Understanding Society: How people decide whether to give consent to link their administrative and survey data

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Non-technical summary

Data linkage is the process by which administrative data held by government or data generated by social media or private companies and held at the individual level are linked with survey responses. However, it is essential to secure participants' informed consent to this linkage; ensuring they know what is being asked, what data will be linked, how that data will be used, and for how long.

ISER commissioned Kantar Public to conduct 25 in-depth face-to-face qualitative interviews to explore the mechanisms underpinning the decision to consent, to help inform activities related to the data linkage consent process on Understanding Society. The research builds upon the growing body of knowledge about practical, legal and ethical issues related to data linkage of survey responses to process-generated records.

Overall there was a lot of confusion about what data will be linked, how the data will be used, and what organisations are involved in the data linkage process. Participants were supported in their understanding of the consent request by particular words and phrases, supporting material and the presence of a researcher. In contrast, participants also misunderstood key components of the consent request; this undermined their ability to make an informed decision.

Changes to improve understanding of consent questions were shared by participants. Suggestions included providing greater clarity about why data is needed and the purpose of data linkage (including tangible examples), reassurances that linking participant information will not lead to repercussions for the participant, and clarification that data linkage is not requested because ISER thinks that participants do not always tell the truth.

The extent to which a participant correctly understood the consent request was a necessary pre-condition for being informed about the consent request. However, a good understanding did not always lead to the decision to consent. Some participant's decisions were driven by subconscious factors, such as heuristics, and for others rational decision-making interacted with their environment.

When thinking about the risks and benefits of consenting, participants are more likely to consent if they feel the benefits of consent to third parties outweigh the risks to themselves. ISER, researchers and, to a lesser extent, society was thought to benefit from participant consent. Greater accuracy in survey data and improved policy planning were possible benefits of data linkage. Risks to individuals were considered higher than risks to any other party. Identity fraud, reputational damage, harassment by telemarketers and government use were all cited as potential consequences to consent to data linkage. Emphasising benefits, with tangible examples, may help to de-emphasise personal risks and support consent responses.

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Abstract

ISER commissioned Kantar Public to conduct in-depth face-to-face qualitative interviews to explore the mechanisms underpinning the decision of respondents to consent, to help inform activities related to the data linkage consent process on Understanding Society. This research provides valuable insight into the range of influences on panel members' interpretation of consent questions and decisions to consent to requests to link data. Understanding the different factors influencing decisions to consent to data linkage helps to identify good practice to follow to support informed consent and pitfalls to avoid in order to overcome the barriers to informed consent.

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1. Introduction

1.1. Background

Data linkage is the process by which administrative data held by government or data generated by social media or private companies and held at the individual level are linked with survey responses. Data linkage has immense potential value for research, especially when securely linked to longitudinal survey data. It offers the opportunity to improve the accuracy and value of survey responses, save time and reduce burden on survey respondents, and to add deeper insights to a body of knowledge.

Understanding Society incorporates three types of data linkage to ensure findings about people's social and economic circumstances, attitudes, and behaviours are robust. These are:

- geographical identifiers
- administrative data linkage and
- linking data at the level of organisations

Researchers at ISER have collected consents to link to DWP, HMRC, DVLA, NHA and energy use, and are in the process of linking those administrative datasets to survey data.

However, treating data in this way is not only about the technical demands of manipulating large datasets. There are practical, legal and ethical issues related to data linkage. It is also essential to secure participants' informed consent, ensuring they know what is being asked, what data will be linked, how that data will be used, and for how long.

Previous research has revealed some of the challenges to capturing consent and the implications these may have for the quality of data captured from surveys:

- Consent varies by respondent characteristics (Knies, Burton, Sala, 2012; Tate, Calderwood, Dezateux, Joshi, 2006)
- Concerns about privacy and confidentiality in how the data is used
- Consent varies by interview process and characteristics of the interviewer (Sala, Burton, Knies, 2012; Sakshaug, Couper, Ofstedhal, Weir, 2012) - consent rates for CAWI participants are lower than those interviewed face-to-face
- Linked survey-administrative data may be biased because not everyone gives consent and those who do not consent may differ from those who do consent
- The way in which the concept and process of data linkage is perceived by the public (Beninger, Kotecha, Gray, 2014)

ISER commissioned Kantar Public to explore the mechanisms underpinning the decision to consent, to help inform activities related to the data linkage consent process on Understanding Society.

1.2. Research Aims

The primary aim of the research was to explore how people decide whether to give their consent to link administrative data to their Understanding Society survey responses.

Specifically, the research addressed four objectives:

1. Understanding of what the consent questions are asking:

   - What do and don't participants understand by the questions, and what elements drive or hinder their understanding? (e.g. words, concepts, combination or ordering of words, placement of question in question block).

   - What changes would they make to improve understanding of what each of the consent questions is asking?

2. The decision-making process for consenting for external data to be linked to survey responses

   - what are the factors influencing the decision to consent to data linkage (e.g. the top of mind/rational, subconscious, social and environmental factors)?

   - what are the factors driving changes to consent at different time points?

   - How does the decision to consent differ when presented with multiple consents?

3. Understanding of consent

   - expectations of what will happen following their consent decision (whether to consent or not to), including the benefits and risks to the decision made, and the perceived likelihood of those benefits and risks, for them/for others.

4. Why consent to data linkage is higher in face-to-face interviews compared to online interviews?

1.3. Methodology

We conducted in-depth face-to-face interviews in Greater London and Hull with a total of 25 participants taking part in Understanding Society's Innovation Panel. Fieldwork took place between 10th March and 13th April, 2017, and interviews lasted 60 minutes. Participants received a £40 incentive in the form of a voucher as a 'thank you' for taking part in the research and interviews were digitally recorded, with participant consent.

Participants were purposively selected from the Understanding Society Innovation panel. To ensure the broadest range of views were captured, the research included participants with a mix of characteristics, listed below.

- consent type: has consented, changed consent (either from consent to non-consent, or vice versa), not consented

- mode used at last interview: face-to-face or web

- education: range of qualification achieved

- benefits: Child Benefit, JSA, Working/Child Tax Credit, Other

- finances: extent of difficulty to meet financial obligations each month

- age: 16-21, 22-34, 35-44, 45-64, 65+

See Figure 1 below for target (columns three to five) and achieved sample (final column) and Appendix B for a full breakdown of the sample

Figure 1 Achieved sample

Criteria	Description	Consent type			Complete
		Consent	Changed consent	No consent	
Location	Greater London	4	8	2	14
	Hull	5	5	1	11
Mode	Face-to-face		Min 10		12
	Web		Min 10		13
Age	18-21		Recruit a range (Min 10)		3
	22-34				7
	35-44				5
	45-64		Recruit a range (Min 10)		5
	65+				5
Gender	Male		Min 10		10
	Female		Min 10		15

Interviews took place in participants' homes and were supported by a semi-structured discussion guide (See Appendix C for the guide) and involved a range of stimulus and activities. Specifically, two consent questions were used to explore the mechanisms of informed consent. These related to:

- economic information held by Department for Work and Pensions and

- health information held by the National Health Service.

Participants were presented with these two consent questions with accompanying information booklets and researchers changed the order of questions presented to minimise the likelihood of ordering bias. Participants were asked about their understanding of as well as responses to the questions. See Appendix D for copies of these questions.

Participants were also shown Understanding Society's *Data flow for administrative records* showcard and were asked to comment on the flowchart in relation to their expectations for what happens to their information following consent (see Appendix D for flowchart).

Additionally, researchers used projective techniques to facilitate freer discussion and to access thinking or beliefs that are less conscious or may be difficult to speak about. Specifically, the projective technique of construction was used, where participants 'constructed' a position or set of views by taking a third-party perspective on the opportunities and risks of data linkage (for a full list of stimulus see Appendix D).

Analysis

Our analytical approach to the research was iterative and inductive – building upwards from the views of participants – incorporating elements of 'grounded theory' analysis i.e. the thematic review and continual analysis of hypotheses from participants' transcriptions and dialogue. The data was thematically organised and analysed using a Matrix Mapping approach. This is a process-driven approach whereby insights from interviews are coded and then recorded thematically for each participant within a bespoke framework, organised around the aims of the research. This technique synthesises all the recorded material into an analytical framework, allowing for systematic thematic analysis. This enables researchers to draw out the diversity of opinions expressed by participants, as well as identify common themes across interviews.

2. Participant interpretation of what the consent questions are asking

This chapter provides a summary of participants' level of understanding of the consent questions, categorised as 'accurate', 'confused' and 'inaccurate' (Section 2.1), before exploring the factors supporting and undermining participants' understanding (Sections 2.2 and 2.3 respectively). Finally, it discusses participants' suggestions for improving understanding, including changes to wording and inclusion of further information to clarify the meaning and purpose of data linkage (Section 2.4).

Specific words and phrases are required for understanding the meaning and purpose of the consent questions, such as 'for research purposes'. The accompanying information booklet for each consent question and the presence of a researcher in the face-to-face interviewing setting are both facilitators of understanding. The research found four key elements that together, if understood, would leave to an understanding of the linkage process, but were often misunderstood by participants. These included the direction, and extent of information flow in the data linkage process, the parties involved in data linkage, and the relevance and purpose of data linkage. Challenging understanding were a number of words that confused participants and left room for interpretation, including 'attach' and 'administrative'.

2.1 Interpretation of the consent questions

Across the sample, participants had varied interpretations of the meaning and purpose of the consent questions. Participants' initial and unprompted levels of interpretation fell into three broad categories: accurate, confusion and inaccurate.

Accurate

Participants who interpreted the request communicated in the way it was intended understood the general purpose of data linkage was to achieve greater accuracy of information from participants for research purposes. Most importantly, however, accuracy of understanding was supported by a solid grasp of the direction of flow of their personal information – i.e. from government departments to ISER.

> *"They want access to your health records to help them with the answers that they [have and that] you [are] going to provided them on your health and wellbeing."* (Female, has consented)

> *"From what I understand, they want to get information from the DWP to cross-reference that against the answers I've given you in the survey…"* (Female, has consented)

A less common understanding related to the length of time associated with consenting. Specifically, few participants recognised that consent had no expiry date, but that reminders would be sent annually should participants wish to change their consent decision. Those that were aware of this from reading the information booklet had no issue with the timescales of their consent; those that did not read the booklet assumed that they were consenting to linking both past and future survey responses and records.

> *"I get it. Permission is being given for access [to] historic info. This consent would hold going forward, until I wrote a letter saying I wanted to revoke [my] consent."* (Male, has not consented)

Confusion

A common reaction to the consent questions was that of confusion. In this case, participants misunderstood key components of the consent request, undermining their ability to make an informed decision. While there was basic understanding that personal data would be shared, participants generally did not understand which data departments held about them, the direction and extent of data flow, the parties involved with linkage and the purposes of sharing the data.

There was greater comprehension of the specific records held by an organisation when participants had greater familiarity with the organisation. For example, universal awareness of NHS, and specific cases of direct experience with DWP. But, while many participants were able to communicate the likely types of records held on them by departments, some struggled to understand exactly what data DWP and NHS had.

> *"People will say what is an employment programme, do you mean work or voluntary work."* (Male, changed consent)

The direction and extent of information flow was rarely understood by participants which, in turn, undermined their decision to consent. A recurring view, for example, was that survey responses were shared with government departments, rather than just the name, address, sex and date of birth of participants.

> *"'Administration' sounds a bit name and address, whereas this [referring to the NHS consent question] means anything that is… [in my] file would be handed over."* (Female, has consented)

While all participants understood that ISER would have access to their information from departments or organisations, there was less clarity on which individuals within those departments would have access to their information. Participants were also confused about whether consenting would enable third parties to access their information and/or whether the government departments would access survey responses and use them for purposes other than research.

> *"It's odd, because I would have thought it would be the NHS giving you info and not the other way round...It's not clear which individuals within the NHS would have it…if it was my GP I wouldn't mind because I have a good relationship (with him), but if it was others...not sure. I'd be happy to give my consent, but I would want to know...which individuals within the NHS would get it...administrative records...it's a bit vague what that means."* (Female, has consented)

> *"Who is actually getting the information, what is it being used for, is it being kept, is it going to be with my name?"* (Female, changed consent)

> *"The first thing you always want to know is who would use it; the other stuff is incidental almost."* (Male, has consented)

The purpose of seeking data linkage also caused confusion among participants. For some, the request was interpreted as a lack of trust on the part of ISER that participants' survey responses would be accurate, or even truthful.

