

MCS6 and Understanding Society Participant Engagement Research

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Longitudinal Studies at the Institute of Education and the Institute
for Social and Economic Research at the University of Essex

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Executive Summary

Executive Summary

This report presents findings from research that Ipsos MORI carried out with young people aged 10-15 to inform participant engagement approaches on the Age 14 Survey of the UK Millennium Cohort Study (MCS)¹ and the youth panel of *Understanding Society: The UK Household Longitudinal Study* (UKHLS).² The main objective of the research was to develop an understanding of key issues around young peoples' engagement in research, which can be applied to engagement approaches relevant to both the MCS and *Understanding Society*. Qualitative discussion groups and household depth interviews were carried out with young people aged 10-15 and parents of young people aged 10-15 across England, Wales, Scotland and Northern Ireland.

Summary of findings

Though familiarity with research is limited, perceptions of research with young people tend to be positive

Young people (and parents to an extent) were not very familiar with social research; they were more aware of market research or customer satisfaction surveys. However, upon further discussion, research (particularly social research) with young people was judged as important in that it enables them to give their views.

There are certain key factors that determine views towards research and the likelihood of participation: an assessment of the value or worth of research; whether it will be interesting or fun; and, the importance of their personal participation. Both young people and parents want information on these issues before making decisions

Despite lack of familiarity with research, there was an appetite for information to inform judgements about research, personal participation and engagement. Generally participants' initial perceptions of research were positive, given that they thought its purpose is to 'make things better' and saw it as necessary for improvement.

However, judgements about the benefits of research were made on a case by case basis; the purpose/ subject matter, perceived value, and importance of a piece of research were the key factors used to initially assess its worth. The value that participants placed on these key factors when assessing the benefits of a research study is a theme that could be seen when motivating factors for personal engagement and reasons for participation were discussed.

Participants considered a range of factors when deciding whether to participate in research. Communicating these factors in engagement materials and explanations about research studies is therefore key. Particularly important was whether taking part would be fun (for young people) and interesting (particularly for parents) and also that there was some merit in the research (e.g. participants agreed with the purpose of the research or felt that it offered some social benefit). Another factor was the feeling that they were valued for their individual contribution; something that was particularly important for engagement in longitudinal research. Furthermore, some parents encouraged their children to take part if they felt that participating would be 'good for them', for instance, by providing them with experience of expressing their views.

¹ The Millennium Cohort Study is run by the Centre for Longitudinal Studies (CLS) at the Institute of Education.

² The *Understanding Society* survey is run by Institute for Social and Economic Research, University of Essex.

A sense of ‘control’ over the process is important

Young people often wanted a sense of control over the process in order to feel more comfortable participating. Part of this lies in feeling informed about the process and young people often called for more information about the research – what it entailed and what the potential outcomes might be. Similarly parents often asked for greater reassurance, not just about the process but also about the legitimacy of the organisation and the interviewer.

The issue of control was also evident when young people discussed research methods, where they demonstrated a preference for self-completion methodologies that allowed them time to consider and amend their answers. There was a concern that interviewer administered methods provided them with less input into exactly how their answers were conveyed.

The importance of the incentive can vary in relation to judgements about the value or interest of the research

The value placed on an incentive as an engagement tool varied amongst participants. For some, the incentive was the primary reason for participation and views towards the research were less relevant. For others though, whilst some recognition of their contribution may still be expected, the importance of the incentive was weighed against other factors. Young people and parents often explained that the importance of the incentive varied according to how interesting or useful they considered the research to be. For example, where the research was seen as particularly engaging and/or valuable in itself, participants often felt more motivated to take part and said that, while they still expected an incentive, a lesser value would be acceptable.

There are certain factors that are especially important when considering engagement in *longitudinal* research

Participants often talked about wanting to feel comfortable with interviewers if they were visiting them more than once and many said that the more familiar they felt with an interviewer the more likely they would be to want to participate over an extended period of time. Provided their previous experience of research had been positive, young people, and parents on their behalf, were much more willing to stay engaged over several years. Parents talked of the need to build rapport with an interviewer and the fact they and their child would be more likely to feel assured during the visit if they had some contact, for example by phone or email, with the interviewer beforehand.

Some participants noted that longitudinal research felt like it required more work on their part and they wanted some recognition of this in the initial efforts at engagement. They said it was especially important that they understood the purpose of the research, rationale for multiple visits and its social value in order to secure and sustain their engagement.

For longitudinal research, transparency is vital in terms of explaining the commitment that will be required from respondents as well as the reasons for the frequency of visits. Making respondents aware that they can opt-out in future could actually help engagement by removing the sense that by participating they are agreeing to a long term commitment; a factor that some participants in the research found off-putting.

The extent to which young people are involved in decision-making generally – and decisions about participation in research specifically - can vary, even amongst those of the same age

We found a wide variation in the degree of autonomy young people have in decision-making and the role that parents play in this process. Parental involvement ranged from instances where parents allowed their child a large degree of autonomy to those where parents were heavily involved in decisions and often made them on their child's behalf. The most common approach, however, was a middle ground whereby parents and young people discussed decisions and came to a joint agreement or compromise.

The materials being age appropriate and easy for young people to understand would appear to be especially important in cases where parental involvement in decision-making is minimal. Where parents have more involvement in whether their child participates, providing examples of how the research may prove enjoyable might be useful in helping them to encourage their child to participate.

Amongst participants in this study, age was not the key factor driving the degree of autonomy young people exercised. Instead, within age groups the extent that young people were involved in decision-making was based on a more individual factor; parental assessment of their child's maturity. Individual factors such as gender and the child's placement amongst other siblings in the household also played a role in parental perceptions of their child's capability to make appropriate decisions independently of them. It is clear that not all young people of a certain age will behave in the same way when it comes to making decisions about participation in research.

Young people like their parents to be involved in the decision and want time to consider and discuss participation with them; they do not want to feel pressured

When asked about the process of deciding whether to take part in research, young people often mentioned they felt reassured by knowing their parents remain involved in the decision even as they gain more autonomy themselves. Similarly, parents tended to want some involvement in the decision. Therefore, the approach of obtaining consent from the parent to talk to the young person and then asking the young person if they would like to participate was generally considered most appropriate by both young people and parents.

Despite the differences between families in how they made decisions (discussed above), the 'ideal' decision-making approach was identified as one that allowed young people and parents the opportunity to discuss involvement in the research. Therefore, it was felt that the approach that a research company adopts in order to encourage young people to participate should facilitate this – for example, by providing sufficient information in advance mailings for both young people and parents. This was considered better than the company relying on providing young people and their parents with information during a household visit, as many young people said that made them feel they were being 'put on the spot' to make the right decision.

Whilst young people wanted involvement in deciding whether they participate in research, they do not necessarily feel they need to provide written consent. While some suggested that this would make them feel valued as respondents, it could also make the process appear unnecessarily formal and daunting to young people.

Whilst young people want to feel that their individual contribution is important, they need to be reassured about how individual data will be used

Many participants felt valued when they found out that their data was being used for a specific purpose and data about them could contribute to a wider project. Indeed many saw this as an important part of what kept them engaged. However, many also expressed concerns about exactly how data about them and sometimes quite private information would be used and analysed.

For physical measurements, for example, some young people – especially girls – felt self-conscious and were concerned about others finding out their measurement, particularly for weight. Additionally, when asked how they felt about taking part in cognitive assessments, several girls across all school years were put off because they thought the assessments felt too much like being tested, and were worried and embarrassed about getting the answers wrong. These participants were clearly concerned about the perception interviewers and researchers had about them, and as with physical measurements, struggled to see past individual results to the wider picture.

Young people in general (particularly those in the lower age groups) often struggled to grasp the concept that items of personal data, for example height and weight measurements, might be analysed as an aggregate. Sensitivities were especially pronounced regarding weight measurements as many young people wanted reassurance that others would not be told their results. They wanted to know that the measurements would be conducted in a private setting and with the option of having no-one else in the room at the same time (this sometimes included parents and interviewers).

Data collection methods have a significant impact on young peoples' survey experience and engagement

Common concerns among young people when considering data collection methods included: ability to answer the questions, ability to amend answers, having enough time to reflect and/or discuss responses with others they trusted.

Surveys via pen and paper, computers, laptops or tablets were generally found acceptable, given the right reassurances and adequate information being provided to both young people and their parents upfront. Telephone and mobile (as a CATI device) were widely rejected as data collection tools – in some cases to the extent that using these methods would discourage participation – as young people felt this would put them on the spot.

Collecting saliva samples for DNA was controversial; whilst some participants remained firmly against it, for others, the provision of appropriate information is key to ensuring their participation

Collecting saliva samples for DNA extraction was the most controversial topic of all those broached amongst parents and young people. Some parents were firmly against the concept of DNA samples and would not change their views. For others, explanation about what would and would not happen to their child's DNA sample reassured them and with further discussion they became more open to the idea; it is amongst these parents that information materials providing explanation would play a role in encouraging engagement/ willingness to participate in DNA extraction. Many young people struggled to fully understand the purpose of DNA extraction and how DNA would be used. Whilst providing appropriate information – especially reassurances of what it will *not* be used for – was beneficial in increasing many young people's understanding, not all young people could comprehend what DNA extraction would mean. Many young people wanted their parents to be involved in consent to give DNA

samples given confusion surrounding its purpose and/or unease at the process of collecting saliva itself.

Introduction and methodology

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This report presents findings from research that Ipsos MORI carried out with young people aged 10-15 to inform participant engagement approaches on the Age 14 Survey of the UK Millennium Cohort Study (MCS)³ and the youth panel of *Understanding Society: The UK Household Longitudinal Study* (UKHLS).⁴

Background

The MCS and *Understanding Society* are large-scale longitudinal studies which are amongst the most important research studies in the UK.

The MCS follows the lives of over 19,000 children⁵ in the UK born in 2000/1. The cohort has been surveyed on five prior occasions: aged 9 months, 3 years, 5 years, 7 years and 11 years. Given the longitudinal nature of the study, if respondents leave the sample their numbers are not replenished with new contacts. Therefore, maintaining engagement of existing cohort members with the study is key to its success. To this end, extensive focus is put on participant engagement activities, both between and during survey sweeps, as well as respondent experience of participating in the study.⁶ Vital to this is the age appropriateness of engagement activities and materials for cohort members at each sweep of the survey.

The next sweep of the study will take place in 2015, when the cohort is aged 14 years. This will present specific challenges in relation to engaging young people. The cohort members will be of an age where they may see themselves, and are seen by others, as young adults capable of taking their own decisions, including whether or not to take part in the survey. There is evidence from the previous birth cohort studies that the transition from parents to children as primary respondents can lead to a drop-off in participation and so the next sweep will be crucial to the long-term success of MCS. It will therefore be a major challenge to ensure the survey is designed to be as appealing as possible to these young people and carried out in a way that engenders their participation. Another consideration is the extent to which young people of this age understand the implication of decisions around participation and therefore the extent to which the consent they give is fully informed.

An added factor is that there are various elements involved in the MCS study over and above the survey including physical measurements and cognitive assessments. Therefore, it is important to understand what young people of a similar age to cohort members and parents of young people understand by these elements and possible barriers to participating in them. The MCS also needs to continue to engage with parents, as both respondents and continuing gatekeepers for cohort members, and thus there is an imperative to understand parental perspectives on coverage, content, consent and engagement of and direct communication with young people of this age so as to ensure their buy-in.

³ The Millennium Cohort Study is run by the Centre for Longitudinal Studies (CLS) at the Institute of Education.

⁴ The *Understanding Society* survey is run by Institute for Social and Economic Research, University of Essex.

⁵ These children are referred to as 'cohort members'.

⁶ Such as a detailed advance mailing introducing that sweep of the survey, leaflets explaining individual survey elements and a thank you certificate for young people.

Understanding Society: The UK Household Longitudinal Study covers the full age range from new-borns upwards, but does not solely focus on young people as is the case with MCS. As a household panel, all original household members and any children born to those household members remain part of the study regardless of whether they remain living together and wherever they move to, within the UK.

