National Statistics or ONS as it is also known. ONS is responsible for carrying out lots of different surveys, as well as the census every ten years, and producing statistics on topics like the economy, health, unemployment and so on.

We've asked you to come along to this focus group this evening because the Office for National Statistics is thinking about possible changes to the way that it collects and manages personal information about the population, but before it does this it wants to seek the views of the general public. So, we are holding these focus groups in order to hear your thoughts and opinions on how the government handles personal information; what you think happens at the moment to all of the information that is held by the government about you, and what you'd like to happen to the information that is held about you. Plus we'd also like to hear your thoughts on some ideas that the Office for National Statistics has for the future.

There is no fire alarm test planned for this evening, so if the alarms do go off then we'll need to evacuate, all you need to do is follow myself and ....

The focus group will last for approximately one, so we are aiming to finish at about ...pm. I'd like to encourage everyone to participate in the discussion. Please feel free to voice your opinions; there are no right or wrong answers to anything that we discuss today. You might have the same or different views to other people in the group, and we want to hear them all, but please remember to respect the views of others, even if you feel differently. Because we want everyone to talk openly and honestly, I will ask you to maintain the confidentiality within the group; that is what is said here tonight stays between you as the participants.

It is very important that we try to not talk over one another, as this makes it difficult to hear everyone's views. It's also important that we talk one at a time so that the recorder can pick up what people are saying.

We will be recording the discussions that we have this evening, as it makes it much easier for us rather than trying to write down everything that you say. Everything that we talk about will be kept confidential, and when we report our findings we never identify any one by name. Once the report has been produced the recording will be deleted. Is that ok with everyone (if there is any objection ask for an explanation and try to reassure)?

Please can I ask everybody to switch their mobile phone off, or turn it to 'silent', for the duration of the session, so that we don't have any interruptions?

### **START RECORDING**

To start with, it would be good if we could all introduce ourselves to the group and tell us your first name and something about yourself. I'll start and then we'll go round the table, so...

#### **A) Understanding of the main concepts behind data sharing (approx 20 mins)**

**The purpose of this stage in the focus group is to determine what participants understand by the processes which underlie data sharing, more specifically the terminology which is used when discussing the above.**

Start the discussion off by informing the respondents that you want them to think about the idea of data sharing and the ways in which this might take place as well as the idea of data linking. Inform them that you are going to provide them with a list of ways in which data can be collected and tell them that you want to know what they understand by the terms that you are about to present before them. Ask them to tell us what they think about the concepts and how they might relate to them personally and what this might mean for them in terms of their own demographic (personal) information. The assistant moderator will note down the examples that respondents give on flip chart paper. The moderator should acknowledge that the assistant is doing this just so that we can remember what was discussed later on. This will be used as a reference later in the group.

The discussion needs to cover:

- administrative/operational/Statistical data use
- data sharing
- data linking
- social statistics database
- confidentiality and anonymisation.

### **B) Views towards sharing information with different types of organisations (approx 20 mins)**

Now we know what respondents *think* about the main ways in which information can be collected and some of the issues that may arise from collecting data using these methods, we want to move on to look at how they feel about the concept of their information being collected from external organisations and whether obtaining information from these sources would be deemed acceptable. As with the above question respondents are asked to outline what they understand by the terms outlined below and to think about how this would relate to them personally and whether or not they would find this practice to be acceptable. Ask the respondents whether they think there would be any benefit to collecting information in this way e.g. reduction in respondent burden and whether there would be any potential drawbacks e.g. security, confidentiality, storage of information etc. The discussion needs to cover:

Views towards data sharing with different types of organisations

- other public authorities such as GPs and LAs
- commercial organisations such as supermarkets and energy suppliers
- financial organisations such as banks and credit reference agencies
- views towards providing information on different data items e.g. health information, income housing information and address one year ago.

Then introduce more specific scenario, which gives respondents more detail about the register:

Now, I'll give you a more specific example to think about. Imagine that the ONS wants to create a register of everyone who lives in the UK. The aim of the register is to help produce better statistics which will mean that money can be better allocated to places like schools and hospitals. The information on the register will not be used for any other purpose and will be kept under strict confidentiality rules. This register will start off containing people's name, address, sex and date of birth. Over time, other information will be added to it. The ONS would need to get people's name, address, sex and date of birth from other government departments. For example, they could create this register by looking at the NHS' patient register, by looking at people who receive benefits from DWP, and by looking at people who have a NI number from HMRC.

Then, the discussion needs to cover:

- Respondents' level of support for the register, in light of the specific information (e.g. the type of information that will definitely be on the register, how that information will be obtained and who from, that it will only be used for statistical purposes)
- What personal information is ok to go on the register, what information isn't (in light of the specific information) – if not already mentioned, probe around NI number, NHS patient number, health information, passport number, ethnicity, marital status, nationality, migration status, employment status, housing information
- Which government departments should be able to contribute to the register, which shouldn't (remind respondents of flip chart list if necessary) – prompt for HMRC, NHS, DWP, Job Centres, Passport Service if not already mentioned
- Who should be allowed to use this register and why
- Feelings/thoughts about this register
- Benefits/concerns about this register
- Burden – the potential for this register to replace/reduce questions on surveys
- Respondents' reasons for their views

**Final 5 minutes**

Assistant moderator to provide brief (couple of minutes) summary, then ask if anything has been missed.

Thank you for your participation. It's been a very interesting discussion and you've provided us with lots of valuable information which will be really useful to the project.

## Glossary

Abbreviation	Meaning
DCMCS	Data Collection Methodology
DCMCSCS	Data Collection Methodology Census and Social
HMRC	Her Majesty's Revenue & Customs
ONS	Office for National Statistics
RSS	Royal Statistical Society

## References

Onwuegbuzie, A. J., & Collins, K. M. T. (2007). A typology of mixed methods sampling designs in social science research. *The Qualitative Report*, 12(2), 281-316. Retrieved August 31, 2007, from <http://www.nova.edu/ssss/QR/QR12-2/onwuegbuzie2.pdf>

Ritchie J, Lewis J. (2003). 'Qualitative Research Practice: A Guide for Social Science Students and Researchers'. SAGE publications.

Social Survey Division, Office for National Statistics (2009). 'Data sharing between Government Departments: Report on public acceptability'. Published online: <http://www.ons.gov.uk/about-statistics/methodology-and-quality/imps/beyond-2011/data-sharing-between-government-departments---report-on-public-acceptability.pdf>

Teddlie, C. and F. Yu. 2007. Mixed Methods Sampling: A Typology with Examples in *Journal of Mixed Methods Research* 1 (1) pp. 77-100.

Tourangeau, R.& Rasinski, K.A. (1988) Cognitive processes underlying context effects in attitude measurement, *Psychological Bulletin*, 103: 299-314

Willis, G.B., (1999), *Cognitive Interviewing: A Tool for Improving Questionnaire Design*, Sage, London.