Meanwhile, participants who claimed that specific government departments did not actually hold records on them questioned the value in them consenting for ISER to access these.

> *"I'm not sure they would get an answer; I would love it see but the last time I went to them they (NHS) didn't have anything (his records)."* (Male, has consented)

Inaccurate

A few participants expressed inaccurate interpretations of the consent questions due to their interpretation of the way the question was framed. These participants tended to communicate that they expected their survey responses would be shared with government departments for them to use, rather than ISER receiving department records on the participants to match with their survey responses.

> *"They want to share all this info with DWP about my records and when I've been working and not working I suppose." (*Male, has consented)

This misinterpretation caused concern among participants who feared that data linkage was a way for government departments to monitor them.

2.2 Factors supporting understanding

Factors supporting understanding of what the consent questions were asking included the use of specific words and phrases, supporting material and the presence of a researcher guiding comprehension and instilling trust in the participant.

Generally, participants who had an accurate understanding of and those that were confused by the questions perceived the explanations and corresponding consent questions to be clear, simple and succinct. Phrases in bold such as *for research purposes only*, descriptions of the department and its purpose, and data protection reassurances (e.g. *restricted access* in the NHS question) were all identified as factors supporting understanding.

Meanwhile, though not all participants read the information booklet that was provided to all participants the booklet proved effective in supporting understanding for those individuals that reviewed it. Specifically, those that engaged with the booklet commented that the phrase, 'your personal details will not be passed on to anyone else' provided clarity on the parties involved in the process. More generally, participants communicated that specificity and clarity were particularly effective in explaining the use of linked data and the lifespan of consent decisions in the booklet.

Finally, while research conducted by ISER (Burton, Sala, Knies, 2014) has found that participants rarely ask researchers questions, the presence of the researcher (both during this research, and during waves of Understanding Society) was reassuring to participants. Participants felt reassured they could seek clarification about question meaning and requirements.

2.3 Factors undermining understanding

Participants' interpretations of words and phrases, as well as personal habits (driven by personal needs) were factors undermining participants' interpretation of what the consent questions were asking.

Interpretation of words and phrases

Words and phrases presented obstacles for participants which challenged understanding. Words that participants queried the meaning of included:

- 'attach' (DWP and NHS)
- 'employment programme' (DWP)
- 'good use of them' (DWP)
- 'us' (DWP and NHS)
- '…for this purpose' (DWP and NHS)
- '…maintains routine..; (NHS)
- 'other health-related' (NHS)
- 'lives, well-being, experiences' (NHS)
- 'administrative records' (NHS)

Moreover, the introductory paragraphs in the questions were believed to be at odds with the consent question. For example, the phrase, "We would like to ask for your permission to add information from **administrative health records** to the answers you have provided in the interview" was felt to contradict the

consent question, asking for permission to share participants' names, addresses, sex and dates of birth. In this case, participants communicated a contradiction between the type of information held by government departments and the consent request. Ultimately, participants were left questioning the nature of the consent question and, more specifically, the type and extent of information being shared.

The questions also asked whether participants were willing to give permission for ISER to pass their information on to departments[1] which caused confusion about the direction of data flow. In other words, the statement suggests one direction, whilst the consent flow chart shows information being transferred in multiple directions. Describing the direction information is shared incorrectly, based on interpretation of the research questions, and was a recurring finding in the research. This, in turn, influenced consent among participants who were mistrusting of government and who expected that by consenting, government departments would have access to their survey responses.

Habits of participants

Another important factor that impacted understanding related to participants' habits. Rather than reading the full consent question, for example, those participants with limited literacy, dyslexia, and of an older age communicated that they tended to read small sections of the question deemed to be important, rather than the full text. This was described by participants as habitual behaviour, adopted to help manage the process of reading, and tended to involve 'skimming' the first and last sentences.

2.4 Suggestions for improving understanding

Despite initial difficulties in participants' accurate interpretation of the concept of data linkage, following clarification, participants were able to share suggestions to improve how ISER communicates to participants about data linkage. Suggestions included:

- Tangible examples of why data will be linked, such as a case illustration, briefly describing which areas of research would benefit from the participant consenting.

  "We want to attach to survey answer so we can say so many survey respondents said they weren't earning enough and this many people claimed JCP." (Male, changed consent)

- More explicit and simplified explanation in the question (rather than in the supporting booklet) of how exactly personal info would be used, when and by whom

  "I'd probably make it really simplistic'; 'there's this interview that's going to take place, you're going to be asked questions and then they have the opportunity if you allow them to apply those questions to say the administrative records that are held by the NHS." (Female, changed consent)

- Greater clarity about why the data is needed and the purpose of data linkage.

- Personalised messaging and greater clarity as to who will access the data. For example, a participant suggested a new statement might be: "'As a participant in Understanding Society, who we've interviewed several times and value the information you've shared with us…if we alone were able to access those records without limitation."

- Reassurances that linking participant information would not lead to repercussions for the participant.

  "I'd like something like 'This will not affect your benefits'." (Female, consented)

- A phrase that minimises concern about the purpose of data linkage while also clarifying that data linkage is not requested because ISER believe participants lie/give inaccurate information. An example suggested by the research team is "You may not remember everything so this is a way to more accurately record details of your life."

- While not a particularly prominent finding, the remit of the department may also require clarification.

  "A lot of people may not fully understand what the department for work pension does because it is a technical description of a function rather than what they do so unless you've had interaction with them you might not know what that means." (Male, changed consent)

3. The decision-making process for consenting

This chapter provides a summary and detailed discussion of the different factors influencing participant decisions to consent to the data linkage request, including subconscious, rational, social, and environmental factors as well as changes to consent at different time points, and mode (Section 3.1). Two case studies are included to illustrate the way in which these factors practically present in an individual (Section 3.2). Practical suggestions for changes to the approach to the consent request and for leveraging some of these factors to encourage informed consent are then discussed (Section 3.3). Finally, it discusses the implications of a multiple consent question on decisions to consent (Section 3.4).
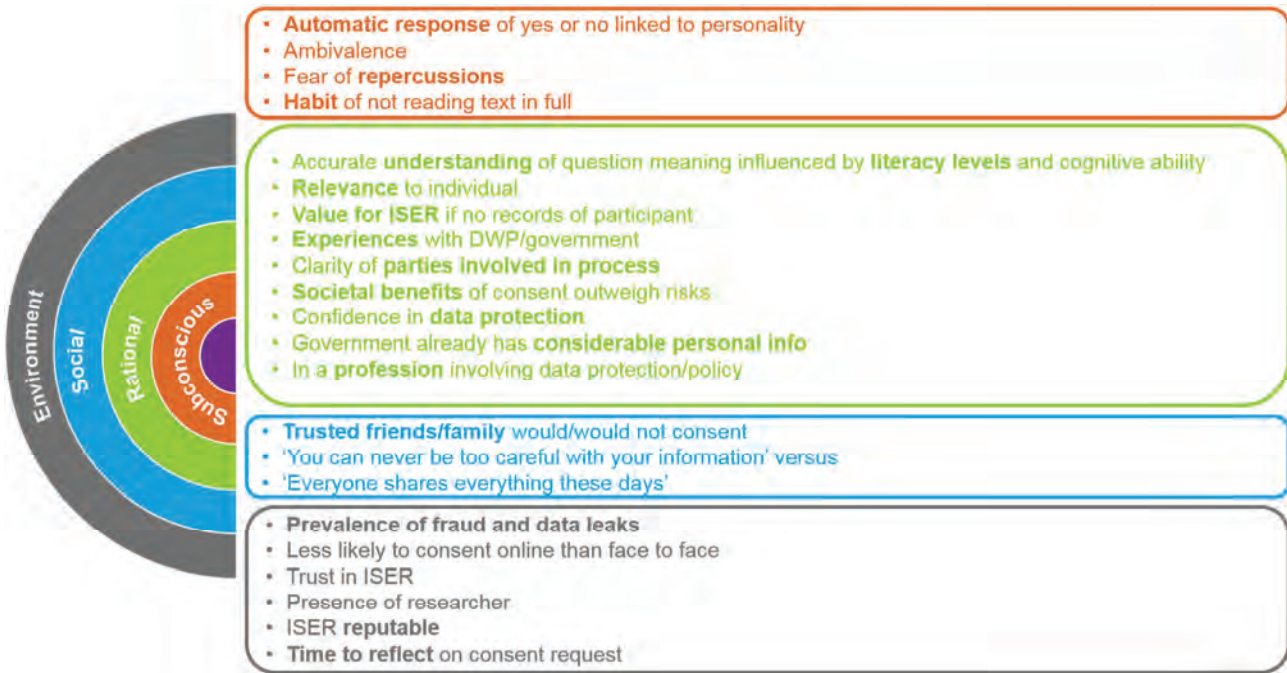
Personality traits, such as 'openness' or 'suspicious', and habitual actions – to default answer yes or no to consent-type questions - were key drivers to whether a participant decided to consent or not. Friends and family were also influential in decisions; some participants either noted they would likely consult their spouse before consenting while others referred to friends or family members that they believed would be hesitant to consent, which prompted the participant to consider the reasons against consenting. Participant assessment and judgement of the cost/benefits of consenting to either consent question also influenced decisions. Those who consented were more likely to explain they 'have nothing to hide' such as a health concern or financial circumstances that would make them feel vulnerable to ISER having access to those records. Participation in Understanding Society in the past had helped to establish trust between the participant and ISER, supporting the decision to consent for those that did. ISER was viewed as a reputable organisation that has "too much riding on the survey to mishandle information" and this perception helped to diminish concerns about consent and thus supported the decision to consent.

3.1 Factors influencing decisions to consent

The level of understanding of what the consent questions were asking (discussed in Section 2.1) was not found to be correlated to participants' decision to consent. In other words, it was not a pre-requisite that those likely to consent necessarily had a clear understanding of what they were signing up to. Instead, subconscious, rational, social and environmental factors were key drivers of attitudes and behaviours towards consent.

Figure 2 below, based on the Kantar Public behavioural model, summarises these drivers.

Figure 2 Kantar Behavioural Model summarising the factors influencing the decision to consent

- **Automatic response** of yes or no linked to personality
- Ambivalence
- Fear of **repercussions**
- **Habit** of not reading text in full

- Accurate **understanding** of question meaning influenced by **literacy levels** and cognitive ability
- **Relevance** to individual
- **Value for ISER** if no records of participant
- **Experiences** with DWP/government
- Clarity of **parties involved in process**
- **Societal benefits** of consent outweigh risks
- Confidence in **data protection**
- Government already has **considerable personal info**
- In a **profession** involving data protection/policy

- **Trusted friends/family** would/would not consent
- 'You can never be too careful with your information' versus
- 'Everyone shares everything these days'

- Prevalence of fraud and data leaks
- Less likely to consent online than face to face
- Trust in ISER
- Presence of researcher
- ISER reputable
- **Time to reflect** on consent request

3.1.1   Subconscious factors

Personality traits and habits were key drivers of consent. By self-identifying as a private, suspicious person or conversely, as a more open, trusting person, participants described how the risks they associated with their personal data being shared and stored were either dismissed or strengthened.

> *"It isn't in my nature; I don't tend to [worry about those kinds of things]."* (Male, has consented)

> *"My default is not to... I'd definitely, outside of the Understanding Society, say no but I trust them."* (Male, changed consent)

Findings also suggested that habitual actions – For example, to default answer yes or no to consent-type questions – tended to be associated with these personality traits.

> *"I think I was just so in the habit, and I still am, of if a site asks you for information you don't give it, unless you trust the source."* (Female, changed consent)

3.1.2   Rational factors

Participants' assessment of the risks and benefits of consenting to either question was a prominent factor driving decisions. In particular, participants considered the likelihood of repercussions compared to potential benefits.

Those who consented were more likely to explain that they 'have nothing to hide' - such as a health concerns or financial circumstances that would make them feel vulnerable in light of ISER accessing their records.

> *"I would say yes because there is nothing I would say that could be used against me. If I was doing something dodgy, working and claiming and avoiding tax and stuff like that I would say 'no, I don't want to do it'."* (Male, has consented)

The motivation to consent was also driven by the belief that the benefits of consent outweighed concerns about personal privacy or data protection.