Unlike the MCS, *Understanding Society* sample members are approached annually. One household member, generally the main householder and/ or his/ her spouse or partner, is asked a relatively short household questionnaire. Additionally, each adult aged 16 or over is eligible for a full individual interview and self-completion questionnaire, while young people, aged 10-15, are asked to fill in a paper self-completion questionnaire. There has additionally been full biomarker collection and cognitive assessments from a significant proportion of the adult sample, but not the young people. *Understanding Society* faces issues of immediate engagement with the youth panel in relation to their response to the youth questionnaire. For *Understanding Society*, as with MCS, it is also important to explore how to encourage engagement as young people become older given that there is a transition to a different type of instrument at age 16, when, as for the 10-15 questionnaire the role of parents as 'gate-keepers' is likely to remain significant, even as they are asked for their independent consent. At some point the young people will leave the household and be followed up individually in their new household circumstances. In this situation the 'buy-in' of parents or others in supporting their participation will cease to be relevant and it will be important that their independent commitment to the study has been developed to ensure they continue to take part.⁷

As a result of these issues, Ipsos MORI was commissioned to conduct qualitative research to understand 10-15 year-olds' responses to research, surveys and their patterns of engagement more generally. As part of this programme of work, the National Children's Bureau (NCB) also carried out some supplementary work to understand the actual MCS cohort members' (and their parents') specific understanding of the meaning and value of MCS, to find out their views about their experience of the study so far and, in particular, any concerns about it from their experience up to this point. The findings in this report focus on the study carried out with 10-15 year olds in general by Ipsos MORI. The research conducted by NCB with cohort members and their parents is reported on separately.

Objectives of the research

The main objective of the research was to develop an understanding of key issues around young people's engagement in research, which can be applied to engagement approaches relevant to both the MCS and *Understanding Society*. This study addressed several issues that could be important factors in determining the extent of young peoples' engagement in research. As they are issues that are likely to be relevant to consider in many longitudinal studies with young people, they are of shared interest for both MCS and *Understanding Society*. These include:

- Young peoples' attitudes to research and their role in it;
- Young peoples' understanding of the consent process, both for participation generally and for data linkage;
- Young peoples' responses to the collection of biomarkers and their use in research;
- The role of parents as gatekeepers and how the decision-making process works between parent and child;

⁷ If one or more original household member(s) move to a different address interviewers attempt to trace them and conduct the survey with the new household.

- Engagement with particular modes of data collection;
- Preferences in terms of direct communication throughout the research process; and,
- The suitability of different materials and survey approaches for young people.

As well as these general issues, there are also some factors specific to each survey. Findings from the research will, for instance, feed into material development and testing work and thus form the basis for MCS cohort member communications from autumn 2013 onwards. For *Understanding Society*, it was important to understand what would be the best approach for youth panel members; how the youth questionnaire should be presented and implemented within the study, issues around potential future collection of biomarkers with under-16s, engagement on transition to the adult questionnaire at 16 and the longer term attrition strategy.

Research design

Qualitative research was carried out with young people aged 10-15 and parents of young people aged 10-15.⁸ Qualitative research offers the opportunity to gain considered views from participants and examine in detail the reasoning behind their opinions. The research involved a mix of in-home depth interviews and discussion groups. The in-home depth interviews were conducted with both the young person and their parent, with questions asked to each participant separately and then a joint discussion with both young person and their parent towards the end of the interview. Separate discussion groups were held with young people and parents⁹. This mixed-mode approach was used as it allowed the family dynamic to be observed at a household level (via the in-depth interviews) as well as young people to give their opinions in a more independent environment with their peers (via the discussion groups).

On average, between six and eight young people took part in each young person discussion group, while the parent groups were slightly larger with between eight and ten participants attending. Discussion groups with young people consisted of groups with sets of friendship pairs (where possible) from the same school year as it was felt that this approach was most likely to put participants at ease and enhance the group dynamic. Parent groups were also split by school year of their child as we hypothesised that decision-making would vary greatly by age of young person. Discussion groups and interviews lasted approximately 90 minutes and, before taking part, participants were asked to complete a pre-task exercise (explained in more detail on page 12).

Participants were recruited using a free-find approach by specialist recruiters. To recruit friendship pairs, one young person was recruited initially and then they/ their parent were asked if they could recommend another young person to take part. Recruitment questionnaires were used to ensure demographic representation.

Fieldwork was carried out between 3rd June and 28th June 2013. Overall, the research comprised:

- 10 discussion groups with young people;
- 7 discussion groups with parents; and,
- 22 in-home depth interviews with young people and their parents.

⁸ These were 'general public' young people in that they were not recruited on the basis of having had prior involvement in *Understanding Society* or being an MCS cohort member.

⁹ Parents recruited to the discussion groups were not parents of young people also taking part in the research.

Fieldwork was conducted in a mix of urban and rural areas across England, Wales, Scotland and Northern Ireland as highlighted in Table 1.

Table 1

Area	Fieldwork conducted
England (London)	2 discussion groups with young people 1 discussion group with parents 5 household depth interviews
England (Liverpool)	2 discussion groups with young people 1 discussion group with parents 4 household depth interviews
England (Long Eaton)	2 discussion groups with young people 1 discussion group with parents 3 household depth interviews
Northern Ireland (Portadown)	1 discussion group with young people 1 discussion group with parents 4 household depth interviews
Scotland (Glasgow)	1 discussion group with young people 2 discussion groups with parents 4 household depth interviews
Wales (Bridgend)	2 discussion groups with young people 1 discussion group with parents 2 household depth interviews

Discussion groups were split by:

1. Young person's school year;
2. Young people groups were split by gender whereas parent groups contained a mix of male and female parents;
3. Parent's social grade; and,
4. Whether the area was deprived or more affluent.

Table 2 shows the characteristics of the achieved sample.

Table 2

Characteristic	Number of young people groups	Number of parent groups	Number of household interviews
Young person year group¹⁰			
Year 6	2	1	3
Year 7	2	1	3
Year 8	2	1	7
Year 9¹¹	2	2	4
Year 10	2	2	5
Young person gender			
Male	5	Aimed to achieve a mix of parents with male and female children	11
Female	5	Aimed to achieve a mix of parents with male and female children	11
Social grade of parent¹²			
ABC1	5	3	12
C2DE	5	4	10
Area type			
Affluent	5	3	12
Deprived	5	4	10

Participants in the research represented a range of ethnicities based on the ethnic makeup of the local population in areas where fieldwork was conducted. For discussion groups with parents and in-home interviews, we also aimed to achieve a mix of couple parent and lone parent families, parental working status, families in which the young person was the eldest child versus having older siblings and families where there were multiple children versus the young person being an only child. The reason for the last two quotas is that it was felt that family composition (number and age of children) would impact on the family dynamic in terms of decision-making; something that was extremely relevant for this piece of research.

¹⁰ Throughout the report when discussing year group we present English and Welsh year groups rather than the equivalents in Scotland and Northern Ireland. Recruitment materials contained reference to the nationally appropriate year group. Year 6 young people are aged 10-11, Year 7 young people are aged 11-12, Year 8 young people are aged 12-13, Year 9 young people are aged 13-14, Year 10 young people are aged 14-15.

¹¹ Whilst the *Understanding Society* Youth Panel includes 10-15 year olds, this research was slightly weighted towards those aged 13 and over in terms of representation in the sample. This purposive sampling by age was done because it was felt that those in the 13-15 age range will be more independent, more able to respond (and refuse) in their own right and more important to engage long-term with *Understanding Society* as well as overlapping more with the MCS cohort.

¹² Understanding views of young people and parents accordingly to whether they live in a deprived or more affluent area was important to the research. Interviewers were briefed to recruit some groups and depths in deprived areas and some in affluent areas. As the extent to which an area is deprived could be a fairly subjective issue, we also added a quota on parent social grade as a sense check.

Fieldwork and analysis

In order to frame their thinking about research, young people were asked to complete a pre-task before taking part in a discussion group or interview. Two different pre-tasks were used; one asking participants to record the sorts of information they looked up in the days prior to taking part in the group/ interview. The other asked young people to look into what research is. The sample was split with half of the young people participants receiving each of the tasks. Copies of the pre-tasks can be found in Appendix B.

Discussion guides containing topics and prompts were used by researchers to facilitate discussion in both the groups and in-home interviews. Discussion guides were designed in conjunction with the Centre for Longitudinal Studies, the Institute for Social and Economic Research and NCB. Separate discussion guides were used for parents and young people and a single, combined guide was used during in-home interviews conducted with parents and young people.

Throughout the report we mention a 'hypothetical' or 'mock' research study. During the discussions – both in-home and groups – participants were introduced to the idea of a research project that follows young people and families throughout their lives. This hypothetical study was used as a method of encouraging discussion around longitudinal research as well as different types of data collection methods. The discussion focussed on this study in order to make concepts around longitudinal research and methodologies easier to understand. This was particularly important given that the research was with general public young people rather than cohort members, and so the hypothetical study provided a way of making the topics being discussed easier to relate to for those unfamiliar with research.

Analysis of the findings from the interviews was conducted throughout the fieldwork period through the collation of open field notes, coded analysis in Excel spreadsheets and in regular analysis sessions with the interview team. In these sessions initial hypotheses were developed and discussed. Ongoing analysis of findings meant that research materials were revised once during the field period to reflect emerging findings. Copies of each of these guides can be found in Appendix A.

Ethical considerations

Participants were made aware that they would remain anonymous and no responses would be attributed to them in reporting the findings of the research. All participants were informed of the subject to be discussed in the research prior to taking part and consented to participate. In all instances when recruiting young people, parents were asked for consent for their child to take part before the young person themselves was asked if they wished to participate in the research. In addition to ethical considerations, the consent process also held additional importance in this piece of research as participants were asked about it during the discussion as part of thinking about the process of deciding to participate in research. In all cases where consent was given by participants, the groups and interviews were recorded.¹³

¹³ There were less than a handful of cases when participants did not give consent to be recorded, all of these were in-home interviews.

Interpreting qualitative findings

Qualitative research is not by its nature designed to be statistically representative. It is intended to be illustrative, providing detailed and insightful levels of in-depth understanding around a research topic. Therefore, claims cannot be made about the extent to which the conclusions may be generalised to the population. Instead, we present the broad range of views given by participants, and where appropriate make reference to overall balance of opinion or general consensus.

Verbatim quotes and case studies are used throughout the report to illustrate particular bodies of opinion, but these should not be taken to define the opinions of all participants. In some cases, sample sizes are small.

This study presented a unique challenge in that when conducting research with young people and parents about their likelihood of participation and engagement in research, we were already speaking to an engaged audience (in that they were sufficiently engaged to be taking part in the discussions in the first place). It did not therefore draw on the views of harder to reach audiences who perhaps present more challenges in engaging in research. It is important to consider these findings with this in mind.

Structure of this report

The report begins by discussing findings about top of mind views towards research amongst young people and parents. Following this, we examine the way in which decisions are made between young people and parents. We then discuss factors that influence decisions around participation in research, both top of mind factors and more considered factors that emerged during discussions around the hypothetical study. This is followed by a section detailing how decisions about participation are made in practice within the household including how different types of consent to research and for the handling of data are considered. Finally, we examine views towards different types of data collection methods and the impact that these are likely to have on engagement in research.

Existing experience and views of research

Existing experience and views of research

At the start of the discussions, participants were asked about their information gathering habits and any research they may have done. This was a helpful way of introducing the concept of 'research'; something that young people in particular were unfamiliar with. We also discussed top of mind understanding and perceptions of research. Gaining these views was important because, as highlighted throughout the report, they framed attitudes towards participation and were therefore key to understanding engagement.

Information gathering habits

Types of information young people and parents search for

Many young people we spoke to told us that they search for information for their school work. This included looking up facts – historical or geographical for example – and using revision websites and dictionaries to aid their studies. Like their parents, they also looked up information for their social lives – about dance troupes to join or cinema listings – and about things to buy; whilst parents compared insurance policies and holiday prices, young people searched for ideas for toys (such as computer games) or clothes.

Sources of information

Most of the young people that we spoke to turned to the internet to find information; it was perceived to be 'faster and easier' than other sources, and also offered more information in one place.