"I do regard it as for the greater good of society, if people do research society. I think it is a valid form of research … I'm happy to support it." (Male, has consented)

Additionally, individuals in professions where they were aware of data exchange and data protection had the capability to rationally assess the risk of consent. For some, dismissing the risks was commonplace. For others, heightened concerns undermined decisions to consent.

"I work in an environment where data protection and security is a big deal. My default position in my industry is why has that information been requested... if it doubt we are told to say no." (Male, changed consent)

Those that were less likely to consent were concerned about the possible personal repercussions of consenting, such as hacking and, ultimately, financial loss.

"Not sure because it is to with the money I'm getting and there's a lot on the telly about them wanting to cut you down. Is this one of these things when they've got ya." (Female, changed consent)

"I don't know enough about Understanding Society, all the questions before have been multiple choice and not information as deep as that. Before and because there is so much of it (data theft) going around the world and even if Understanding Society were using it properly and in the right ways there's still so much hacking." (Male, has consented)

These participants were particularly concerned about the NHS question when they had health issues that they feared may be used to prevent future employment.

"Even when it comes to getting a job, there are certain things that you don't want to share, say if it was me applying for a government job in the future, then like, I'm not saying this is the case but say I had an alcohol problem in the past and then it came up in my records." (Female, changed consent)

Concerns undermining consent went beyond the individual. A minority view was the possibility of the participants' personal information being used in a way that may impact their loved ones.

"There is something that you want to keep private and if your records are open for a certain amount of time it links to the children. I know it is only for survey purposes and your confidentiality is assured but how many times in the press recently had you seen people losing records. What are they going to do with it, probably nothing but I'm a private person anyway." (Male, changed consent)

However, some participants believed that the government and ISER already had considerable personal information on them which led them to deduce that there was 'nothing they don't already have', ultimately increasing the likeliness of consenting.

"I've already sold myself to the devil..." (Female, changed consent)

Closely tied to this was participants' involvement and trust in Understanding Society. Having already agreed to take part in the survey, participants communicated the view: 'why stop there'. This ultimately led them to agree to give researchers the opportunity to gather the most effective insights possible.

"If you're not prepared to give consent don't do Understanding Society it the first place, because it is a lot of personal information already." (Male, changed consent)

Literacy levels and cognitive ability also influenced participants' ability to consent. A few participants were unable to comprehend the question – a finding that was either determined by the researcher or communicated by the participant. And, ultimately, without the ability to understand what was being asked of them, these participants communicated being unable to consent.

3.1.3   Social factors

Friends and family were influential in participants' decision-making journey. Some participants either noted they would likely consult their spouse before consenting; while others mentioned friends or family members that they believed would be hesitant, which prompted them to seriously consider the reasons for not consenting.

> *"Mates are worried about me doing the survey so they would likely question this request."* (Female, has not consented)

Similar to rational judgements associated with the risks of data protection discussed above, differences in established norms around data sharing among participants were also influential. On the one hand, participants communicated the view that 'everyone shares everything already'; on the other hand, participants commented that 'in this day and age, you can never be too cautious' in sharing personal information because of the risks of hacking, etc.

3.1.4   Environmental factors

The nature of interactions with and length of participation in Understanding Society helped to establish trust between participants and ISER, ultimately supporting participants' decisions to consent. In this case, ISER was viewed as a reputable organisation that had 'too much riding on the survey to mishandle information'. This rationale helped to reduce concerns about the risks associated with consent.

The media was noted as raising awareness about the prevalence of phishing scams, fraud, identity theft and data leaks which were top of mind to some participants. As a result, the wider environment increased participant concern about consenting to share their information.

3.1.5   Changes to consent at different time points

Changes to consent response at different time points (e.g. participants who had not consented in the past but who consented during the interview or vice versa) reinforced the importance of subconscious, environmental and social factors in driving decisions to consent. Participants were generally unable to recall whether they had consented in the past and, once the researcher made this clear, some found it hard to rationalise changes to consent. For example, one participant was surprised when she found out she had not consented in the past and found it hard to explain reasons for her decision to consent during the interview. She queried how common this was amongst participants.

For those who were able, rationalisation after the fact of the reasons their consent had changed were wide-ranging. Some commented that in the past they may have been more or less concerned about infringements on their privacy; some thought perhaps there was a change in their understanding of the purpose of linking their personal information to their survey responses. Another factor related to a change in environment which a number of participants claimed had impacted their willingness for consenting. For example, one participant had not consented in the past, but decided to consent following a change in lifestyle and a subsequent 'change of heart.' She explained that developing an illness had resulted in her being more open and willing to consent, particularly given recognition of the societal benefits associated with data linkage. Moreover, she highlighted that having more time to complete the survey due to being 'bed-bound' allowed her to seriously consider consenting, rather than defaulting 'no'.

> *"[Decision to consent] would depend on what was happening at the time."* (Female, changed consent)

Another reason expressed for changing consent was trust in Understanding Society built up over years of taking part and recognition that sharing details with ISER had not led to infringements on privacy. Participants claimed that this was reassuring and made them more likely to consent.

"Perhaps I just sort of got to a point and realised you know I've been doing it for however many, 6 years, and everything's been fine thus far and they are using it for research purposes." (Female, changed consent)

A number of participants attributed a change in consent to the perception that the increased use of technology resulted in a rise in hacking and therefore claimed to be more cautious as a result.

"Now with a lot more people hacking companies through personal details and everything developed through technology you need to me more careful of what info you are passing on to people." (Male, changed consent)

"As time is moving on you see more breaches of personal security." (Male, changed consent)

Meanwhile, some were surprised they had consented in the past to share information. These participants claimed they would not have consented if they had known (based on a misunderstanding of direction of data flow) their information would have been shared with finance-related departments such as DWP and HMRC. A few participants commented that the change was probably arbitrary and dependent on how they were feeling on the day.

3.1.6 Influence of mode on decision to consent

Participants anticipated not consenting as readily or at all if responding to the consent question online because of perceived difficultly of reading lots of content on a computer screen. The tendency was for these individuals to skim content rather than read it in full which meant they were more likely to overlook key content in the consent question.

"Because the impact isn't as great is it, if you read something online. It's like, you know, it's like reading an email at work - you might not take that information in. But when you're doing it face to face, and you're sitting there, you know, I'm going to read this, aren't I, because you just asked me to." (Female, has not consented)

Concern about privacy and security of personal information shared online was a prominent factor in undermining the likelihood of participants consenting online. Conversely, when asked in person, participants communicated high levels of trust in Understanding Society researchers and reassurance in seeing where their responses were going – to the interviewer.

"I guess I am more likely to consent in person because I don't know who is asking [questions] online." (Male, changed consent)

"They may think online it could go anywhere because we all know once it's online it is for everyone to see. I think face to face they would feel more comfortable." (Female, changed consent)

The encouragement that comes from the possibility of a researcher offering clarification or reassurance when interviewing in person was a persuasive factor for participants to consent in person rather than online. And, while we know from internal research conducted by ISER that the actual number of cases in which interviewers provided this level of support was low, this research found that it was the idea of support that motivated participants.

"Doing it online is much easier to say no because usually it is just click a box whereas if someone is talking to you about it they can either be persuasive depending on whether they are supposed to be doing that or alleviate the concerns that just can't be answered by reading on the screen. You never feel you are quite getting enough information to make an informed decision when you are doing it through a screen". (Male, changed consent)

"If (regular interviewer) had done it face to face she usually gives extra detail and sometimes she can tell by the blank look on my face. She does tend to go into more detail sometimes." (Female, consented)

Moreover, the physical presence of the interviewer was also influential because of the perceived social pressure to conform.

> "Subtle pressures you get in a face to face…you don't want to let that person down." (Female, has consented)

Access to and confidence using computers was also influential in participants' decision to consent online, though this finding was related more to survey participation in general rather than responding to the consent questions specifically. Meanwhile, some participants did not have laptops or tablets and those that had low confidence in using them did not feel equipped to take part online.

> "I just wouldn't do it. I do not touch computers at all". (Female, changed consent)

A minority view was that responding online would not prevent participants from consenting, though participants communicated that they may be more cautious given the risks of hacking.

> "It would be the same thing, it doesn't matter; like I said if it was laid out like this and I had a good understanding and it was bold like that...'; 'if it was face to face or on the internet I'd just be like go ahead." (Female, changed consent)

3.2 Case studies

Two case studies were developed to illustrate the differences in understanding and the key influences of each type of consent request on an individual. The case studies are composite, based on the views and attitudes of multiple participants who consented. The name given is not of any individual who took part in the research.

Muhammad – Consented to link survey responses to NHS records

Muhammad is in his 40s and works in the police force. He was recently diagnosed with an illness and is currently on sick leave. He is committed to Understanding Society and has been taking part for more than give 5 years.

Understanding

- NHS as an organization is familiar ✓
- Explains how the NHS currently holds health records
- Clear explanation of how consent might help USOC
- Flow of information aids understanding each point leads on from the next

"It's odd…I would have thought it would be the NHS giving you info and not the other way round..."

- Reference to two type of records – "administrative records" and "other health-related records" - is confusing/misleading ✗
- Confusion around direction of information flow (e.g. from NHS to USOC or vice versa). Body of text implies NHS to USOC; consent question implies USOC to NHS

Key influences

- Generally open and trusting person
- Commitment to research and sharing data
- Positive association with NHS which is familiar and does not hold personal financial details
- Nothing to hide
- Works in police force and aware of importance of sharing data – "community minded"; although some concern about data security from professional experience – is it really secure?
- Circumstances of being ill - has more time to consider consenting (e.g. taking time to read and understand question) and more committed to the NHS due to service provided

"All different organizations need to share info...it's not like you're giving out your banking details…This is about Understanding Society…giving consent."

Jessica – Did not consented to link survey responses to DWP records

Jessica lives in London and is a full-time mother. She and her family have taken part in Understanding Society for several years.

Understanding

✓
- = **Cognitive ability** and previous exposure to the concept of data sharing
- = "For research purposes only" in bold; although nervous about DWP checking info
- = **Data security**
- = Clear flow of info
- = Info reads well

✗
- = Purpose behind information sharing is unclear – assume DWP will use information to check up on people
- = Confusion around direction of information flow (e.g. USOC to DWP or DWP to USOC)
- = Unclear why this info needs to be shared with DWP - already has info e.g. age, name, sex, and NI number

" [I'd be] worried about where the info was going... where it's going to end up and who is going to see it. "

Key influences

- = Generally conservative
- = No benefit to individual, but a number of risks
- = Sensitive information (i.e. financial)
- = Concern about implications of cross-checking (e.g. threat to benefit claims)
- = Influence of advice of friends and family – concern about maintaining personal security
- = USOC does not trust participants to tell the truth/give accurate information
- = Data security – DWP hold sensitive information that could be leaked

- = X
- = X
- = X

" "I don't know anyone who would consent...A lot of people are scared of...[DWP] because they could use the information against you...they kind of twist things so they get their own way." "

3.3 Participant suggestions for how consent to single questions can be encouraged

A range of suggestions for encouraging individuals to consent to single questions were discussed and have been grouped into three themes: data handling and protection, purpose and value, and support and guidance.

3.3.1 Data handling and protection

More explicit reassurances of the safe-handling and use of personal information was desired by participants. For example, consent questions should specify whether information will be shared with a third party or not at the bottom of the question, and offer reassurance that the server on which data is stored is secure with low risk of hacking or mishandling.

> "When you pull that data out is it then stuck on a server somewhere… and if so how do you monitor that nobody has accessed it than shouldn't have." (Male, changed consent)

> "They would also need to have some idea of how secure the website is going to be, so people with commercial gain couldn't hack into it." (Female, has not consented)

A participant went further in suggesting an independent auditor of quality and information security should monitor the appropriate handling of personal information.

> "Should be an affiliated government site for data sharing like an ombudsman for data sharing and research." (Male, has consented)

Those that engaged with and grasped the data linkage flow chart recognised the importance of their name being deleted after their records were identified by a department. These individuals felt this was an important point to make in the consent question. Yet, this should be considered alongside participants' recommendations to keep the question as short and simple as possible.

"If I knew that at the start I might not have been so adamant not to consent to the NHS one, but knowing it [name] would be deleted, I wouldn't say it completely swings my decision but it definitely makes me more willing to consent." (Female, changed consent)

3.3.2 Purpose and value

Participants expected greater clarity on why the request for consent was being asked and the outcomes associated with an individual consenting. Ambiguity as to the purpose and value of consenting due to the question phrasing prompted participants to express the need to specificity with respect to the outcome of the research.