'I don't really read books as much... [the internet] can do a lot more things than a book... about history, geography...it can have a lot more in it.'

Young person, Year 8, ABC1, Long Eaton

Young people were confident about finding information on the internet, and conducted targeted searches to get exactly what they needed: for instance BBC Bitesize for revision, news websites for football results and YouTube for make-up tutorials. Social media such as Twitter, Facebook and blogs were mentioned as sources of information by some, which alerted them to events in the lives of their peers and the wider world.

'I saw on Facebook about the soldier who died in Woolwich, so I turned on the news.'

Young person, Year 8, ABC1, Glasgow

Parents also used the internet to find the information they needed; using search engines, comparison websites and forums such as Mumsnet for help.

Magazines, newspapers, radio and TV were also commonly used by parents and young people to find information: magazines and newspapers for checking the news and TV listings, and the radio for information about the local area (e.g. road closures).

Levels of trust in these sources

Relying primarily on the internet for their information, young people often found themselves faced with conflicting information on any given topic. These situations highlighted something that most of the young people we spoke to knew already – that they should not trust every source equally. However, as highlighted in the following examples, young people had different views on which ones to trust, and different methods for deciding what was ‘good’ information.

Own Judgement and Caution

Some of the young people we spoke to tended to rely on their own judgement to decide which sources were trustworthy. Confident they could discern good information from bad, they were happy to judge the trustworthiness of sources on a case by case basis, to approach with a bit of scepticism and to go with what seemed right.

‘If it doesn’t sound right, you can tell.’

Young person, Year 8, ABC1, Long Eaton

They were happy to look at sources they knew they should not entirely trust – such as Wikipedia – and only take from them what they judged to be probably correct: ‘I decide myself’. This approach could be helpful, allowing young people to roam sources freely and ‘take it all in’, rather than feel constrained in their search

Cross-checking and Coherence

Many who used their judgement to navigate information sources also mentioned some sort of cross-checking, for coherence. For instance, they might cross-check information against what they’ve been taught:

‘If sounds a bit funny, I would not go for it and I would only go for the parts that I have learnt in school.’

Young person, Year 9, ABC1, Bridgend

Alternatively, some would check for coherence between different websites, or check a website against a book, especially when they knew a website – such as Wikipedia – can be changed by anyone.

Authority

Trustworthiness was most powerfully indicated for some by the authoritativeness of a source. Authoritativeness was associated with thoughts of rigor (books were to be trusted because publishing houses would have checked facts) and, for some, conveyed by known brand-names: big TV companies, including BBC and Sky, might be trusted over smaller ones. Furthermore, a website that a teacher recommended was perceived as credible by some, whilst of internet forums one year 9 boy said:

'They are answered by people who [do not really know] so I would say that a newspaper is probably more reliable because it has got to be published.'

Young person, Year 9, ABC1, Bridgend

Consensus Opinion

Another approach to handling the glut of information available to young people was to trust the most popular answer to a question.

One of the young people we spoke to described using Yahoo Answers to help with his homework: he would pose his question on a forum, await answers from across the world and go with that offered by the most people. He used the number of holders of an opinion to indicate its usefulness to him: if a fact is popular, it might be the right one to work with.

However, young people told us that the extent to which they deemed a source of information to be trustworthy was not the only factor they considered when deciding where to look for information. The speed of accessing information and convenience were also important; and both were offered by the internet, particularly due to mobile access meaning that internet sites can be viewed on a Smartphone when young people are outside of the home.

Spontaneous perceptions of research

We asked participants for their views on research early on, before they had gained greater knowledge of the research process through their participation in the fieldwork. The aim of this section is not to discuss the nuances of attitudes to research participation in detail but to present initial reactions to the concept of research. Factors that may encourage participation in research are discussed later in the report.

Awareness of research

Participants all had some awareness of research, with market research being the most familiar. Both parents and young people could think of companies that might do market research and most of the parents we spoke to were aware of customer service, or consumer satisfaction surveys. Medical research was also familiar to many participants.

In contrast, we found relatively low awareness of social or opinion research, especially among young people. A few young people thought that the Government would do research relating to schools – their performance and what qualifications they should offer – and to help the economy, but this was often little more than speculation. A few young people were able to give specific examples of social research, for instance there was a mention of the Census. Similarly, some parents expected the Government to conduct research to influence policy and determine services, although the specifics of this were mysterious to most.

Many young people reported undertaking research at school, as part of subjects such as Design, Technology and Science, although they often did not immediately consider it research. To illustrate this, one young person explained that they had taken part in an

experiment to determine ideal growing conditions for plants for a Science class, but only realised this might be research when prompted.

Perceptions of research

Generally participants' initial perceptions of research were positive, given that they thought its purpose was to 'make things better'. Research was perceived to be useful and necessary for improvement.

'If they don't research things, they are not going to get things right, are they?'

Parent of Year 10 young person, C2DE, Bridgend

Whilst some parents understood the role of research in improving experiences in relation to customer services (for example, one participant referred to customer satisfaction surveys in the bank she works in), young people tended more towards associating it with 'getting the answers right' and learning.

The belief that research was positive because it was a way to acquire or broaden knowledge was also common among those young people who had grasped the concept of primary research. Some stressed the importance of maintaining up-to-date information, and, for these participants, research was readily associated with understanding and learning.

The idea that research was beneficial was closely associated with the idea that it could effect, or inform, change. It might do this by identifying problems and testing solutions, and many valued the idea that it did so, in part, by gathering a diverse range of opinions and points of view. To be truly useful though, participants felt that research must be acted on. In this sense, research was closely associated with being an instrument for change.

'Research is to change things, to see if there's something that can be done better or ... if it can be changed to be made better to be made more effective.'

Parent of Year 6 young person, ABC1, Liverpool

Whilst we came across no unambiguously negative perceptions of research, there were a few caveats around positive views of the use of research.

Judgements as to whether research played a positive or negative role were often made on a case by case basis relating to the perceived importance and value of a piece of research. Evaluation would depend on the subject matter, aims, methods, or quality of the research. Further, participants told us they would have to be sure the outcomes of the research were actively for the common good; there was concern that 'sometimes people think of pointless things' which culminate in a wasteful research project. Similarly, a few parents we spoke to associated research with interfering or being 'intrusive'. For these people, an association with a nanny or surveillance state was held, and they were concerned that such research was somehow sneaky and suspicious.

'Government shouldn't be intruding into our lives.'

Parent of Year 8 young person, ABC1, London

Research with young people

Whilst issues around young peoples' participation in research are explored in more depth later, most parents generally had a positive attitude towards research with young people, believing it could aid understanding of their lives and interests. Some suggested certain areas they would be particularly keen to see research in: one parent of a year 8 boy said she would be interested to know more about what shapes children's behaviour, and a parent of a year 7 girl was keen for there be more research into child development.

Thinking more specifically about social research with young people, parents were positive about the opportunity it would offer to let young peoples' voices be heard and have their opinions listened to; something they perceived rarely happened. Parents also expected that it would be helpful for policy research to gather the opinions of people of various ages, including those of 'the next generation' who will shape the future. Young people too thought that the chance to have their opinions heard was a valuable part of research, and appreciated it when their views had been sought in other circumstances. For instance, one year 10 boy mentioned that he was pleased that his school had consulted pupils before changing their school uniform.

Implications for engagement

- Young peoples' reliance and familiarity with the internet as a source of information indicates that this may be a useful channel for communicating with and engaging young people in surveys (e.g. having survey-specific information that young people can locate on a website).
- Young people (and parents to an extent) are not very familiar with social research and therefore it is important that research is explained in a way they can relate to (e.g. without too much jargon or discussion about policy).
- The purpose/ subject matter, perceived value, and importance of a piece of research are the key factors used to initially assess its worth; a theme that can be seen in motivating factors for personal engagement and reasons for participation.
- Research with young people was judged as important in that it enables them to give their views; therefore the importance of young peoples' opinions should be emphasised in engagement exercises with parents as well as young people.

Young people and decision-making

Young people and decision-making

Increasingly, as young people make the transition towards adulthood there is likely to be a shift whereby they assume more responsibility for decision-making. At the same time though, parents are likely to retain some input. Understanding the way in which the process of making daily choices is managed, both by young people and parents, provides useful context for later discussions about the research decision process and how consent should work.

Young people tended to find it difficult to explain how they were involved in decision-making. They were able to list occasions when they had been included in decisions, but the actual process was difficult for them to reflect on. On the other hand, parents were a lot more conscious of this dynamic because they were the ones setting the parameters on the decision-making. Therefore, this section is more focused on parents' perspective of how decisions are made and the extent to which young people are included in the process. However, we have also drawn on observations made in the household interviews – where we saw both participants together - as to how the parent and young person interacted to make decisions.

How were decisions made in the household?

Households varied greatly regarding the way in which decisions were made within them. Whilst all parents felt they had a degree of responsibility for overseeing their child's decisions, the extent to which they gave their child autonomy over decision-making varied. As would be expected, the type of decision¹⁴ along with factors such as their age, had an impact on the amount of decision-making responsibility a young person was given. However, the degree of autonomy a parent allowed their child – and therefore a young person's experience of decision-making in the household – could be broadly categorised into three mindsets:

1. The parent and child **discussed** at length the **different options** before coming to a **compromise or decision together**;
 2. The parent **allowed their child more autonomy in making decisions**; depending on the type of decision they would often consent for their child to lead the way; and,
 3. The parent wanted to be **well-informed** about what their child was involved in and often **made decisions on their behalf**.
- **Households where parent and their child discuss and come to a compromise or decision together**

In these households the parent and young person discussed the different options extensively, with the young person's viewpoint genuinely taken into account. After talking through the different arguments, it would usually be the young person who made the final decision about the course of action to take, sometimes involving compromise.

¹⁴ The types of decisions participants were thinking about for the purposes of this discussion were food shopping; holiday planning; car purchasing; school choice; and, perhaps most importantly, decisions around going out, such as going into town by themselves, or with friends.

While this type of decision-making was the one we came across most frequently in the research – and was the one that parents perceived to be ‘ideal’ – this is not to say that it always happened in practice. For instance, while families may approach big decisions, such as deciding what school to go, in this way, they may not do so for more routine ones like everyday household purchases.

One parent used the example of choosing what secondary school her son should go to. He told her that he wanted to go to the same selective school as his sister. In order to do so though, the mother explained to him that he would need extra tuition in order to sit the exam and that it would mean that he probably would not be with his current friends.

The son understood and accepted this and decided to press further with his decision to go to the selective secondary school. She liked that he had come to this decision himself with the knowledge that it was not what his friends were doing and she felt it was for his benefit in the long term.

- **Households where parents allowed their child more autonomy in decision-making**

These parents tended to be confident in their child making day-to-day decisions, such as those around their social life or the activities they participate in, often because they saw their child as mature enough to make informed choices or because they were confident that their parenting approach had instilled their child with the right tools to make sensible decisions.

‘I’d hope I’d done a good enough parenting job after 15 years to let him make his own decisions.’

Parent of Year 10 young person, ABC1, Long Eaton

However, although the young person took on some responsibility for decision-making, they would still be expected to let their parent know what they had decided and planned to do.

One parent gave the example of an upcoming camping trip with school for her son. They had a letter through the door from the school about a four day camping trip. The son judged whether he would like to go or not based on the information given and then checked that it was OK for him to do so with his parents.

There tended to be certain characteristics associated with young people whose parents allowed them more autonomy when it came to decision-making:

- They were often older young people (in the year 9/10 age group); and,
- They were usually not the eldest child: the eldest child had typically set the boundaries and as a result the parent was more likely to be relaxed and confident with their parenting style after their first born.

- **Households where parents wanted to be well-informed about what their child was involved in and often made decisions on their behalf**

In these instances, the child would always need to ask the parent for permission before doing most things and, furthermore, the young person might be encouraged to do certain activities they would not do voluntarily because the parent deemed it to be 'good' for them.

'I think adult decisions are probably ones for the greater good. For example, when my children come in from school and want to spend all evening on the Xbox, this isn't good for them.'