"More information on what is going to be done with your research as to why we are doing this research and what are our goals for the research and just making questions more simpler and less jargon because it will make sense to researcher but at the same time won't make sense to someone doing the survey." (Male, changed consent)

"Tell them how it's going to be used because then you can make an informed choice whether you want your data to be used that way and then if you definitely know it will be used to drive some good in the country or even in academia. If you know it will do something positive, you'll think yes actually I want to contribute to that." (Male, changed consent)

More explicit reassurances on who exactly would use participants' personal information was suggested. Reassurances would help to minimise concerns about personal information being used for purposes which an individual may disagree with.

"[Participants] need to be told that Understanding Society isn't looking for consent to support government departments to link data for [government] purposes. It's for Understanding Society to have access to some data within their walls for research purposes." (Male, has not consented)

3.3.3 Support and guidance

Participants recognised the challenge associated with striking a balance between the need for questions to be short and simple while also providing enough information for an individual to make an informed choice.

"The questions need to be simple enough that people understand it from a lower level, but at the same time needs to have the ability for somebody to read more about it." (Male, has consented)

For this reason, participants required access to additional information covering the range of anticipated questions and concerns. For example, signposting to government websites, terms and conditions page about consenting, FAQ page, a telephone helpline or online chat facility were recommended by participants.

"For those online, provide a telephone number so people can clarify concerns and talk to someone. If the question came up online on my computer I would probably skip unless I could click on every website possible for more info." (Female, has consented)

3.4 Implications of multiple consent question on decision to consent

The research included discussions about participants' attitudes and views towards a document that asked multiple consents at one time (see Appendix D for a copy of the multiple consents question). While many participants understood the direction of information flow when discussing the individual questions, when discussing the multiple consent questions, it became clear that participants believed their survey responses would be shared with the departments listed. Underpinning much of the anxiety and reluctance to consent to the multiple consent question was the fear of the department receiving all their personal information, rather than their name, date of birth and address only. The following findings should be considered with this in mind.

Assuming a relationship between the departments and requests listed was another common interpretation of the multiple consents question. The order of requests and the inclusion of the requests on one page supported this interpretation.

Overall, participants were overwhelmed by the multiple consents question which triggered a number of questions and concerns that undermined decisions to consent:

Who are some of the organisations listed (e.g. BEIS, FCA)?

> *"There's a lot of information all at once, there are just a lot of departments. Some that you might not have even known existed, like this Business Energy and Industrial Strategy - I don't know what it is or what information they hold."* (Female, changed consent)

What information do these departments hold on participants?

> *"Anybody would hesitate because you're then thinking crumbs what else do these departments hold about me. It is quite difficult to know. NHS is the easiest for me because I worked with those records, but even with that there are other records than just case records".* (Male, has consented)

> *"There's just a lot of words and I just don't know what they are. For my age, I don't really know what my national insurance contributions are. I know what national insurance is but not the contributions, and tax credits. I am not really sure."* (Female, changed consent)

What is the rationale for that number of departments being approached?

> *"Why these specific departments? Money involved here, and it's just personal, it's just got too personal now, like money, finances, and employment."* (Male, has not consented)

Attitudes towards the multiple consents show card varied. Some participants perceived multiple consents to be more transparent than single consents because it suggested ISER was not hiding anything.

> *"It just makes you feel uneasy. HMRC is the worst...I'd be hesitant about that. Though, I prefer it all in one go...it makes more sense...for the sake of transparency...it makes sense to have it all there for you."* (Female, has consented)

The directness and simplicity of the list of consents was also viewed as being low pressure on the individual to consent, which in some cases was a barrier to consent because it triggered an automatic decision not to consent.

> *"There's no real pressure to say yes, it's very easy just to go, no thanks, not for me."* (Male, has not consented)

In contrast, others viewed the list as less transparent because it lacked the explanations and signposting to further information that accompanied the health and DWP questions. Multiple consents in one place heightened concerns raised when considering a single consent question about the need for departments to receive and share information.

> *"It's a lot of information spread to a lot of people and you have no assurances from them that it won't be passed on to other people for any other reason."* (Male, changed consent)

> *"It's 7 requests by 9 different organisations. At that point you go that's a lot of personal information that I'm consenting to or not consenting to. Why is it now 7 different requests and why do 9 different organisations need my information to share with."* (Male, changed consent)

Even those that understood that ISER would receive the records and had expressed trust in the organisations felt the amount of personal information ISER would have on them might put the individual at risk. Data protection became the focus of discussion again at this point, with participants fearing the possible repercussions of ISER having the ability to build a detailed 'profile' of an individual.

> *"It's a lot of information spread to a lot of people and you have no assurances from them that it won't be passed on to other people for any other reason."* (Male, changed consent)

> *"In terms of wider consent and data sharing do I think the DWP, and NHS, and HMRC, and the Land Registry, and blah, blah, blah should all be in one centralised area? And Tescos, you know, bolting on all these things so there's a profile of [name]. I think that's a particularly bad idea."* (Male, changed consent)

Perhaps unsurprisingly, participants were more likely to consent to those departments that were deemed to be less 'threatening', for example, DfE, BEIS. The most concerning departments were finance-related. Participants were either selective of the departments they would consent to sharing their information with, or defaulted to not consenting. In fact, no participants defaulted to consenting immediately.

> *"If [Hannah]...knew which departments her information is going to...she would change her mind...I wouldn't want my information shared with DWP and HMRC. I would have said yes to all of them apart from the financial [departments]."* (Female, has consented)

Overall, the preference was for consent requests to be sequential rather than all at once. This was because each request was understood to be slightly different and therefore required individual consideration. However, participants expected if the approach of multiple consents was implemented, it should be at the beginning of the survey 'to combat fatigue from filling out the survey'. Moreover, there should be a limit of 4-5 questions on a page and the question should include the context and explanation associated with the single consent questions.

> *"I would hope there was a way to click on each request and find out more. Exactly what info is included and what used for, and link back to the section in the survey it was referring to.*" (Male, changed consent)

4. Understanding of implications of consent

This chapter explores participants' views on the benefits (section 4.1) as well as the risks of consenting to data linkage (section 4.2). It concludes with a discussion of the influence of the data linkage flowchart on participants' understanding of the implications of consenting (section 4.3).

Overall, there was almost no understanding of what happens following consent. A general, vague awareness that information is uploaded to a computer and used for research purposes was understood by participants. Participants did not anticipate any personal benefits from consenting but communicated benefits to others such as ISER researchers, other researchers, and government and, for some, society. Personal risks related to the collection, handling, storage and sharing of personal data, embarrassment from leaked information and the expectation that the government could investigate participants. The benefits to third parties included greater accuracy of information collected from panel members and a greater understanding of a topic leading to changes in policy and service planning.

4.1 Benefits of consenting

Participants did not identify any personal benefits of consenting, reinforcing the view that participants primarily carry the risks while other parties benefit from data linkage.

> *"Giving consent doesn't help me, it doesn't help us personally, you're doing it because you're happy to potentially provide a better result, and potentially a more accurate result."* (Male, changed consent)

There was a general understanding that consenting would benefit academics because the information would be used for research purposes. In particular, for greater accuracy of information collected from participants in the survey.

> *"It would provide a wider picture. if I was the one doing the research I would want as much information as I could have."* (Female, changed consent)

An expected benefit of having access to more accurate information was for the government in policy planning and this was seen as possibly leading to societal benefits in the future.

> *"It gives the government something to think about, if you link it all together you can see, instead looking at statistics and try to number crunch this should work, you are actually getting a feel for how this is actually effecting people and how people are actually coping with it from real life people and not just a computer programme that tells you how people should be coping with it".* (Female, has consented)

Misunderstanding about the direction of flow of information led some to believe a benefit of consent was the improvement of services. Participants believed that government departments would be granted access to survey responses which they could use to improve the provision of health care or pensions to survey participants. This view was further reinforced in the context of the NHS question by those who conflated the consent request with requests from GPs for participants to share personal details with the practice.

For some, lack of understanding as to the purpose of data linkage led to the view that consent represented no benefit to any individual or party.

"I can't see any benefits. How does it help planning in the community or whatever?" (Female, changed consent)

4.2   Risks of consenting

Most recognised that they held the potential risks to data linkage rather than any other party. Discussions of personal risks were dominated by concerns about the storage, handling and sharing of personal data. Data protection concerns underpinned three key risks: identity fraud, reputational damage, and harassment by telemarketers. A fourth key risk was associated with the misuse, rather than mishandling or storage of information by government departments. Without any information to suggest the contrary, belief in these risks meant that participants were less likely to consent.

> *"Even though research is for the greater good...people aren't interested in that, they're interested in themselves...as soon as you think about risk it's just easier to close it down."* (Female, changed consent)

Concern about the safety of personal information was widespread and participants frequently discussed the potential for identity fraud. While websites and servers were understood to be encrypted, data was 'never truly safe', with the risk of data being misplaced by, for example, politicians leaving personal records on trains. Exposure to stories of fraud or identity theft via the media or having personal experience prompted participants to dwell on these risks.

> *"The more information you share, the more chance of identity theft, whether you delete the information or not it will still be in the systems at some point."* (Male, has consented)

> *"You have to bear in mind each time you use data you have more chance of it being adversely used, it's a small risk but not an negligible one either because the impact can be massive."* (Male, changed consent)

Another personal risk identified was associated with the stigma or embarrassment associated with leaked data revealing sensitive or compromising personal information. For example, participants communicated fear that the fact that they claim benefits or have intimate and less understood health issues may be exposed.

Participants with experience of cold-calling believed a risk of sharing their contact details was becoming the victim of harassment by telemarketers.

> *"I think in terms of information getting leaked it's more annoying, I think it's annoying when people call you up because they've got your phone number and they start calling you up about a dishwasher or something or PPI...I would be more concerned about my contact details than the other details."* (Female, changed consent)

Misuse of personal information by government departments to 'catch out' individuals for illegal or inappropriate behaviour was a recurring view among participants. The fear of being caught out and the repercussions with this was frequently discussed by participants.

> *"Well, I don't know if he claimed benefits when he perhaps shouldn't have so there's always that risk of being found out…Is it an elaborate scheme to find out who's been swindling the system?"* (Female, changed consent)

> *"I think personally if I said go ahead and then all of the sudden the dole office flicked through and my name came up, and then they would say oh will just check on all of her, what is she getting and where is she and I'll be the unlucky bugger that will happen to."* (Female, changed consent)

The implication of consenting to data linkage as the basis of government decisions to drive a particular agenda that the participant disagrees with was another concern.

> *"The cynic in me says the data is used to prove or disprove whatever you're looking to achieve."* (Male, changed consent)

4.3   Influence of the data linkage flowchart on understanding of implications

While the focus of this research was not to test an illustration provided to panel members when they are completing the annual survey to help illustrate the data linkage process, we did capture feedback on the stimulus that is summarised here. See Appendix D for a copy of the data linkage flowchart.

Participants found the data linkage flowchart confusing. Only a few who understood the detail felt 'reassured' about consenting. There were several reasons for this confusion. Firstly, participants noted that the use of certain words such as 'match' and 'separate' were unclear and led to confusion. This was primarily because participants were not sure what these words meant in this context.

> *"I don't really like the diagram. You know where it says separate and match? I don't really get that. I don't know that you need the words and the lines because that makes it more confusing."* (Female, changed consent)

Participants were also concerned by the phrase 'other researchers' and what this meant for the transfer of their data. They questioned whether their details would be used by third party organizations or only those that are involved in the study.

Secondly, the 'deleted' box was viewed by many to have been removed entirely from the diagram and so disregarded this box from consideration. Those participants that understood that the box represented the removal of personal data were generally reassured by this. These participants recognised that their name and address would be deleted to ensure confidentiality which increased trust in the process.

> *"I feel ok with that because the information you are receiving back from them has all the personal data removed..."* (Male, changed consent)

> *"If I knew that at the start I might not have been so adamant not to consent to the NHS one, but knowing it [my name] would be deleted, I wouldn't say it completely swings my decision but it definitely makes me more willing to consent."* (Female, changed consent)

> *"I didn't realise it would be separated off completely, it makes you more willing to share things because you are not going to be linked to it."* (Female, has consented)

Thirdly, some participants remained confused about exactly who would be processing and using their data.