Parent of Year 8 young person, ABC1, London

Typically, these parents did not tend to recognise that they could be considered relatively strict and instead thought that their approach was quite democratic in that their child usually did what they suggested without too much resistance. However, when speaking to the young person, they normally recognised that they did not get too much say in what happened around the household and that they were satisfying their parents' wishes. A lot of the time the young person seemed accepting of this dynamic, partly because of their age but mainly because they trusted and assumed that their parent knew what was best for them.

Where this was the case, these young people tended to be from the younger age range of school years 6 and 7 and were less confident about their own decision-making abilities. They were also more likely to be the eldest in the household or be an only child.

What were the universal patterns?

Despite the differences discussed above, there were still some commonalities regarding the decision-making process that seemed to apply to all households.

Involving young people in decisions

Firstly, in almost all households, young people were involved to some degree in decisions **that affected them** – even when the final decision was made by the parent. Parents did this because they thought it a good way of ensuring that their child would be happy and engaged with whatever it was they were being asked to do.

In one of the year 10 parent groups, a parent spoke about deciding about where to go on holiday. One year he and his wife decided without consulting their children and they did not enjoy it at all. Since then they have been including them in these decisions and this has meant that they have all enjoyed the holidays since.

'So we listen to them, where they want to go. You know it's just better...'

Parent of Year 10 young person, C2DE, Long Eaton

Young peoples' perspective also reflected a similar experience in relation to holiday choice, an example of this was seen in a group with Year 6 boys. One participant mentioned that he was asked his opinion about where they should go on holiday and he was listened to by his parents.

'On holiday I got to go to Germany. The others wanted to go to Spain and then they asked me and they asked me to choose do I want to go there or there.'

Young person, Year 6, C2DE, Long Eaton

Increasingly involving young people in decisions

Secondly, all parents either envisaged or already saw how the role of their child in decision-making in the household changed over time with there being a consensus that, as young people got older, they would have more of a say.

'I had more of a say in decisions when he was younger, but the balance has tipped the other way now that he is 15.'

Parent of Year 10 young person, C2DE, London

It was felt that as young people become **more mature** they should gain **more autonomy and influence**. Maturity rather than age was important; parents were very keen to stress that the point at which young people are deemed more responsible should depend on the young person themselves and **how quickly they develop** rather than a set age.

'She's got more of a say than my older daughter did at her age. She's just matured quicker.'

Parent of Year 8 young person, C2DE, Liverpool

That said, part of this development seemed to start as the young person began **secondary school**. It was widely acknowledged that this brings more independence through the style of learning practiced and the fact that the young people spend more time with their peers. As a result of this, parents expected that their children would grow during this time in terms of both their confidence and maturity.

'When they go into High School, they become very much more independent, because they're given totally different roles [in] High School...to what they were when they were in junior school...I think it starts from the age of 11, 12, and naturally, and it depends how they progress within that system.'

Parent of Year 9 young person, ABC1, Liverpool

Gender and household composition affects autonomy of decision-making

Rather than just age, the rate of development was also thought to be dependent on **gender**, with girls expected to mature sooner than boys.

'But girls you're constantly looking to try and compromise, because you just feel that they're much older.'

Parent of Year 9 young person, ABC1, Liverpool

The **placement of the young person amongst siblings** was also believed to make a difference. For instance, where older siblings were present it was often thought that a young person would be more likely to mature faster, the only exception being if there was a large age gap between the young person and their older siblings. In contrast, in the case of **only or eldest children**, parents appeared to have a tendency to be more protective and therefore they were not seen to mature as quickly.

One aspect which was mentioned frequently by parents was the difference between how mature young people are now compared to how they considered themselves at a similar age, with advancements in technology typically cited as part of the reason for this.¹⁵ Parents therefore felt that their children had considerably more autonomy than *they* did when they were children.

'They're at least 2-4 years ahead developmentally than what we were. My 16 year old, I was semi-independent at that age, but she is far more grown up, travels alone, has a job. Even the younger one, 13 years old is much older than I was.'

Parent of Year 8 young person, ABC1, London

Implications for engagement

The impact of the differences in the way in which decisions are made in households on research participation are discussed in more detail later in this report. However, it should be highlighted that engagement approaches need to take into account that there is a wide variation in the degree of autonomy young people have in decision-making and the role that parents play in this process. Age is not the key factor driving the degree of autonomy young people exercise and therefore care needs to be taken when taking a blanket approach to engagement and decision-making around participation based on age. Instead, within age groups the extent that young people are involved in decision-making is based on a more individual factor; parental assessment of their child's maturity. Although secondary school was seen as a benchmark of increased independence for some; more individual factors such as gender and the child's placement amongst other siblings in the household also played a role in parental perceptions of their child's capability to make appropriate decisions independently of them.

¹⁵ It was cited that technology allows young people to grow up quicker because they are given more liberties when they are contactable through their mobile phones.

Factors influencing decisions to participate in research

Factors influencing decisions to participate in research

In order to develop engagement strategies and messages, it is important to understand what motivates young people and parents to participate in research and also what commonly held uncertainties about the research process need to be addressed in communication with potential respondents. Therefore, this chapter looks in more detail at personal participation in research. In order to understand this, participants were asked why they took part in the current study. They were also presented with a hypothetical longitudinal study and asked how they would feel about participating in that. This section presents findings from both of these elements of the work; many of the themes that emerged and which are discussed in the initial part of this chapter can be applied to research in general, whether longitudinal or not, however given the time requirements of longitudinal research these factors often took on greater importance when participants considered research in which they took part multiple times. The subject of how personal (contact) data is stored and the need for transparency regarding the length of time it is kept for is covered towards the end of this chapter. There are also some factors that are more specific to participation and engagement in longitudinal research, which are discussed in the closing paragraphs.

Mindsets that influence participation

The four main factors informing the decision to participate (both by young people themselves, as well as parents' views towards their child's participation), as well as being likely to inform whether participants were engaged longer term, were as follows:

- **Personal benefits/ rewards of participation:** 'Taking part will be fun/ interesting/ a good opportunity'.
- **There is merit in the research and therefore participation is important:** 'Taking part will go towards something useful/ there is a bigger overall point to my participation'.
- **Belief that *personal* participation is important:** 'I feel valued by the people running the research'.
- **Feeling at ease with the process.**

We discuss each of these points in further detail below.

- **Personal benefits of participation: Taking part will be fun/ interesting/ a good opportunity**

For young people, a key factor determining their likely participation in research was whether they judged that it was likely to be fun. Indeed, this was given as a driver for them participating in this research study, and would also inform future decision-making.

'[I took part today] for fun...I thought it might be interesting.'

Young person, Year 9, ABC1, Portadown

'[Came along today because] I thought it would be fun.'

Young person, Year 8, C2DE, Glasgow

Similarly, for both young people and parents, having an interest in the research topic emerged as an important driver to both *initial* (e.g. why did they participate in the current study) and *continued* participation (what would encourage them to participate in future studies). The subject would either have to be interesting or appeal to them on a personal level to merit their investment in terms of time and input.

'I would not like to take part in anything boring, insurance or something like that.'

Parent of Year 7 young person, ABC1, Glasgow

'[Would not agree to take part] if it was a subject that I really wasn't interested in.'

Young person, Year 9, ABC1, Glasgow

Parents also mentioned that participating in research could be a positive opportunity for their children (although this was dependent on the nature of the research). For instance, for those parents with children who had experienced difficulties speaking – due to shyness or stutters – they perceived that research would present a useful opportunity for their voice to be heard, and to gain confidence. Building on this, other parents thought that their child's participation in research was good preparation for adult life, and 'could potentially be like going to an interview', for example. Similarly, others spoke of their participation as being akin to a civic duty.

- **There is merit in the research and therefore participation is important: Taking part will go towards something useful/ there is a bigger overall point to my participation**

As highlighted in the 'Existing experiences and views of research' chapter, many young people and parents said that being made to feel that they were participating in something useful would motivate them to both participate initially, and maintain engagement over the long term. In order to generate this sense, participants stated that they wanted to know the purpose of the research study in question, and how the findings would be used.

'If it was something I felt strongly about, I would definitely take part, no hesitation.'

Parent of Year 10 young person, C2DE, Bridgend

'They should get a sense of pride about being involved in something important.'

Parent of Year 7 young person, C2DE, Bridgend

Participants offered examples of research considered to be useful. These included research that reflected the realities of the way young people live today, and informed the design of policy and services – rather than relying on assumptions based on the lifestyles of previous generations. Welsh participants suggested that research that could be used to advise the Welsh government of how their region was distinct, and so guide the devolved administration, would be beneficial. In Northern Ireland, young people saw the potential for the results of research to feed into improving the running of services at a very local level,

such as through the Council. Several were encouraged by the thought they might themselves be direct recipients of benefits to local public institutions like their own schools.

- **Personal participation is important: I feel valued as a respondent**

Following on from this, participants also raised how important it was for them that their contribution to research was valued, both in terms of initial participation as well as maintaining engagement. They felt that if they were aware of the importance of their contribution, they would be more likely to care about the accuracy and quality of their responses. Others speculated that feeling valued would create a sense of duty, dissuading participants from dropping out for fear of letting the project, or research organisation, down.

In terms of how to engender this sense, participants identified communications between respondents and the research organisation – for instance about progress and findings – as being key. Further, while incentives are discussed in more detail later in this chapter, it is worth highlighting that others also suggested some token of thanks – not necessarily monetary – would be needed:

'[I would like] feedback on what's going on...statistics and that sort of thing that you could see what way...I think if you were kept informed you'd be happier to do it.'

Parent of Year 10 young person, ABC1, Portadown

'Just something to show your appreciation.'

Young person, Year 9, ABC1, Bridgend

It should be noted that participants raised this issue after much consideration and, therefore, it can be seen as less of an immediate priority for them in contrast to whether the research is perceived to be fun and/ or useful. That said, it is a particularly pertinent for longitudinal research given the greater time commitment involved and, therefore, worth bearing in mind.

- **Feeling at ease with the process**

As research was often an unfamiliar concept, especially to young people, offering reassurances about what would be involved was an essential first step in building the confidence necessary for participation. Similarly, parents felt that they needed reassurance about what participation would involve in order to feel comfortable with their children taking part. In some instances they sought reassurance from their peers, with one parent reporting that they turned to a friend for advice about what to expect before signing up for this study.

'I did mention it to a friend and she said, 'I've taken part in that type of thing and it's fine,' ... as soon as you have that reassurance, you think, 'Right, fine'.'

Parent of Year 8 young person, C2DE, Glasgow

Reassurance about the legitimacy of the organisation conducting the research was also important to some of the young people and parents we spoke to. For some, this legitimacy would be offered by being aware of the organisation in question, and knowing it had a good reputation. Others would ask for assurances that staff were CRB-checked (specifically mentioned by a few parents) or equivalent, and might even want to be introduced to interviewers by, for example, an email with their photographs and credentials before a visit.

'You want it to be reputable, a recognisable organisation, not Joe Bloggs. It is branding, the knowledge that they would not do anything inappropriate.'

Parent of Year 7 young person, C2DE, Bridgend

Building on this, some parents and young people expressed unease about being left alone with an interviewer. For instance, one boy in year 8 said that he would want someone with him in the room who he knew as he felt daunted by the prospect of meeting the interviewer because they were someone new. Whilst this is unavoidable for ad hoc research where an interviewer visits the home on a one-off basis (although some suggestions were made to address this e.g. interviewers of the same gender as the young person), parents felt that this was something that was important to consider if there were to be multiple visits. They felt if young people were to take part in research over time, it should be the same interviewer on each visit as the rapport that would be built up would help to reduce any unease young people may feel.

The importance of information

While the factors highlighted above were all important for both encouraging participation and maintaining engagement, participants – both parents and young people – acknowledged that their impact as drivers of participation and engagement would be reduced without good quality information. In fact, there were often caveats around participation based on the need for information.

'I would need to know a lot more about it [the research project] before I would even consider it.'

Parent of Year 8 young person, ABC1, London

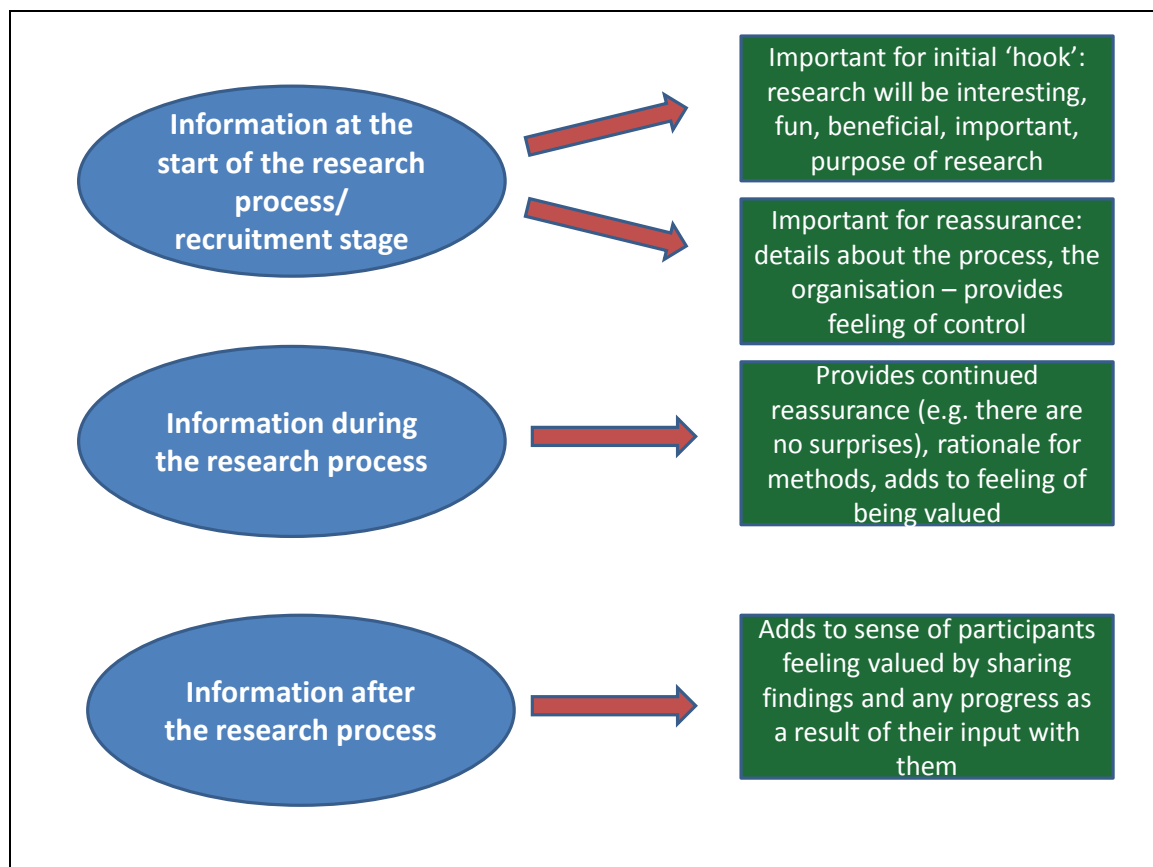
'Depends more on the criteria...how long it's going to be, how many hours, what the tasks are, I can't just say yes without seeing the spec.'

Parent of Year 8 young person, ABC1, London

'As long as I had a general idea about it what it was about, I'd be happy about it.'

Young person, Year 6, ABC1, Liverpool

Parents had a number of stipulations for this information. In particular, they wanted to know what the subject matter would be (to judge if it was age-appropriate) in the short- and long-term, what methods would be used and how long the study would be, who the research was for, what the aims of the study were, and what would happen to the data collected afterwards. Young people were keen to have information that would make them feel confident that they could answer the questions asked – including what they would be asked about and how – and what the study would be used for, as they too wanted to know the research would be helpful.



For a few of the young people we spoke to, however, information was not a prerequisite to their involvement. Whilst most wanted to know what it was about to aid their confidence and pique their interest, others did not feel this was the case. For example, one year 6 girl was happy to take part in our research without knowing much about it all, because she knew her parents believed that it was a good idea. The role of parental advice and encouragement in decisions around participation is discussed in the next chapter.

The extent to which the incentive is a 'hook' for participation

The study aimed to gauge the extent to which an incentive acted as a hook for engaging participants in research versus other factors. Before discussing views towards incentives in more detail it is worth highlighting an important contextual factor: all participants received a monetary incentive¹⁶ to participate in the study and therefore their responses should be considered with this in mind. Whilst we discuss their reported views about the extent to which the incentive played a role in their decisions about participation, we do not know what would happen in practice if this had not been the case.

Views towards incentives varied amongst participants. Some considered a financial incentive as not only a necessary condition of their participation, but as the overriding factor driving it. For instance, one young person in year 9 mentioned that she did not feel she needed to know anything else about the research apart from that she would receive an incentive before deciding to participate. Older young people, and the parents of older young people, appeared more likely to place a premium on an incentive as a motivational tool, with parents speaking

¹⁶ In the case of young people this was high street vouchers of a certain value whereas parents received a cash incentive.

of needing to 'buy [young peoples'] time'. In some cases, however, the desire for an incentive was related directly to families' personal circumstances:

'At the moment, money is quite hard in my family. So if it came along now, I would be selling it [to my son], saying 'This looks like a good idea and could really help us now'. And my boy would understand that we need money, we need to work to go on holiday.'

Parent of Year 7 young person, C2DE, Bridgend

For others, although the incentive remained a hook in terms of them considering participation, its motivational power was weighed up against other factors including interest, perceived value of the research, and the importance of them participating. In cases where research appealed less in terms of these then the incentive assumed greater importance, but where participants could relate to the purpose of the research or considered it to be of interest to them then the significance of the incentive decreased.

'I would say that it [taking part in research] is really important, depending on the subject. I think it would be interesting to take part in. And there are benefits [i.e. money] for doing it. But I would not say to do it just because there is fifty quid in it.'

Parent of Year 7 young person, C2DE, Bridgend

Parents who held this view typically thought their children would have the same balance of motivations.

'I would explain to [my son] the importance of developing things for the future. And how he is in some ways honoured to be a part of it, to say what he thinks about the future. Then the issue of the money would be covered. It would be 50/50, those two issues.'

Parent of Year 7 young person, C2DE, Bridgend

There was some evidence that the threshold whereby the incentive assumed more or less importance in relation to other factors was different depending on the age of the young person. Older young people appeared to need to be more convinced about whether participation in the research would be interesting and useful before these factors assumed more importance than the incentive, perhaps because they were used to having more say in how they spent their time. The amount of money offered as the incentive was also a factor here. Some older participants said the higher the incentive the less important it was that they found the research interesting or that they were convinced of its future use. For example, one year 11 participant suggested that £20 would catch his attention and make him consider participating regardless of the subject matter. However, this view contrasts starkly with that held by several parents of the same age group, that money alone would rarely be enough of a draw for their children (unless it was a very substantial amount such as £50 or £60 which was beyond what they would have expected it to be for a couple of hours of their child's time). These parents stressed that communicating that the research would be interesting and valuable and therefore worthwhile taking part in would be far more powerful than the financial incentive was.

Transparency around personal data storage

The majority of parents were happy for theirs and their child's personal details to be stored, as long as the data was secure. A few parents also felt comfortable as long as they had trust in the research organisation and were sure that their details would not be shared with a third party.

'It's a good thing to keep it... it's a good thing to archive it, because you may go back in ten years time and realise why that generation was like that, and why they're not like that now.'

Parent of Year 9 young person, ABC1, Liverpool

A few parents were unhappy about the storage of personal details due to a fundamental distrust of organisations to keep data securely. This sentiment was linked to media stories about personal data being left in public places and therefore being open to abuse. For instance, one parent in Portadown expressed concerns that her data would be hacked and her identity stolen.

'You have to worry, don't you? You give all this information about your child and then you read that people leave files on trains, and lose child benefit numbers.'

Parent of Year 7 young person, C2DE, Bridgend

There was a general expectation amongst parents that data would be destroyed at the end of a research project, although a few parents were happy beyond this and applied arbitrary time-frames such as 5 or 7 years because these seemed like a reasonable amount of time. One parent in London, however, felt that research data should be kept forever in order to be useful.

Overall, parents tended to voice slightly louder concerns relating to the storage of personal contact details than young people. However, it is important to see these views in the context of wider societal concerns around data protection and recent scare stories of personal contact information being lost. Furthermore, parental worries surrounding personal data security were only pronounced enough to act as a barrier to engagement in research in a handful of cases. Most parents simply wanted clear information upfront about how personal contact details would be stored and that anonymity of research results was guaranteed.

The views of young people mirrored those of parents, with the majority agreeing that they were happy for their data to be stored if kept secure and destroyed when no longer needed. There was generally implicit trust amongst young people that their data would be secure. Whilst many older or more mature young people understood this discussion, some participants from years 6 and 7 struggled to understand. This reflects wider societal differences between younger and older generations, with young people often tending towards a more relaxed attitude towards data security and storage of personal contact details. With increasing numbers of younger people spending a large amount of their time online and conducting social lives via social media sites, the concepts of privacy and data security are, in many cases, a secondary concern.

Engagement in longitudinal research

By introducing participants to a hypothetical example of a longitudinal research study which 'aimed to gain understanding of young people today and throughout their lives', we were able to gather their views on the topic in more detail.

Many parents were open to the idea of both themselves and their child being researched over time; several of these parents made a link between the 'Seven Up' and 'Child of Our Time' television programmes, and so the concept and purpose of a longitudinal study was easier for them to grasp.

'I think it is interesting because there have been television programmes about children every seven years and I think it is interesting to see what peoples' ideas are, see how these change, and how their attitudes change over the years.'

Parent of Year 10 young person, ABC1, Glasgow

However for some, the thought of being tracked or monitored over a long period was uncomfortable with them believing that it was too intrusive.

'I think a lot of people might not like that sort of thing because it's like having big brother looking down on you, and getting your kids to talk about your family life.'

Parent of Year 9 young person, ABC1, Liverpool

Some young people were receptive to the idea, although it was a difficult concept for others to grasp. To some (mainly boys), it felt like hard work and they thought it might be boring because of being asked the same questions or doing the same task on each visit, which would be a major challenge to engagement.

In terms of encouraging participation in longitudinal research, the factors mentioned in the 'Mindsets that influence participation' section assumed even greater importance. In addition though, willingness to participate in this kind of project tended to depend on certain caveats and questions. Typically these included requirements of more information about:

- The purpose of the study and what the data would be used for;
- The organisation conducting the research in order to judge their integrity;
- What involvement would require and the broad topic areas;
- Practical concerns about the time involved, length and frequency of participation; and,
- Theirs and their children's rights regarding confidentiality and opting out.

'I think it's got to be mapped out a bit more...you want to know when it starts, when it finishes, what's involved, what's the pluses and minuses and where...when it's finished, what's it going to be used for? What if your child goes away to university, a few years down the line, have they got to follow them up wherever they are?'

Parent of Year 9 young person, ABC1, Liverpool

While some of these information requirements are likely to be necessary in any research study, it was considered particularly important for longitudinal research given the greater involvement required from participants. For instance, a group of parents of year 10 young people went as far as to ask for a 'contract' outlining the purpose and requirements of projects.

The increased involvement necessitated by longitudinal research meant that child wellbeing and safety took on increased importance. Knowing their child felt comfortable with the study was key to parents; interviewer rapport played an important role here, with some parents suggesting that the same interviewer should visit each time. Additionally, knowing that the organisation conducting the research was reputable and that all interviewers were CRB checked was also mentioned.

In terms of maintaining engagement in longitudinal research projects, many of those we spoke to thought that if participants had an initial positive experience and found taking part in the research satisfying, they would be more likely to take part again. Similarly, for young people, previous positive experiences of research studies would play a major role in them being willing to take part again by providing them with a sense of confidence and reassurance. Some parents told us this would be particularly likely to be the case with longitudinal research: whilst an incentive would be an important initial hook, after a positive experience of the research process on one visit young people would be easier to engage on the next visit without one. Over and above this, some wanted to be kept informed about what researchers were doing with data in years to come and thought this would help keep young people interested and engaged.