> *"Doesn't address the question of who actually does it (the linkage), the people who manage the databases will have to do."* (Male, has consented)

Finally, participants' cognitive ability which was communicated by the participant or inferred by the researcher played an important role in understanding.

> *"I've always been the worst at understanding diagrams and things like that."* (Female, changed consent)

Conclusions and recommendations

Qualitative research with 25 Understanding Society Innovation Panel respondents explored how individuals process two questions about consent to data linkage, and which factors influenced their decision. This research provided valuable insight in the range of influences on panel members' interpretation of consent questions and decisions to consent to requests to link data. The research builds upon the growing body of knowledge about practical, legal and ethical issues related to data linkage of survey responses to process-generated records.

Overall there was a lot of confusion about what data will be linked, how the data will be used, and what organisations are involved in the data linkage process. A number of factors affect understanding of the consent request. Participants were supported in their understanding of the consent request by particular words and phrases, supporting material and the presence of a researcher. In contrast, participants also misunderstood key components of the consent request; this undermined their ability to make an informed decision. Aspects of the request leading to confusion were ambiguity in the meaning of specific words, confusion as to whether information was going to or from ISER, or both, whether and in what way policy researchers differ from academics and government departments, and the inability to see the relevance or purpose of the request.

Changes to improve understanding of consent questions were shared by participant. Suggestions included providing greater clarity about why data is needed and the purpose of data linkage (including tangible examples), reassurances that linking participant information will not lead to repercussions for the participant, and clarification that data linkage is not requested because ISER thinks that participants do not always tell the truth. These are clear and relatively easy suggestions to implement to support interpretation of the consent requests. Amends to consent question wording, and revisions to supporting materials are suggested to improve understanding of consent requests in general. There may be population-specific needs not captured in this research due to the sample characteristics and size. As a result, further qualitative research with particular populations, such as those with dyslexia, or among those Understanding Society sample groups not featured in this study may be needed.

The extent to which a participant correctly understood the consent request was a necessary pre-condition for being informed about the consent request. However, a good understanding did not always lead to the decision to consent. Some participant's decisions were driven by subconscious factors, such as heuristics, and for others rational decision-making interacted with their environment. This was the case for those who had been involved in Understanding Society for many years and thus had established trust in ISER and gauged the personal risk to giving consent to be low as a result.

Understanding the different factors influencing decisions to consent to data linkage helps to identify good practice to follow to support informed consent and pitfalls to avoid in order to overcome the barriers to informed consent. The key levers and barriers for ISER to consider acting upon to encourage informed consent are summarised in Figure 3.

Figure 3 Key levers and barriers to influence to encourage informed consent
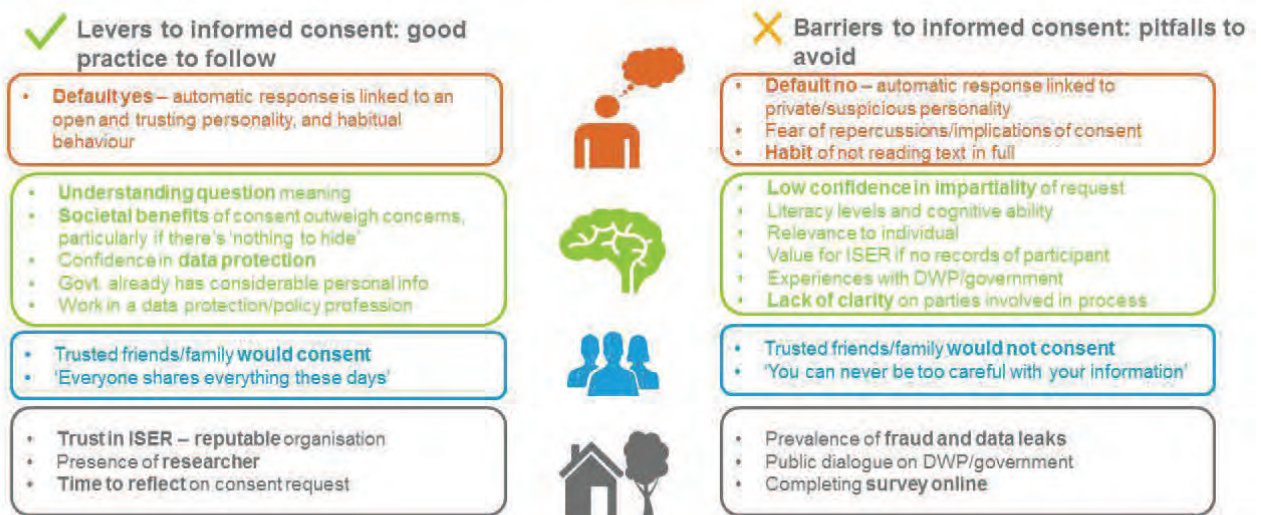
The research cannot indicate the prevalence of these influential factors in the sample population. Further, quantitative research is needed to determine the prevalence of these influential factors in the Understanding Society sample population, and to test some of the suggestions made throughout the report to improve understanding and consent amongst panel members.

The research also included exploration of participant's attitudes and views towards a document that asked multiple consents at one time. While many participants understood the direction of information flow when discussing the individual questions, when discussing the multiple consent questions it became clear participants believed their survey responses would be shared with the departments listed. Underpinning much of the anxiety and reluctance to consent to the multiple consent question was the fear of the department receiving survey responses, including income for people claiming benefits, in addition to personal information such as their name, date of birth and address.

The mode used in interviewing on Understanding Society (face to face versus online) appeared to influence decisions to consent. Participants were less likely to consent if completing the survey online due to the lack of an interviewer to instill trust and to answer questions participants may have, and due to the perceived increased security concerns simply because the survey was hosted online.

When thinking about the risks and benefits of consenting, participants are more likely to consent if they feel the benefits of consent to third parties outweigh the risks to themselves, and vice versa. ISER, researchers and, to a lesser extent, society was thought to benefit from participant consent. Greater accuracy in survey data and improved policy planning were possible benefits of data linkage. Risks to individuals were considered higher than risks to any other party. Identity fraud, reputational damage, harassment by telemarketers and government use were all cited as potential consequences to consent to data linkage. Emphasising benefits, with tangible examples, may help to de-emphasise personal risks and support consent responses.

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Appendix A – Recruitment screener

B001 - B001: QUAL SCREENER	**Begin block**

B002 - B002: RESPONDENT DETAILS	**Begin block**

Q001 - NAME:	**Open**

TITLE:

FIRST NAME:

SURNAME:

Q002 - CONTACT_DETAILS:	**Open**

ADDRESS:

POSTCODE:

HOME PHONE NUMBER:

BUSINESS PHONE NUMBER:

MOBILE PHONE NUMBER:

EMAIL ADDRESS:

PLEASE WRITE CLEARLY

Q003 - INTERVIEW: Open

INTERVIEW (RESPONDENT) NUMBER:

DATE:

TIME:

LOCATION:

RESEARCHER:

NOTES FOR RESEARCHER (eg have a dog/cat, are in a gated community, directions to location etc):

Q004 - Recruitment_method: Single coded

Normal

1   Client sample
2   Recruiter's own database
3   Telephone
4   On the street
5   Face to face
6   Delivered invite
7   Other: (please record) _____

Q005 - Recruiter_declaration: Open

The person named above has been recruited by me in accordance with the instructions and within the Market Research Society Code of Conduct.

SIGNED

NAME

DATE

BACKCHECKED: YES / NO

B002 - B002: RESPONDENT DETAILS End block

Q006 - QUOTAS:	Open

INTERVIEW NUMBER: #

LOCATION OF DEPTH: ___IN HOME/ALTERNATIVE LOCATION_____

DATE : _____

TIME: _____

RESEARCHER: _____

RECRUIT 25 PEOPLE

QUOTAS:

RECRUIT 25 PARTICIPANTS FOR IN HOME INTERVIEWS

Depths to be spread across a mix of locations and should be with the named sample contact:
- Greater London
- Hull

Mix of profiles across the following categories:

- FROM SAMPLE: **consent type from previous IP Waves** - has consented consistently, changed consent ever (either from consent to non-consent, or vice versa), not consented consistently
- FROM SAMPLE: **mode used** – face-to-face or web
- FROM SAMPLE: **education** – Degree, Other higher degree, A-level etc, GCSE etc, Other qualification, No qualification
- FROM SAMPLE: **benefits** – receiving or not receiving
- FROM SAMPLE: **age** – 18-21, 22-34, 35-44, 45-64, 65+
- FROM SAMPLE: **gender** – male, female, other
- FROM SAMPLE: **location** – Hull, London

- ASK DURING SCREENING: **financial management** – extent of difficulty to meet financial obligations each month
- ASK DURING SCREENING: **health** – general health

SEE NEXT PAGE FOR SAMPLE FRAME

N=25		Consent type			
		Consent	Changed consent	No consent	Total
Location	Greater London	Min 3	Min 3	Min 3	12 to 13
	Hull	Min 3	Min 3	Min 3	12 to 13
Mode	Face-to-face	Min 10			25
	Web	Min 10			
Education	Degree	Recruit a mix			25
	Other higher degree				
	A-Level etc				
	GCSE etc				
	Other qualification				
	No qualification				
Benefits	Yes, receiving	Min 10			25
	No, not receiving	Min 10			
Health	Very good health	Min 10			25
	Fairly good health				
	Somewhat good health				
	Somewhat poor health	Min 10			
	Fairly poor health				
	Very poor health				
Financial management	Very difficult	Min 10			25
	Somewhat difficult				
	Sometimes difficult, but not always difficult				
	Not very difficult	Min 10			
	Not at all difficult				
Age	18-21	Recruit a mix			25
	22-34				
	35-44				
	45-64				
	65+				
Gender	Male	Min 10			25
	Female	Min 10			

B003 - B003: FROM SAMPLE	Begin block

Q007 - GENDER:

Single coded

RECORD FROM SAMPLE 'GENDER'

RECRUIT TO QUOTA

Normal

1   Male
2   Female
3   Other ....

Q008 - AGE:

Single coded

RECORD FROM SAMPLE 'AGE'

| IF CODE 1 = DO NOT RECRUIT |
IF CODES 2-6 = RECRUIT TO QUOTA

Normal

1   Under 18
2   18-21
3   22-34
4   35-44
5   45-64
6   65+

Q009 - MODE:

Single coded

Not back

RECORD FROM SAMPLE 'MODE OF PARTICIPATION IN PREVIOUS WAVES'

RECRUIT TO QUOTA

Normal

1   Face-to-face
2   Web

Q010 - CONSENT:

Single coded

Not back

RECORD FROM SAMPLE 'CONSENT TYPE'

RECRUIT TO QUOTA

Normal

1   Has consented
2   Changed consent
3   Not consented

Q011 - EDUCAT: Multi coded

RECORD FROM SAMPLE 'EDUCATION'

RECRUIT TO QUOTA

Normal

1   Degree
2   Other higher degree
3   A-Level etc
4   GCSE etc
5   Other qualification
6   No qualification

Q012 - BENEFITS: Single coded

Not back

RECORD FROM SAMPLE 'BENEFITS STATUS'

RECRUIT TO QUOTA

Normal

1   Yes - receiving state benefits
2   No - not receiving state benefits

B003 - B003: FROM SAMPLE   End block

Q013 - INTRODUCTION: Text

"Good morning / afternoon, my name is X and I am calling from Kantar Public, an independent research organisation. We're calling about the Understanding Society survey.

Thank you for being a part of the survey, it means a lot to us that you give your time so generously. You'll be receiving a letter about the main survey which will be kicking off again in May.

Before then, we would like to invite you to participate in a separate interview, not a part of the annual study. We would like to talk to you about your views on linking information from various public records to your survey answers, called 'data linkage'. IF NECESSARY: linking information like health records held by NHS, benefits held by DWP etc.

We would like for one of our researchers to come and visit you to talk about your views and opinions on this - it will take around 60 minutes and you will receive a £40 cash debit card as a thank you for participating.

To confirm, this is an additional interview separate to your usual annual interview (this will take place in the coming months). It will also be a different kind of interview, much more like a conversation to discuss your thoughts and views.

IF NECESSARY: There is no online (web) or telephone option for this interview, it will need to be in person.