This does not preclude the fact, however, that there was a concern amongst parents that as their child grows up they may change their mind about participation. Young people too worried about committing to a project longer term. It was therefore considered important that participants know they have the option to opt-out should they wish to.

'I feel OK about it now but I do not know I will feel in a year's time, for example.'

Young person, Year 9, ABC1, Bridgend

For many parents and young people, this opportunity for young people to change their mind and opt-out was an especially important caveat to their acceptance of longitudinal research post-16 as some felt uncomfortable with the prospect of being tracked into adulthood. Having the ability to opt-out, therefore, reassured participants and increased their likelihood to engage in the first place. Several parents and young people could not contemplate signing-up beyond 5 years or so and suggested that consent should be reviewed after this period.

Timings and frequency of visits

Data collection visits once every year seemed reasonable to most parents and young people, provided that all their stipulations already discussed were met and they had been happy with the previous visit. However, one parent queried the extent to which young people change enough over time periods to make it useful and so it would be important that the reason for the frequency of the visit was understood.

Many parents wanted appointments that would be at their family's convenience so that they could be scheduled around their busy lives. Further, whilst a visit of up to two hours was seen as reasonable, it was stressed that interviewers should stick to their allotted time.

Implications for engagement

- Decisions to participate could be categorised into certain participant 'mindsets'. Particularly important was whether taking part would be fun (for young people) and interesting (parents) and also that there was some merit in the research (e.g. participants agreed with the purpose of the research or felt that it offered some social benefit). Another factor, which would assume increased importance when engaging people in longitudinal research, was the feeling that they were valued for their individual contribution. Engagement materials should draw on all of these.
- Some parents encouraged their children to take part if they felt that participating would be 'good for them'. A caveat is that research must be age appropriate, both in terms of protecting young people from being involved in research about issues that are not suitable for their age (e.g. sensitive issues), but also designed in a way that enables young people to give their views. Providing parents with a sense of the sorts of topics that will be covered in the research (rather than just the overall subject) could be beneficial here.
- Young people need to feel like they have some control over the process in order to feel more comfortable participating. Key to this is providing them with an understanding of, and reassurance about, the process; they want to know what is going to happen. Similarly parents want reassurance, not just about the process but also about the legitimacy of the organisation and the interviewer.
- The value placed on an incentive as an engagement tool varies amongst participants. For some, the incentive is the primary reason for participation and views towards the research are less relevant. For others though, whilst some recognition of their contribution may still be expected, the importance of the incentive is weighed against other factors. Therefore, where the research is interesting or felt to have an important purpose, the incentive assumes less importance and a lesser value incentive may be acceptable.
- Familiarity and previous experience could act as an important factor in engaging young people and parents in longitudinal research; assuming the previous experience was positive. Building rapport with the interviewer is key to this. Anything that can be done to provide young people with a sense of familiarity with the interviewer before the visit would be beneficial.
- Whilst personal data storage and security was not generally a controversial topic, it was widely felt that research organisations should be transparent with parents and young people at the beginning of a study, providing information about how personal data would be stored and for how long. This would provide the necessary reassurances that parents in particular asked for and would ensure that any concerns about data security (no matter how unfounded) would not impact engagement in research or lead to attrition during a longitudinal study.
- Whilst the motivating factors discussed are likely to be important in deciding to participate in any research, given the greater burden placed on respondents by longitudinal research it is even more important that the purpose of the research, rationale for multiple visits and the social value of the research are emphasised to them.
- For longitudinal research transparency is vital in terms of explaining the commitment that would be required from respondents as well as the reasons for the frequency of visits. The prospect of agreeing to something that is a long term commitment appeared daunting to some, therefore they felt that the understanding they could opt-out in the future actually helped them feel engaged.

Research decision-making in practice: consent

Research decision-making in practice: consent

Whereas the previous chapter examined the factors that emerged as important when considering participation, this section looks at how the decision to participate works in practice between young people and their parents. The chapter also examines perceptions around the consent process and how this could best engage participants. As many had no previous experience of participating in research, parents and young people were asked about how the decision to provide consent to participate in the study had been arrived at.

How the decision for the young person to participate in research works in practice

Whilst parents may be used to the process of giving formal consent for their child to take part in in-school and out-of-school activities, consent to participate in research differs to that given for other activities. For research purposes this consent is *only to ask the young person whether they would like to participate* (assuming they are under 16). A parent giving consent is not taken as consent for the young person to participate; research ethics dictate that that decision still ultimately rests with the young person.¹⁷

Therefore, the process of providing consent for a young person to participate in research involves decision-making responsibility for both parent and young people; the extent to which this is a collaborative process between the parent and their child and the degree of responsibility that the young person assumes in this process depends on a variety of factors. The factors that are relevant to the decision-making dynamic within a household generally (discussed previously) also apply to the research decision-making process.

Households where parent and child discuss and come to a compromise or decision together

For 'mutual decider' households, the decision to take part needed to be a joint one, even though it was the parent who heard about the research study first. The parent presented the information to the young person but they were more likely to have a debate about whether they should take part or not, rather than leaving it entirely to the young person to make their decision. If the young person did not want to take part, they would accept this but if the young person did want to and the parent did not they would debate their reasons together and the possible implications it might have for them as a family.

¹⁷ <https://www.mrs.org.uk/pdf/2012-02-23%20Children%20and%20Young%20People%20Research%20Guidelines.pdf>

In one household, the mother described the importance of involving her children in decisions. She felt that children playing a role in decision-making was part of them growing up and discussing and debating decisions within the household meant children learnt how to make sensible decisions. Although the mother wanted her son to have a role in decision-making, she expected to still be involved in decisions. If she does say no to him doing something, she will explain why.

'It's not really about asking my permission, we have a conversation...he asks me and we discuss.'

Parent of Year 8 young person, ABC1, Portadown

Households where parents wanted to be well-informed about what their child was involved in and often made decisions on their behalf

These parents judged the information available about the research project and only if they deemed it to be suitable would they then ask their child if they wanted to take part. They used certain criteria - based around the factors identified in the previous chapter as influencing participation - to assess the suitability of the research. Parents who took this approach often based their decision on whether participation would be good for their child; if this was thought to be the case, then they would encourage them to take part. Given this, they needed evidence that the research would be appealing to their child and this would help them in giving it an endorsement.

'I think it's got to be a bit exciting for them. I think there's got to be a bit of a fun element.'

Parent of Year 9 young person, ABC1, Liverpool

Often in these households, young people held less of an expectation that they would have a say in deciding whether to take part and tended to defer decision-making to their parent; if their parents approved of the research, then they would be likely to participate.

One example was seen in a household where the parent told us that the decision to take part in the research had been a consensual one where she had explained the benefits, knowing she could not force him to take part, and he had agreed.

'I asked him if he wanted to take part and he asked 'well what is it about?' and then I told him 'you just say what you think'... and he said 'yeah, alright then'.'

Parent of Year 8 young person, ABC1, Liverpool

However, when talking to the son separately he said that his mum had forced him to do it and that he had felt pressured by her to take part because she said it would be good for him to voice his opinions.

'Well, my mum actually forced me. I wasn't sure at first. I found it interesting...I felt pressured because well, I was forced to do it.'

Young person, Year 8, ABC1, Liverpool

However, if the parent judged the research project to be unsuitable or unappealing for their child they were likely to tell the recruiter directly that they were not interested. They were less likely to mention to their child that they were even approached because there would be no point if they have already judged the research to be unsuitable for them to participate in.

'If it was my 13 year old, if I didn't think it was appropriate, I wouldn't even mention it to them.'

Parent of Year 8 young person, ABC1, London

Households where parents allowed their child more autonomy in decision-making

Generally, when these parents were approached about the research they passed on the details of it to their child and let them make their own mind up based on the information they provided. Where parents allowed their child more autonomy in deciding whether to participate, they were conscious not to influence their decision.

One parent we spoke to hoped that she would not try to persuade her son to take part in research even if she wanted him to. For her, she would rather know that he was doing it for his own reasons rather than to please her and so it was important that she did not try to encourage him. She did admit however, that it is hard to be neutral about one's wishes.

'Being realistic, and being human beings, it is very rare that we are neutral, even if not intentionally.'

Parent of Year 9 young person, ABC1, Bridgend

Forcing their children into doing things was considered to be counter-productive because they saw the worth in letting the young person be motivated enough to want to do it without persuasion. This is both in terms of being worthwhile for the young person and for the integrity and value of the research.

'Make sure, when you go into the task that they're happy to take part in it, because you can't force them, no matter what age.'

Parent of Year 9 young person, ABC1, Liverpool

By ensuring that the young person has willingly consented to the research, parents hoped that they would be more engaged with the research as well and be able to give more considered answers. The approach of parents having minimal involvement means that particular emphasis needs to be placed on providing young people with sufficient and age appropriate information about the research so that they can make informed decisions.

'Information would be important to help the young person understand what it is about. Some young people would not need it, but if they did need anything to help them make a decision.'

Parent of Year 9 young person, ABC1, Bridgend

Reactions to the current consent process

Despite these different dynamics between households, it was generally accepted, both by parents and young people, that the approach used in this study (and frequently recommended as ethical best practice in research generally) of obtaining consent from the parent to talk to the young person and then asking the young person if they would like to participate, was most appropriate. This was for several reasons as outlined below.

Firstly, this approach felt reassuring to young people who often wanted their parent to take on a gatekeeper role; given the unfamiliarity of the process young people felt more confident taking part if their parent had endorsed them doing so.

'She's the adult so she won't make rash decisions.'

Young person, Year 8, ABC1, Liverpool

'I wouldn't feel safe [if the parent wasn't asked first] because they wouldn't let you do it otherwise.'

Young person, Year 6, ABC1, Liverpool

Linked to this, it was unlikely that the young person would have experienced what it is like to be a participant in a research study before and so lacked an understanding of what the process involved. Parents, thanks to their wider experience, were therefore able to offer support and guidance to their child who might have questions about it. This was more prevalent in households where parents and their children discussed the decision together.

'It'd be better to ask my mum than me... she'd have a better idea of what's involved.'

Young person, Year 8, ABC1, Long Eaton

'I wouldn't really know what I was doing so I'd rather dad is asked first so he can tell me what I'll be doing... He helped me out quite a lot and told me I'd be a bit nervous at first.'

Young person, Year 6, ABC1, Liverpool

From the parents' perspective, being asked first fitted with the parent/ child dynamic that they tried to encourage. Regardless of the degree of autonomy parents allowed their child in making decisions, they still wanted to 'check-in' with what their child was doing. There existed the idea that until the young person turns 16 years old, they are still a child and the parent as the adult has responsibility for them. This was also often accepted by young people.

'She's the parent so she should decide on things about me taking part.'

Young person, Year 8, C2DE, Liverpool

'Yes I want to be involved. I am his mother, I want to know. Otherwise I worry he has something to hide from me, makes me think something might not be right or he might not be happy.'

Parent of Year 8 young person, ABC1, Portadown

Providing signed consent

Parents seemed quite satisfied with providing written consent, reflecting their familiarity with doing so in other situations.

'Anyone can say yes. But at least if it is in black and white at least you have got proof. Because he is under 16, I think you should ask for my consent.'

Parent of Year 10 young person, C2DE, Bridgend

There was a sense for some that by giving formal consent for their child to be approached, they were being respected and considered as parents in the process. It was definitely a must-have for some and, even among those who did not see it as essential, the consent process did not put them off from participating. Further, there was also recognition that researchers may need this reassurance too.

Once the young person decided that they were happy to take part, they were asked to sign to indicate their consent, too. None of the young people we spoke to had any severe difficulties in signing to give consent; however, it was an unfamiliar process for all of them and made them think differently about taking part.

Those in the younger age group (years 6 and 7 especially) were particularly unfamiliar with the practice of signing forms and tended not to have formed a signature yet. Therefore, a few asked their parents for assistance and some made up a signature on the spot. In some instances, having to make up a signature made them feel slightly uncomfortable.