· The research is completely voluntary, anonymous and confidential
· Kantar Public is completely independent
· Kantar Public will not be giving the client team any details of your individual views that can be traced back to you

Are you available to take part in this interview?

1. Yes
2. No

B004 - B004: ELIGIBILITY   Begin block

Q014 - EXCLUSIONS: Multi coded

Are you or any of your immediate family working in any of the following sectors?

> DO NOT RECRUIT IF ANY OF THESE ARE MENTIONED
>
> IF SAY 'YES' BECAUSE INVOLVED IN UNDERSTANDING SOCIETY = CONTINUE TO RECRUIT

Normal

1   Advertising
2   Market research
3   Marketing
4   Journalism
5   Public relations
6   Lobby or campaign group
7   Local, regional or national politics
8   Employees of Local Authorities

B004 - B004: ELIGIBILITY   End block

B005 - B005: PROJECT SPECIFIC	Begin block

Q015 - HEALTH:

Not back

Broadly speaking, how would you describe your general health? READ OUT

RECRUIT TO QUOTA

Normal

1   Very good health
2   Fairly good health
3   Somewhat good health
4   Somewhat poor health
5   Fairly poor health
6   Very poor health

Q016 - FINANCIAL:

Single coded

Not back

Generally speaking, how difficult do you find it to meet your financial obligations each month?

IF NECESSARY: How difficult is it to pay all your bills and expenses in any given month?

RECRUIT TO QUOTA

Normal

1   Very difficult
2   Somewhat difficult
3   Sometimes difficult, but not always difficult
4   Not very difficult
5   Not at all difficult

B005 - B005: PROJECT SPECIFIC	End block

B006 - B006: GROUP DETAILS	Begin block

Q017 - T2:	Text

We would like to invite you to take part in an in-person interview about your views on linking survey answers to government administrative data (such as health records held by NHS, benefits held by DWP etc).

The discussion will last up to 60 minutes

The discussion will take place:
Date:
Time:
Venue (IN HOME):

You will receive a £40 cash debit card as a thank you for your participation

We will be audio recording the discussions. The discussions will be confidential and anonymous – your details will not be shared with anyone except the Kantar Public research team.

You <u>do no</u>t need to have any prior knowledge to take part in this group. We will not be testing people's knowledge, but simply asking for people's views and opinions.

Would you be interested in participating in this research?

If no, please record reason……..

B006 - B006: GROUP DETAILS	End block

B001 - B001: QUAL SCREENER	End block

Appendix B – Achieved sample

Criteria	Description	Consent type			Complete
		Consent	Changed consent	No consent	
Location	Greater London	4	8	2	14
	Hull	5	5	1	11
Mode	Face-to-face	Min 10			12
	Web	Min 10			13
Age	18-21	Recruit a range (Min 10)			3
	22-34				7
	35-44	Recruit a range (Min 10)			5
	45-64				5
	65+				5
Gender	Male	Min 10			10
	Female	Min 10			15
Education	Degree	Recruit min 8			6
	Other higher degree				4
	A-Level etc	Recruit max 8			4
	Other qualification				3
	GCSE etc	Recruit min 8			6
	No qualification				2
Benefits	Yes, receiving	Min 10			13
	No, not receiving	Min 10			12

Health	Very good health	Recruit min 8	8
	Fairly good health		8
	Somewhat good health	Recruit max 6	5
	Somewhat poor health		0
	Fairly poor health	Recruit min 8	2
	Very poor health		2
Financial management	Very difficult	Recruit min 8	1
	Somewhat difficult		5
	Sometimes difficult, but not always difficult	Recruit max 5	6
	Not very difficult	Recruit max 8	7
	Not at all difficult		6

Appendix C – Topic Guide

Understanding Society Development and Innovation Projects
Consent to data linkage
Topic Guide V3

Background

It is widely recognised that process generated data such as administrative data held by local and central government (e.g. education, benefits claimed, taxes paid, hospital visits) and data generated by private organisations (e.g. credit rating data from banks) have immense potential value for research, especially if securely linked to longitudinal survey data. The Institute for Social and Economic Research (ISER) are looking to undertake qualitative research to support future waves of Understanding Society. This research will directly inform thinking around experiments to test methods of collecting consent for data linkage on Understanding Society, as well as inform wider academic and researcher discussions about implications of consent on ability to link survey responses to process generated data.

Research questions

This research will explore how people decide whether or not to give their consent to link process generated data to survey responses to Understanding Society. Specifically, there are four objectives to address:

1. Understanding of what the consent questions are asking.
   - What do and don't participants understand by the questions, and what elements drive or hinder their understanding? (E.g. words, concepts, combination or ordering of words, placement of question in question block). *(Section 3 & 4)*
   - What changes would they make to improve understanding of what each of the consent questions is asking? *(Sections 4 & 6)*
2. The decision making process for consenting for process generated data to be linked to survey responses.
   - What are the factors influencing the decision to consent to data linkage (e.g. the top of mind/rational, subconscious, social and environmental factors)? *(Section 3)*
   - What are the factors driving changes to consent at different time points? *(Section 3)*
   - How does the decision to consent differ when presented with multiple consents? *(Section 5)*
3. Understanding of implications of consent.
   - Expectations of what will happen following their consent decision (whether to consent or

not to), including the benefits and risks of the decision made, and the perceived likelihood of those benefits and risks, for them/for others. *(Section 5)*

4. Whether and why consent to data linkage is higher in face-to-face interviews compared to online interviews? *(Section 3)*

Key principles for researchers to follow through fieldwork

This guide is intended to be used with a variety of individuals with varying characteristics and backgrounds. As such, it does not contain pre-set questions, but rather lists the key themes and sub-themes to be explored with participants in each interview.

Consent is a fairly abstract concept and we anticipate participants having difficulty with engaging with this. As such we have incorporated a number of projective tasks throughout to help participants unearth the range of factors influencing decision to consent to questionnaire responses being linked to process generated data.

It does not generally include follow-up questions like 'why', 'when', 'how', etc. as participants' contributions will be fully explored in response to what they tell us throughout in order to understand how and why views and experiences have arisen. The order in which issues are addressed and the amount of time spent on different themes will vary between interviews but the key areas for discussion are the same.

Questioning and probing will be framed to ensure we understand participants' situations as they view them. Researchers will adapt the approach, as much as possible, to suit the needs of each participant. The prompts provided are not exhaustive, but rather indicate the types of content we would expect to be covered – this may vary across participants.

There may also be elements of observation of interaction within the interview (e.g. participant looks confused but claims they understand what they are consenting to) – researchers will make notes of observations straight after the interview, capturing any key themes related to the research aims and objectives.

Researchers will keep the Kantar Public Behavioural Model in mind when exploring consent decisions. This helps to ensure responses sought from participations go beyond top of mind or immediate reactions to the discussion.

Our model highlights a range of automatic, non-conscious drivers to behaviour (emotions, heuristics and habit), rational drivers (judgement, capability and confidence), social drivers (culture, identity and norms), and finally but very importantly the effect of external environmental factors (defaults, priorities and opportunities). The model also demonstrates opportunities for interventions to influence customer behaviours against each layer of drivers. It highlights those factors that are known to influence decisions, ensuring we build in questions to discussions which explore the ways in which these factors manifest themselves in each specific context.

Researcher fieldwork checklist	
Topic guide copies Participant characteristics and appointment details (securely stored) Encrypted recorder and charger Charged mobile 3 pens of different colors	Stimulus: DWP and Health question showcard, DWP and Health information leaflet copies, x2 vignette showcards, multiple consents showcard, A4 paper, multi coloured pens Cash, taxi numbers, map of appointment area Participant incentives & incentive consent sheet
Interview reference table					

Participant #	Consent type	Mode type	Showcard rotation (section 3)	Showcard rotation (section 4)	Vignette # (section 5)

1. Introduction (3 minutes)

- **Thanks & introduction**: Introduce yourself and Kantar Public – independent research agency

- **About the client:** research on behalf of the Institute for Social and Economic Research (ISER), based in the University of Essex. ISER are leading research and survey experts that produce and analyse longitudinal surveys to understand how people's lives are changing.

- **If relevant:** introduce the client who is observing the interview and reassure they will not participate and are only there to learn more.

- **Reason for participation:** Explain that they have been selected to participate in this research because they are part of Understanding Society.

- **Clarify difference between this interview and the survey:** This interview will be more like a structured discussion, rather than a question and answer process, like you may have experienced when taking part in the survey with an interviewer. The topic is more focused as well; it will be specifically about your views on joining your survey responses to information held by government and private organisations.

- **How their info will be used**: Their views and experiences will be looked at together with views of others taking part in interviews. These views will be analysed by theme then a report written based on those themes. There will be no way of knowing what an individual said, and no one will be identified in the report.

- **Ethical considerations:** Anonymity, confidentiality, voluntary participation

- **Duration:** Up to 60 minutes

- **Reassurances:** No right or wrong answers - we are simply asking for people's views and opinions; comfort – let me know if you'd like a break at any time

- **Reminder about audio recording**: the discussion will be recorded so that we can accurately capture their views and researchers do not have to make notes during the interview and can listen back when analysing the data. The recorder is encrypted and only the research team will have access to the recordings

- **Incentive:** £40 as a thank you for taking part, in the form of Love2Shop vouchers to be given following the discussion

- Any **questions/concerns**?

- **Start recording**: acknowledge consent for being recorded

2. Background & context (5 minutes)

Section aim: To warm up the participant to the tone/style of a discussion, encouraging them to engage early

- Explore how they spend their time in a typical week e.g. work, education, hobbies
- Explore what is most important to them in their life e.g. family, career, extracurricular activities, health
- Briefly discuss their history on Understanding Society e.g. how long they've been taking part, attitudes towards the experience, why they take part

3. Decision making process for DWP and Health consent questions (15 minutes)

Section aim: To gain insight into the reasons why an individual makes a decision to consent, exploring both the reasons to consent and not to consent.

Researcher note: Refer to table on front page to check the previous consent status of the participant, and the mode used from the time they made a consent decision. Reminder to not share this information with the participant just yet – the previous consent status of the participant will be discussed at the end of this section, before Section 4.

Introduce either the DWP or Health consent question showcard and the accompanying information booklet. Check table on front page for rotation order. Ask the participant to take a few moments to read the showcard. They can refer to the booklet if they like but they don't need to read it fully –just do what they would normally do if given a question and supporting information. Once they have finished reading it, use the following prompts to facilitate the discussion. Researcher will take note of how long they take and what they do while considering the question (e.g. dwell on it, speak out loud to themselves, look confused)

- Initial response to the question – thoughts, questions, concerns
- Whether they would want to talk to anyone else before answering
- Any words that are difficult / confusing?
- Would they consent or not?
- Strength of decision to consent e.g. definitely, no doubt; ambivalent etc.
- How long they took to reach the decision – was it immediate / did they think about it?
- Initial reasons for their consent response?

Task 1: Ask them to think about someone they know who they think would likely consent. Ask them to write down all the reasons they can think of about why that family member would consent (IN BLUE), prompting them to reflect on the DWP/Health question.

- What is important to the person they have in mind?

- How do they think the person they have in mind would feel about the question?

- What would the question make the person they have in mind think about?

- How able would they feel that the person they have in mind would be to respond to the question?

- How would the person they have in mind react if the question for consent was read online?

- How would the person they have in mind react if the question for consent was read to them by an interviewer, in a face to face interview?

Task 2: Now ask them to think about someone they know who would not likely consent; ask them to add to the list all the reasons a friend would not consent (IN RED), using the same prompts above.

Using the completed list as a stimulus:

- Explore whether or not, and why, they personally agree with the reasons they've listed – adding additional reasons IN BLACK pen that are unique to them

Researcher note: Once you have thoroughly discussed the decision making process for a question, inform the participant whether or not their initial consent responses matches what they actually consented at the previous survey wave they took part in, reminding them how they answered last time e.g. face to face / online.

- Discuss their initial thoughts about similarities/differences to their past consent

- Explore reasons for similarities/differences between current and previous consent

- If consent was same at both time points, explore likely reasons for this

- If consent was different between time points, explore likely reasons for this

- Discuss whether they think mode has a bearing on their decision e.g. web or face to face

4. Understanding of DWP and Health consent questions (15 minutes)

Section aim: To gain insight into what is/is not understood by the consent questions, capturing suggestions for how to improve comprehension amongst participants.