'I didn't have a signature so I asked Dad and he just told me to do the first letter of my name and surname.'

Young person, Year 6, ABC1, Liverpool

Some of the older age group were, however, more relaxed about signing the consent forms because they had more experience of doing so. Several mentioned having to sign their planners at the beginning of the year and some mentioned having to sign exam papers as well.

That said, an important point to consider for all age groups is that the requirement to sign led them to believe it was a 'big deal' with their experience of signatures (if any) being based on formal documents such as contracts and, as mentioned, exam papers. These connotations had two main implications for their participation in research: whilst some appreciated this as it made them feel their views were taken seriously, it also had the effect of making the process appear more daunting. It made them feel unsure about what they were then going to be asked to do in the research because it suddenly felt very serious. In turn, this could have an adverse impact on how confident they felt participating.

'Kind of weird because we're kids and we're not asked to do stuff like that [sign] usually.'

Young person, Year 6, ABC1, Liverpool

Whilst some parents liked the idea that it was conveying something serious if the young person needed to sign too, others felt that this step was unnecessary if the parent and young person had decided to participate already between them and the parent had already given consent. Some of the parents were also unsure of whether the young person acknowledged the meaning behind signing to give their own consent.

'Personally I don't think it makes any difference to him whether he signs or not. [On the other hand], by him signing it reassures you that he is doing it off his own back rather than me telling him to do it.'

Parent of Year 10 young person, C2DE, Bridgend

Ideal process of consenting to participate in future research

Parents and young people were asked for their own idea of the best ways of approaching them and their child to gain consent.

When talking through the ideal process, the process that they went through for this research was cited frequently. As discussed above, both the parent and the young person liked that the parent was the first point of call for the recruiter. However, the importance of the young person being asked directly by the recruiter was not always recognised. Due to the young person and parent often wanting a discussion about taking part and what it might involve, it was thought best that the parent acts as the mediator between the young person and recruiter, even after the young person has decided to take part.

As we discuss further in the next chapter, young people were very averse to being put on the spot in case they gave the wrong answer. This also applied when deciding whether to take part or not. They would rather tell their parent whether they would like to participate than the recruiter to avoid this, and were concerned that they might offend the recruiter if they did not really want to take part. This was particularly important to those from the younger age groups and those with parents who liked to be more involved in their decision-making process given that these young people tended to be less confident when talking to adults and deciding on a course of action to take.

'I feel like if it was something I didn't want to do and someone else asked me to do it, I'd feel more on the spot whereas when me mum asks me to do it I'd feel more comfortable talking it through with her.'

Young person, Year 8, C2DE, Liverpool

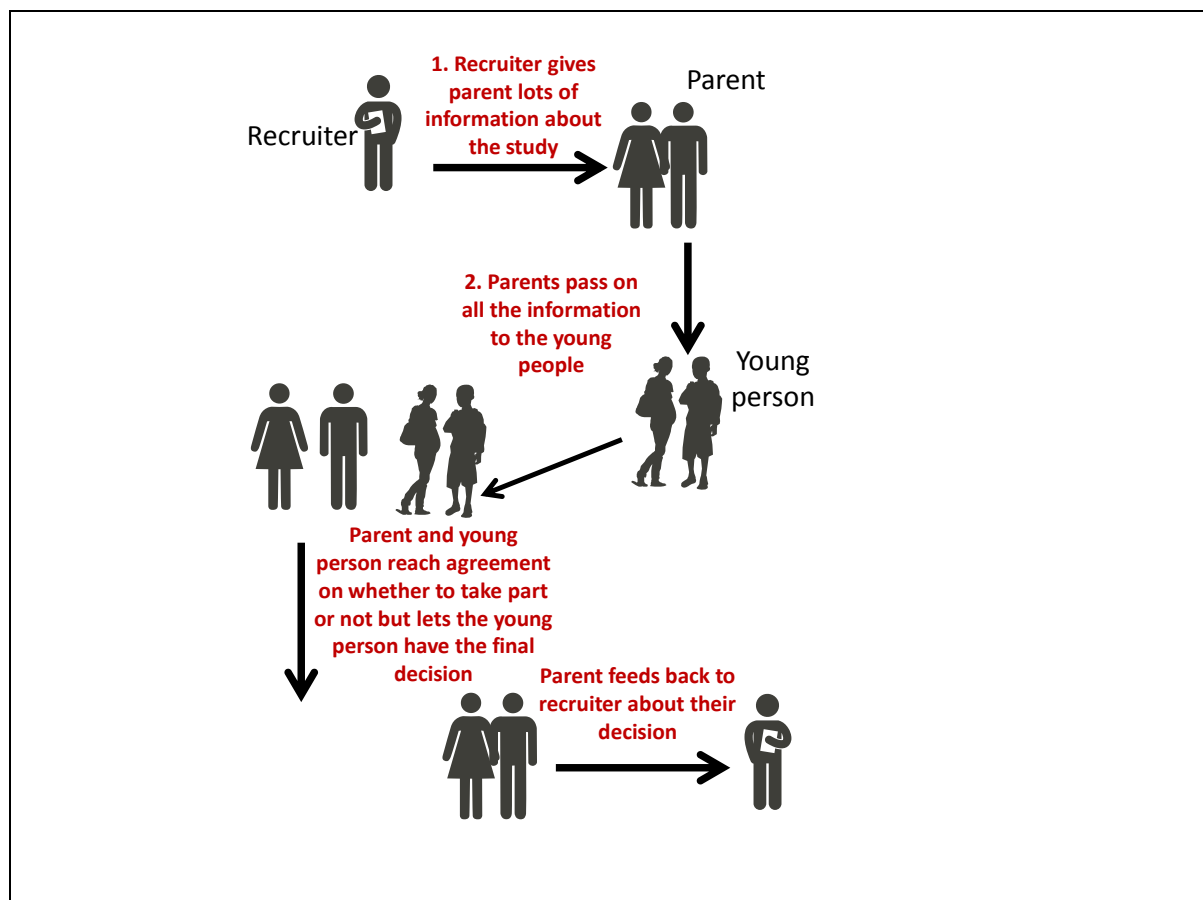
There were, however, a few young people who felt that they would be old enough to be approached first before their parents, although these were in the minority. Even in these cases though, reflecting the desire for their parent to act as gatekeeper to research, they felt that parental consent would still need to be gained.

'It'd be nice to be asked first, even if they have to ask mum really.'

Young person, Year 8, ABC1, Portadown

The following diagram reflects the most commonly reported views on how the decision-making and consent process should work.

Diagram of ideal decision-making and consent process



Responses to children post-16 giving full consent to participate on their own behalf

Both parents and young people were asked about their thoughts on young people post-16 giving full consent to participate on their own behalf and what they would do.

There was a sense of resignation that that is what the law says, but this does not necessarily mean that they agree with it. They cited that once young people reach 16 there are a lot of new things that they can do such as buying lottery tickets and having sexual intercourse but these are only rights because it is the law, not because they have earned these rights.

'I've got used to the fact that once they are 16 they are classed as an adult. Personally I think it is too young... I think they should be asking my permission when they are 45!'

Parent of Year 10 young person, C2DE, Bridgend

'I would be happy [about the change in responsibility for consent] because that is what the law says. But I don't think I'd be that happy. The law states he has that right and I cannot argue with that.'

Parent of Year 8 young person, C2DE, Glasgow

In keeping with the point discussed in the 'Young people and decision-making' chapter, in which it was discussed that parents believed that maturity rather than age should dictate when young people should have autonomy in decision-making, parents felt that the age of 16 was just a number and did not necessarily represent when young people are capable of

giving full consent on their own behalf. For this reason there was concern with the idea of a blanket approach whereby age 16 represented a benchmark of increased responsibility.

One parent we spoke to felt that her two children were very different in character and being able to consent at the age of 16 did not necessarily depend on age.

Although she felt that her 16 year old was already independent and capable of making these decisions, she felt her 17 year old was more vulnerable and susceptible to being told what to do easily.

'You would be able to tell her [the 17 year old] what you want.'

Parent of Year 10 young person, C2DE, Bridgend

The views of the young people, on the other hand, were mixed. The younger age group either found it difficult to imagine being able to make decisions without consulting with their parents first, or they felt that by the time they are 16 they will be more responsible and mature enough to make decisions by themselves. The older age group, being much closer to age 16 themselves, felt that they would be old enough to make the decision but they may still inform their parents of the outcome.

'When you are 16, you are responsible, you have matured a bit more, and you are responsible for your actions.'

Young person, Year 9, ABC1, Bridgend

'In my late teens I would still let them know but I'd ask in a way that would be counting on them saying yes.'

Young person, Year 8, ABC1, Liverpool

Implications for engagement

- Due to the different ways of decision-making whereby sometimes young people assume more responsibility, whereas in other cases parents appear to largely make an initial judgement, engagement materials need to appeal to both young people and parents. The materials being age appropriate and easy for young people to understand would appear to be especially important in cases where parental involvement in decision-making is minimal.
- Providing parents with examples of how the research may prove enjoyable might be useful in helping them to encourage their child to participate (in cases where parents take this approach).
- Young people often feel reassured in knowing their parent remains involved in the decision even as they gain more autonomy themselves.
- Whilst signing for consent could make young people feel that their views are valued, it could also make the process appear unnecessarily formal and daunting to young people.
- The 'ideal' decision-making approach allows young people and parents the opportunity to discuss involvement in the research. Therefore any approach to engaging young people should facilitate this – for instance by providing sufficient information in advance mailings – rather than only relying on information provided by the interviewer during a visit, at which point young people can feel put on the spot to make the right decision.

Research methods

Research methods

An important issue for the research to examine was what participants understood by, and how they felt about, different types of quantitative research methods. This was in order to examine which methods they engaged with most or whether any methods presented a barrier to participation. A mock study was used as a way of helping participants to engage in hypothetical discussions of various quantitative research methods which were often unfamiliar territory.

Different types of data collection

It was explained to parents and young people that information for the hypothetical study could be collected in a number of different ways. Each data collection method was introduced separately and an image was shown to young people and parents to ensure understanding. The specific data collection methods discussed were:

- Pen and paper;
- Tablet (as a CAWI device¹⁸);
- Computer/ Laptop (as a CAWI device);
- Telephone – Landline or Mobile (as a CATI device¹⁹); and,
- Mobile (as a CAWI device).

In addition, parents and young people were asked for their views on collection of physical measurements and DNA sampling, and young people were asked to discuss reactions to taking part in cognitive assessments.

Many parents assumed that pen and paper would not be appropriate because they felt that young people would find this method boring and hard work and, in fact, that it could discourage young people from participating in research. In perhaps surprising contrast, most young people were positive about completing surveys using pen and paper, and were able to explain many advantages of this method. Furthermore, parents overwhelmingly felt that tablets, laptops or computers were most appropriate for young people, because these methods were engaging, interactive and did not require writing. Young people were also very positive about these methods, although did have a number of key concerns, particularly about data security and the inability to change answers. Neither parents nor the majority of young people felt that telephone or mobile (either as a CATI or CAWI device) were particularly appropriate for young people to use to complete surveys.

More detailed reactions to these methods are shown in the table overleaf, and throughout the remainder of this chapter.

¹⁸ CAWI stands for Computer Assisted Web (Online) Interview. A CAWI questionnaire is accessed using an internet browser, and questions are completed by the participant online using a device that supports the internet, eg. PC, laptop, tablet, smart mobile phone. The participant can complete questions themselves, or an interviewer can complete questions for them.

¹⁹ CATI stands for Computer Assisted Telephone Interview. CATI surveys are interviewer-administered. An interviewer rings the participant on their landline or mobile telephone, and reads out questions from their script to the participant. The interviewer records responses using their computer.