Researcher note: Check table on front page for rotation order and introduce either the DWP or Health consent question and the accompanying information booklet. Ask them to read the question, referring to the information booklet if they like, as though they were answering the question for real. Explore in detail participant's understanding of the questions.

- Explore their understanding of what the question is asking
- Explore why they feel that this is what the question means.
    - Could it be understood in any other way?
    - Are there any words that could be misinterpreted / are confusing?
- If they were describing the question to a friend, what words would they use instead of what is written here?
- What comes to mind when they read the question?
- How do they feel about the question content?
- Any concerns about the question content?
- Is there anything unclear about the question? Spontaneous comments, then PROBE:
    - Words / combination of words
    - Phrases
    - Names of organisations/services
    - Location of information that signposts the reader to contact details/more information
- If the question is thought to be unclear, PROBE for reasons why it is unclear:
    - Ordering (e.g. order of information)
    - Amount of information (e.g. too much, too little)
    - Type of information (e.g. complicated, insufficient)
- Explore what they find clear about the question
- If the question is thought to be clear, PROBE for reasons why it is clear:
    - Ordering (e.g. order of information)
    - Amount of information (e.g. sufficient amount)
    - Words used
    - Type of information (e.g. no jargon, includes definitions/explanations)
- Thinking about the information that is held by government offices such as DWP/NHS, what information do they think is held about them?
- Who do they think will have access to their data?
- What do they think will be done with their data when it is shared with a government office?
- Explore their understanding of the timeframe they are consenting for their information to be linked – Do they understand it is for linking all previous data held by the government office, as well as future data?

5. Expectations for data linkage (15 minutes)

Section aim: To explore what participants expects happens after they consent, including the process of linkage and the use of their personal information for analysis.

- Explore what they think happens after they consent to the question

    o What do they think happens immediately, what happens later on?

    o Who is involved at each stage?

- Discuss how they feel about what they expect happens after they consent

Interviewer note: Introduce relevant stimulus: data linkage process showcard. Ask the participant to review it for a few moments.

- Explore influence of the data linkage process showcard on the participants expectations of what happens after they consent for linking their survey responses to information held by government offices

    o What do they think happens after they consent to the question now they've seen the showcard?

    o Whether their feelings about what happens after they consent to the question has changed, since seeing the showcard?

Task 3: NOTE- <u>half of participants</u> will be asked Vignette 1 and half will be asked Vignette 2. Check table on front page for vignette option to use. Introduce vignette on showcard, and read out.

Researcher note: Allow the participant to refer to the DWP consent question showcard when considering their response to Vignette 1, if relevant.

Vignette 1 (Benefits/Risks): Peter is part of Understanding Society. He recently completed the questionnaire, which included a question about whether he agrees that the people who collect his responses can match these to information held by a government department. They want to match to information about a benefit claim he made in the past and the time he was on an employment programme.

While considering his response, he wondered about what the added value was for him agreeing, and who benefited from knowing this information about him. Was it used for planning in his community?

He also started to think about the possible risks to his contact information and his identity if he consented.

- Discuss the benefits to Peter of him consenting – PROBE: generally, to him, to others?

- Discuss how much they personally agree/disagree with these benefits?

- Views on likelihood of these benefits happening

- Discuss the risks of Peter consenting – PROBE: generally, to him, to others?

- Discuss how much they personally agree/disagree with the risks mentioned

- Views on likelihood of these risks happening

REMINDER – Only ask one of the vignettes to each participant. If you have asked Vignette 1, DO NOT ask Vignette 2. See table on front of topic guide for instructions.

Researcher note: Show the participant the showcard with the sequence of consent requests ('multiple consents'). Allow them a few moments to read it before introducing the vignette.

Vignette 2 (Multiple Consents): Hannah is part of Understanding Society. She is at her office, taking a break from her work to complete the annual survey online. She has come to a question that introduces 7 requests to link her survey responses to information held on her by 9 different organisations: the National Health Service, Department of Health, General Registration Office, Office for National Statistics, Department for Education, Department for Work and Pension, HM Revenue and Customs, Department for Business, Energy and Industrial Strategy, and the Financial Conduct Authority.

Hannah is thinking back to a previous year where she recalled being asked to agree to her survey responses being linked to a department, but she doesn't remember having been asked about multiple departments or organisations at once. Hannah begins to provide her response to each question.

- Discuss why Hannah hesitated to answer each of the questions

- Discuss what they think Hannah's responses were to the questions

    o Would Hannah's responses to the question differ if they had not been asked all together?

- Discuss the difference to them between being asked one question at a time (as we did earlier in the interview) compared to being asked multiple questions about consent at one time

- Discuss what they personally would have done in Hannah's situation

6. Suggestions for consent questions (3 minutes)

Section aim: To ensure all suggestions for consent questions have been covered across the interview, and leave the participant thinking about a positive topic.

- Any further ideas for helping others like them to understand what the questions are asking
- Thoughts on how to encourage others like them to consent to questions – what is needed to help individuals understand what is being asked and to agree to consent?
- What would reassure them about giving their consent

7. Thanks and close (2 minutes)

Section aim: to wind down the interview, provide the opportunity for participants to share anything they have yet to, and express gratitude and complete remaining housekeeping tasks.

- Their final messages – thinking about everything we have talked about today, what has most stuck in their mind?
- Thanks, and reminder of confidentiality and anonymity
- Provide incentive, talking the participant through how to use it

Appendix D – Fieldwork stimulus
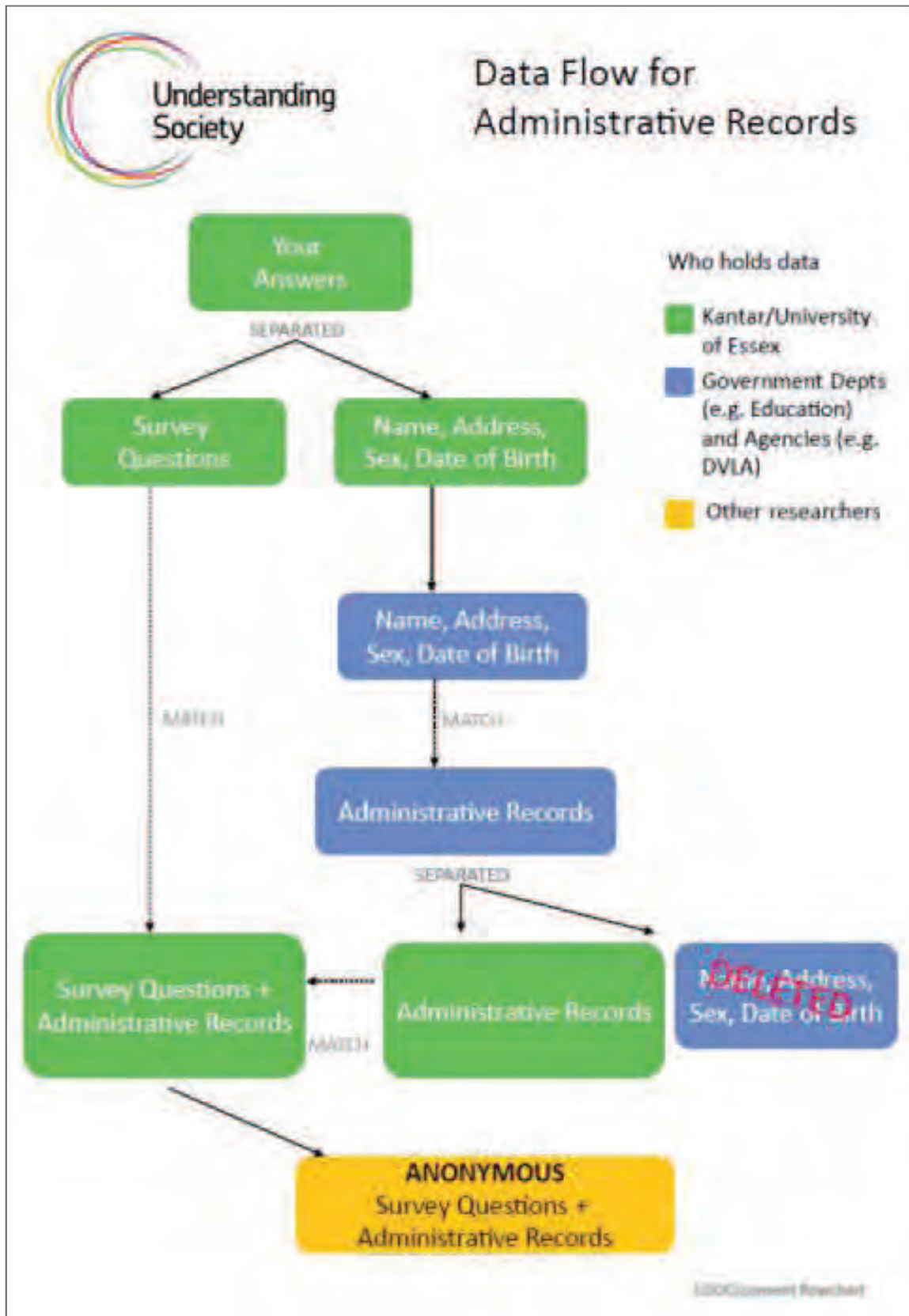
DWP consent (*Understanding Society*)

Thank you for taking part in this study. Your answers are of great value and interest to many academic and social policy researchers who will make good use of them.

We would like to add records held by the Department for Work and Pensions, containing information they hold on your benefit claims and time on employment programs, to the responses you have given to this study. Linking the information will help us to get a fuller picture about who claims benefits or seeks help from the DWP.

All information will be used for **research purposes** only. It will be used by academic or policy researchers under restricted access arrangements which make sure that the information is used responsibly and safely.

Please read this leaflet explaining how we would like to attach your DWP records to the answers you have given in this study. https://www.understandingsociety.ac.uk/participants/economic-records

Do you give permission for us to pass your name, address, sex and date of birth to the DWP for this purpose?

1   I have read the leaflet and am happy to give consent
2   I do not want to give consent

Information
on adding
economic
records

**Understanding
Society**

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W8

Data linking

Government departments and agencies collect a range of information about all of us for administrative purposes, so they can plan and provide services. Added to the responses you have provided in this study the information can inform further analyses and help us get a better picture of those who are using services provided by the government.

What am I being asked to give permission for?

We are asking for your permission to link the information Her Majesty's Revenue & Customs (HMRC) hold about your employment and self-employment history, your National Insurance contributions, income and tax credits. The information goes back to the 1970s, and to the beginning of self-assessment in the 1990s. The Understanding Society study at the University of Essex would like to add these records to the responses you have given to this study. If you give your permission, it will inform further analysis to help us get a better picture of the economic circumstances of private households and how they can best be helped.

What will happen if I give permission?

1) The Understanding Society study will give HMRC your name, address, sex and date of birth.

2) HMRC will use these details to identify the correct records it holds about you, and delete any of the personal information passed on to them.

3) HMRC will send your HMRC records to the Institute for Social and Economic Research at University of Essex using a secure data transfer method.

4) The Understanding Society study will add the HMRC records to your study responses.

What will the research be used for and who will use it?

Like your study responses, the additional information will be held as a resource for use by professional academic and social policy researchers for non-commercial research and statistics over the coming years. Any sensitive information would only be made available to them under restricted access arrangements which make sure that the information is used responsibly and safely. Names and addresses are never included in the results and no individual can be identified from the research.

The data will not be used to work out whether any individual is claiming benefits they should not be and will not affect any current or future dealings with HMRC. Your permission would allow researchers to provide answers to a great deal of highly policy-relevant questions, for example:

- how well prepared individuals and families are for retirement and how this differs across time and generations; and
- in much greater detail, how family circumstances interact with tax credits, earnings and interruptions in earnings.

What if I change my mind?

We will remind you periodically of the permissions you have given, and you can withdraw your permission at any time. While it is not possible to remove historical data, no new data will be added from that point onwards.

Who do I contact?

If you would like any further information or want to withdraw your permission, please contact us at:
FREEPOST RRXX-KEKJ-JGKS, Understanding Society, University of Essex, Wivenhoe Park, Colchester, CO4 3SQ.
Freephone: 0800 252853
Email: contact@understandingsociety.ac.uk

Thank-you!

If you have any questions or concerns, just
call our Freephone number: 0800 252 853
or write to: Freepost RRXX-KEKJ-JGKS,
Understanding Society, University of Essex
Wivenhoe Park, Colchester, CO4 3SQ

TNS

E·S·R·C
ECONOMIC
& SOCIAL
RESEARCH
COUNCIL

ISER

The National Health Service (NHS) maintains routine medical and other health-related records on all patients accessing the health services so they can provide health services to us when we need them. While we can learn about people's lives, well-being, experiences, and behaviour by asking direct questions, it can sometimes be easier to obtain some of this information from administrative records. Administrative health records may also help us to keep in touch with you and keep our records up to date.

We would like to ask for your permission to add information from administrative health records to the answers you have provided in the interview. Please read this leaflet explaining how we would like to attach your health records to the answers you have given in this study. https://www.understandingsociety.ac.uk/participants/health-records

Do you give permission for us to pass your name, address, sex and date of birth to the NHS for this purpose?

1   I have read the leaflet and am happy to give consent

2   I do not want to give consent

Understanding Society

Information on adding administrative health records

Introduction

The National Health Service (NHS) maintains routine medical and other health-related records on all patients accessing the health services so they can provide health services to us when we need them. While we can learn about people's lives, well-being, experiences, and behaviour by asking direct questions, it can sometimes be easier to obtain some of this information from administrative records. Administrative health records may also help us to keep in touch with you and keep our records up to date.

We would like to ask for your permission to add information from administrative health records to the answers you have provided in the interview. This leaflet explains more about this.

Please take a moment to read it.

What information would be added?

The information to be added is collected for administrative purposes by the NHS and held within statistical health databases by the NHS Information Centre, the Departments of Health, the General Register Offices and the Office for National Statistics. Some of this information is linked across central UK NHS and registration bodies.

The information may include, for instance:

- **Admissions or attendances at hospital (including dates of admission, discharge or attendance, diagnoses received, treatments and surgical procedures, waiting times).**
- **Records of specific conditions such as cancer or diabetes (including type of condition)**
- **Health registration details (including name of the Health Authority registered with, NHS numbers, and if a person who took part in the study were to have passed away, the date and cause of death).**

Who will use it?

Like your survey responses, the additional information may be used by academic and social policy researchers for non-commercial statistical analysis. Any sensitive information about specific health conditions or treatments would only be made available to them under restricted access arrangements such as legally binding licences, which make sure that the information is used responsibly and safely. Names, addresses and NHS numbers are strictly confidential and are not available to those using the data for statistical analysis. No individual can be identified from research findings.

Your permission – what does it cover?

Any information can only be released with your permission. In order to access the information, we will provide some necessary personal details such as your name, date of birth and address to the NHS and government departments holding the information. These personal details will only be used to identify your information. Before any information you have authorised is sent back to us, your name and other details will be deleted by the NHS. None of your survey responses will be disclosed to the NHS or government departments for any other purpose.

Like the answers you have given us in the survey, the additional health information will be completely confidential in accordance with the Data Protection Act. Your current or future dealings with the NHS or any government department or agency will not be affected.

How long does your consent last?

We would like to add information relating to your present, past and future circumstances. We are not putting an expiry date to this consent as we do not know exactly when we will obtain and add the information. We will remind you every three years of the permissions you have given, and you are free to withdraw your consent at any time.

What about your children's information?

We would like to add information on your child(ren) from birth up to age 16. We need to seek parental consent to add information on your children aged under 16. We understand that some children would be able to make this decision on their own behalf. You should make the decision that represents your child's wishes and best interests. Please discuss this with your child as appropriate. You can withdraw your consent at any time. Once your child reaches the age of 16 we will ask your child directly for their permission.

What about data security?

Your name, address and other personally identifying information such as your NHS number will always be strictly confidential. Your health records and your survey answers will only be used for research and statistics. We are very security conscious and all of our systems are password protected and your personal details can only be accessed by a small number of authorised staff. Your information will be encrypted and sent via secure transfer systems. We are compliant with the standards of the ISO 27001 data security protocols and procedures. Your personal details will be secure at all times.

What if you change your mind?

If you wish to withdraw your permission at any point in the future, please write to **Freepost RRXX-KEKJ-JGKS, Understanding Society, University of Essex, Wivenhoe Park, Colchester, CO4 3SQ** stating: " I < your name>, currently living at < your address and postcode> am a participant on *Understanding Society* and I wish to withdraw my permission for administrative health data and health registration details to be added to my survey data." Please sign and date your letter.
You may choose to withdraw only part of the permissions you have given.
To withdraw permissions you have given on behalf of your child(ren), you need to include their full name in your letter.

Thank-you

If you have any questions or concerns,
just call our **Freephone number 0800 252 853**
or write to **Freepost RRXX-KEKJ-JGKS,
Understanding Society, University of Essex,
Wivenhoe Park, Colchester, CO4 3SQ**

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I authorise the **National Health Service**, the **Department of Health**, the **General Registration Office** and the **Office for National Statistics** to disclose to the organisation responsible for this survey information about my health treatment and use of health services for future research studies of the frequency, causes, treatment or outcome of diseases and health conditions.	Yes ☐	No ☐
I authorise the organisation responsible for this survey to obtain information about my **National Health Service** registration from the National Health Service Central Register, and to follow my registration and health status.	Yes ☐	No ☐
I authorise the **Department for Education** to disclose to the organisation responsible for this survey information from my educational records.	Yes ☐	No ☐
I authorise the **Department for Work and Pensions** to disclose to the organisation responsible for this survey information from my records, containing information they hold on my benefit claims and time on employment programmes.	Yes ☐	No ☐
I authorise the **HM Revenue and Customs** to disclose to the organisation responsible for the survey information from my records containing information on your employment and self-employment history, your income, National Insurance contributions and tax credits.	Yes ☐	No ☐
The **Department for Business, Energy and Industrial Strategy** (BEIS) have information on energy use and energy efficiency for each address in the country. I authorise BEIS to allow the organisation responsible for the survey to link the information for this address to my survey answers to enable valuable research on the energy use of different types of household.	Yes ☐	No ☐
People's experiences of financial services would be useful to share with the regulator of financial services, the **Financial Conduct Authority** (FCA), which has an objective of protecting consumers. I authorise the FCA to link my answers from the survey, anonymously, to other data it can obtain from regulated firms as part of its ongoing remit to help protect consumers. In addition, selected aggregated date from my credit files will be included in the anonymised data set that are provided to researchers for research purposes only.	Yes ☐	No ☐

Peter is part of Understanding Society. He recently completed the questionnaire, which included a question about whether he agrees that the people who collect his responses can match these to information held by a government department. They want to match to information about a benefit claim he made in the past and the time he was on an employment programme.

While considering his response, he wondered about what the added value was for him agreeing, and who benefited from knowing this information about him. Was it used for planning in his community?

He also started to think about the possible risks to his contact information and his identity if he consented.

KANTAR PUBLIC=

Hannah is part of Understanding Society. She is at her office, taking a break from her work to complete the annual survey online. She has come to a question that introduces 7 requests to link her survey responses to information held on her by 9 different organisations: the National Health Service, Department of Health, General Registration Office, Office for National Statistics, Department for Education, Department for Work and Pension, HM Revenue and Customs, Department for Business, Energy and Industrial Strategy, and the Financial Conduct Authority.

Hannah is thinking back to a previous year where she recalled being asked to agree to her survey responses being linked to a department, but she doesn't remember having been asked about multiple departments or organisations at once. Hannah begins to provide her response to each question.

KANTAR PUBLIC

Appendix E - Example of completed fieldwork stimulus

To overcome issues of over-rationalisation or social desirability bias, a projective task was used with participants. Participant examples are included below to illustrate the outcome of this task. Researchers asked participants to think about someone they know who they think would likely consent to the consent question being discussed. Participants used blue pen to write down all the reasons they can think of about why that person would consent. Following discussion to investigate reasons for their responses, participants then used red pen to add the reasons the person they had in mind would not consent. Once completed, this list was then used as stimulus, to explore whether and why participants personally agreed with what they wrote.
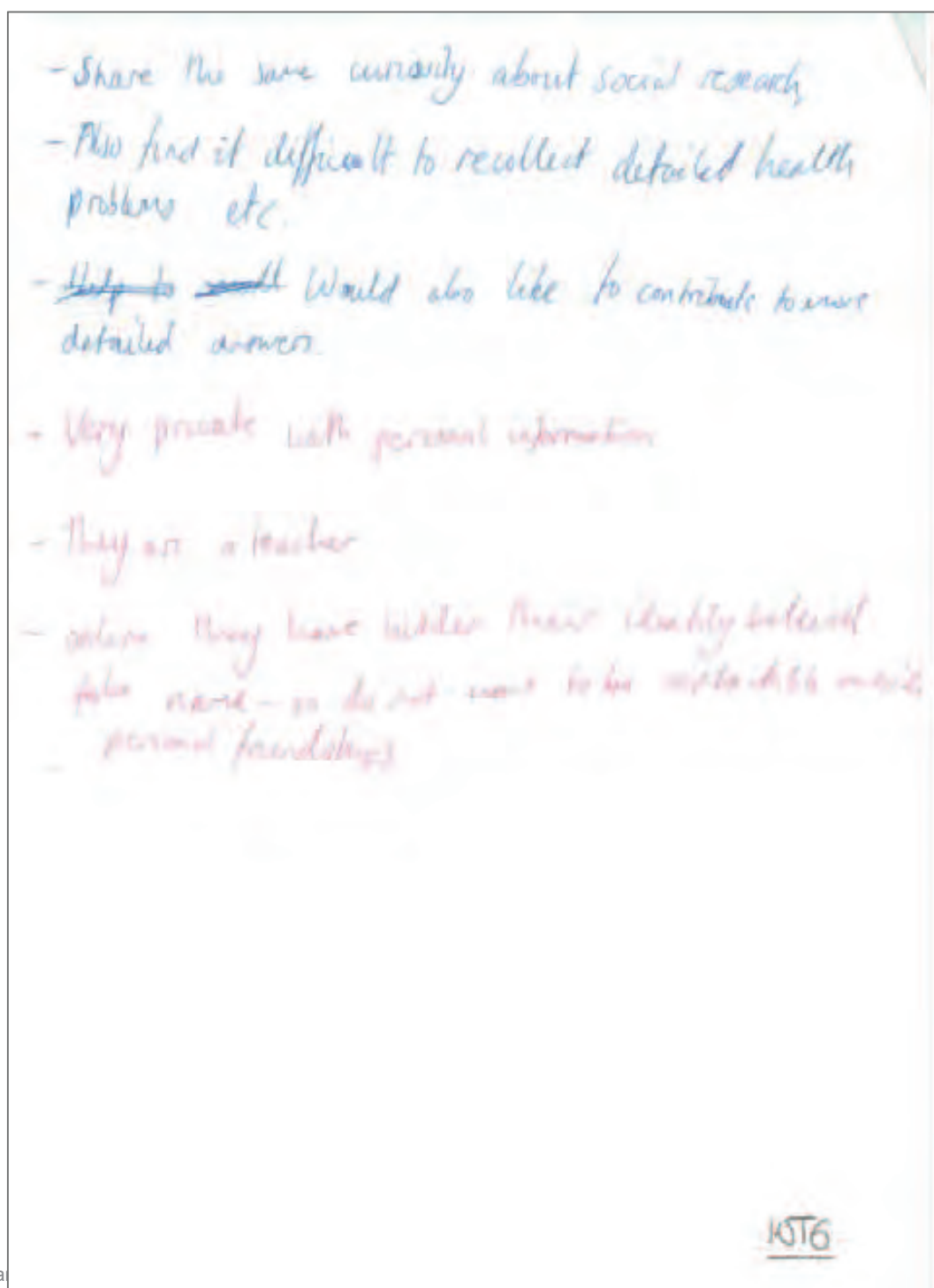
1) To help governmental departments
   work out programmes for benefits pensions
   etc.

2) To help the govt. get statistical evidence
   of the population's benefits / pensions etc

3) To get geographical evidence.

1) Concerned about security of the website

2) Having financial sources they do not want
   to admit to.

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GIVE CONSENT

* NOTHING TO WORRY ABOUT IN REGARDS TO DWP.

* DWP DOES NOT CONCERN THEM.

* INTERESTED IN POLITICAL VIEWS PERTAINING TO DECISION MAKING.

DON'T CONSENT

* SOMETHING TO HIDE

* DO NOT WANT GOVERNMENT EXAMINE IN THEIR PERSONAL BUSINESS