Method		Young Peoples' Views	Parents' Views (thinking about their child)	Verbatims
Pen and Paper	+	<p>Many felt:</p> <ul style="list-style-type: none"> • Comfortable using this • Familiar with this from school • Gives them time to think • Data is secure and cannot be hacked <p>Some felt:</p> <ul style="list-style-type: none"> • Method is serious and so answers would be taken more seriously • Gives ability to change answers • Lets them go back and see previous answers • Enables them to write long answers • Appropriate for personal questions • They know where it has come from • In control of responses • They know where answers are going 	<p>Some felt:</p> <ul style="list-style-type: none"> • Gives them time to think • Data is secure and cannot be hacked • Gives ability to see all questions 	<p><i>'No one can hack you on a piece of paper.'</i></p> <p>Young person, Year 8, C2DE, Bridgend</p> <p><i>'It's the hardest way of doing it, well not the hardest...but like it's not the quickest way of doing it, but I'd say definitely it's the safest way of doing it'</i></p> <p>Young person, Year 6, ABC1, London</p> <p><i>'It's easier, you can think about it.'</i></p> <p>Young person, Year 6, C2DE, Long Eaton</p>
	-	<p>Some felt:</p> <ul style="list-style-type: none"> • They do not like writing • Would feel like a test • Would take too long to complete 	<p>Many felt:</p> <ul style="list-style-type: none"> • Boring to complete • Will not engage young people <p>Some felt:</p> <ul style="list-style-type: none"> • Difficult to complete • Hard work • Would feel like homework 	<p><i>'They would see that as homework.'</i></p> <p>Parent of Year 7 young person, C2DE, Bridgend</p>

Method		Young Peoples' Views	Parents' Views (thinking about their child)	Verbatims
Tablet	+	<p>Many felt:</p> <ul style="list-style-type: none"> Would be fun to use Would be quick to complete <p>Some felt:</p> <ul style="list-style-type: none"> Would be easy to complete More interesting than paper Less effort than paper Do not have to write 	<p>Many felt:</p> <ul style="list-style-type: none"> Would be fun to use Would be interactive to use Would engage young people Young people are used to this Young people are good with technology <p>Some felt:</p> <ul style="list-style-type: none"> Young people do not have to write More interesting than paper Quick to complete 	<p><i>'A lot of young people see writing as a bit of a bore whereas if you're using electronics which appeal to a lot of people, younger people, I'd be more willing to spend a bit longer on it.'</i></p> <p>Young person, Year 9, ABC1, Long Eaton</p> <p><i>'Tablets are more fun, interactive, they are moving their fingers around, there's pop-ups, you can make it more interesting for a child.'</i></p> <p>Parent of Year 7 young person, C2DE, Bridgend</p>
	-	<p>Many felt:</p> <ul style="list-style-type: none"> Worried about data security and hacking <p>Some felt:</p> <ul style="list-style-type: none"> Touch screen is fiddly and could take longer as a result Concerned about pressing wrong button Cannot write long answers Cannot go back and change answers Would feel more rushed/ pressured than paper Uncertainty about where data goes Method is not serious and so may not be taken seriously Not appropriate for personal questions Pop-ups are annoying 	<p>Some felt:</p> <ul style="list-style-type: none"> Does not give ability to see all questions Touch screen is fiddly Worried about data security 	<p><i>'I'd feel like my results could be tampered a bit.'</i></p> <p>Young person, Year 9, ABC1, Long Eaton</p> <p><i>'It would take ages.'</i></p> <p>Young person, Year 10, C2DE, London</p>

Method		Young Peoples' Views	Parents' Views (thinking about their child)	Verbatims
Computer/ Laptop	+	<p>Many felt:</p> <ul style="list-style-type: none"> • Familiar with this from school and home • Quick to complete <p>Some felt:</p> <ul style="list-style-type: none"> • Easy to complete • Less effort than paper • Do not have to write • Ability to delete mistakes • Easier to use than tablet • Easier to type long answers than tablet 	<p>Many felt:</p> <ul style="list-style-type: none"> • Would be fun to use • Would be interactive to use • Would engage young people • Young people are used to this • Young people are good with technology <p>Some felt:</p> <ul style="list-style-type: none"> • Young people do not have to write • Quick to complete 	<p><i>'It would be easier on a computer or a laptop than a tablet because you can...it's easier to type.'</i></p> <p>Young person, Year 9, ABC1, Long Eaton</p>
	-	<p>Many felt:</p> <ul style="list-style-type: none"> • Worried about data security and hacking <p>Some felt:</p> <ul style="list-style-type: none"> • Cannot go back and change answers • Uncertainty about where data goes • Not as fun as tablet • Pop-ups are annoying 	<p>Some felt:</p> <ul style="list-style-type: none"> • Worried about data security • Does not give ability to see all questions 	<p><i>'Just the insecurity of it and where's it heading to and that sort of thing.'</i></p> <p>Young person, Year 10, ABC1, Portadown</p> <p><i>'With online, you're not always sure that it's safe.'</i></p> <p>Young person, Year 9, C2DE, London</p>

Method		Young Peoples' Views	Parents' Views (thinking about their child)	Verbatims
Telephone (Landline/ mobile as CATI device)	+	Some felt: <ul style="list-style-type: none"> • Landline better than mobile – can check answers with parents • Quick, easy way to explain something in depth 		
	-	Many felt: <ul style="list-style-type: none"> • Put on spot/ under pressure • No time to think • Cannot change answers • Cannot see previous answers • Not used to using telephone Some felt: <ul style="list-style-type: none"> • Cannot see/ do not know who talking to • Might not be who they say they are • Someone else might be listening • Might not be able to hear questions • Might not understand interviewer accent • Mobile is personal, not for adult/ formal interactions • Do not want to give mobile number out • Association with cold-calling 	Many felt: <ul style="list-style-type: none"> • Young people not used to using telephone • No time to think • Cannot go back Some felt: <ul style="list-style-type: none"> • Intimidating for young people • No ability to see what questions are coming up • No ability to check what young person is being asked • No ability to control pace • Cannot check credentials of interviewer • Association with cold-calling 	<i>I don't want any type of call. I'd be put on the spot, wouldn't know what to say.'</i> Young person, Year 7, C2DE, London <i>'Anything by phone I won't be doing.'</i> Young person, Year 10, ABC1, Portadown <i>'I don't think their phone skills are very good. Like when my mum calls my sons, they're like 'yes, no, here's the phone mum', but when they see my mum, they love my mum! But on the phone, they just don't talk to adults.'</i> Parent of Year 8 young person, ABC1, London

Method		Young Peoples' Views	Parents' Views (thinking about their child)	Verbatims
Mobile (as CAWI device)	+	Some felt: <ul style="list-style-type: none"> • Quick for very short surveys • Same as computer, just smaller 	Some felt: <ul style="list-style-type: none"> • Gives the ability to complete surveys anywhere • Quick for very short surveys 	<i>'As long as it's quick, and there's not hundreds of questions and you don't have to scroll through loads of pages...'</i> Parent of Year 6 young person, ABC1, London
	-	Many felt: <ul style="list-style-type: none"> • Would take too long to complete • Difficult to use keyboard or touch screen – computer/ laptop is better • Worried about data security and hacking Some felt: <ul style="list-style-type: none"> • Concerned about pressing wrong button/ sending wrong information • Cannot write long answers • Difficult to delete answers • Not trusted mode for personal information • Mobile is personal, not for adult/ formal interactions • Do not want to give mobile number out • Could cost me money 	Many felt: <ul style="list-style-type: none"> • Would take too long to complete • Difficult to use keyboard or touch screen – computer/ laptop is better Some felt: <ul style="list-style-type: none"> • Cannot write long answers • Not trusted mode for personal information • Worried about data security and hacking • Does not give ability to see all questions • Not formal/ appropriate format 	<i>'That would take forever. We have to press the buttons like three times to get to a letter.'</i> Young person, Year 6, C2DE, Long Eaton <i>'I'd be slightly annoyed because you'd have to use your internet to look at it. And if you're on pay as you go it sucks the money.'</i> Young person, Year 6, C2DE, Long Eaton

Young peoples' preferences for different data collection methods were varied

Many young people said they would be open to using pen and paper, tablets, fixed computers and laptops and these were often positioned as the top three methods in the ranking exercise. Younger children were generally more immediately drawn to the idea of using pen and paper to provide answers and preferred this to the technological alternatives which they felt less comfortable using. However, a few young people in the lower years (years 6 and 7) said that pen and paper (as well as online methods) felt more like they were being 'tested' and they preferred the idea of talking someone through their responses instead of being asked to record them on paper by themselves. There was also a sense among several older children that pen and paper allowed them to provide more reflective responses and mirrored the format they were used to using during exams which they associated with thought-out and serious answers.

Some young people preferred the idea of more 'modern' survey methods involving tablets, computers and laptops, because they expected it would be easier to go back and change their answers compared with pen and paper, which some worried would mean they had to get their answers right first time. This was particularly true of older children (those in years 9 and 10). However, despite there being a general openness among young people to using tablet assisted and online methods, there were some concerns around data security and retention.

It is worth noting at this stage that, for most young people, all online or computer based methods (tablets, computers and laptops) were considered very similar and often discussed interchangeably because they all involved similar technology. Although some young people acknowledged differences between these methods in terms of usability, many classed them together and invariably put them in the same or consecutive positions in the ranking exercise. Preferences for one online method over the other were usually driven by individual taste, how much detail individuals wanted to give in their answers and which seemed the easiest to use.

Surveys conducted using landline telephones or mobile phones were not considered appropriate by most young people and these methods tended not to feature in participants' top-three. Furthermore, it was clear that any method featuring landline telephones or mobiles had the potential to actively *discourage* many young people from participating in research as discussed in more detail below.

Although telephone and mobile (as a CATI device) were widely rejected as data collection tools, a few young people suggested that completing a survey using a landline was more acceptable to them than a mobile. Several young people referred to their mobiles as part of their personal 'space', appropriate for friends but not adult or formal interactions. A landline call also meant that their parents would be home to help with answers and to check the legitimacy of the survey. For telephone surveys in general, some young people felt that they wanted the reassurance of having their parents nearby, both to guide them and help them confirm the legitimacy of the research. Interestingly, this was not raised as much of a concern for other methods and perhaps indicates additional sensitivities surrounding research conducted over the phone compared with face-to-face or, for some participants, online. Many concerns surrounding telephone surveys related to the negative associations young people (and parents) had of cold-calling. Consequently, many participants were greatly reassured by pre-scheduled telephone appointments, underlining the importance of initial recruitment and set-up calls.

Telephone surveys were, however, thought more appropriate when sensitive topics such as bullying might be discussed. A few young people felt a telephone interview would allow them to express themselves quickly and easily in a way that other forms of interviewing might not.

That said, many young people preferred to give responses on personal and/ or sensitive topics like this online and were hesitant about the level of privacy that discussing these topics over the telephone would provide.

Common concerns among all age groups and related to all methods of data collection included: ability to answer the questions, ability to amend answers, having enough time to reflect and/ or discuss responses with others they trusted.

Method of data collection impacts young peoples' levels of engagement

The study findings suggest that data collection methods are likely to have a significant impact on how young people feel about taking part in surveys, and on their engagement in research overall. Although CATI methods (and mobile as a CAWI device) appear unpopular and so should be considered carefully as an interview method for young people, surveys via pen and paper, computers, laptops or tablets were generally found acceptable, given the right reassurances and adequate information being provided to both young people and their parents upfront.

The perceived advantages of pen and paper in offering opportunities to amend and reflect on responses, as well as concerns that telephone surveys put participants on the spot, suggest that young people want to feel in control of their responses and at ease when giving them. This puts the onus on research organisations and interviewers to design and administer surveys, no matter what the data collection method, to ensure that young people feel they have control and ownership of their responses, and do not feel rushed or pressured when taking part.

Interviewer-administered versus self-completion

As part of the discussion of different data collection methods, young people were asked about whether they would prefer to read questions and complete answers themselves, or for an interviewer to do this for them. Most young people questioned about this indicated that they would prefer a self-completion survey. For many, this was because they felt it would give them more time to think, and they would not feel pressured because an interviewer was waiting for an answer. Some young people preferred self-completion methods for personal questions so that they could keep their responses private, although several agreed that they would be happy for an interviewer to administer a survey if questions were not of a personal nature. A third view voiced by several young people was that self-completion was preferred because they had no control over what an interviewer wrote and self-completion was a way of being sure their responses were an accurate reflection of that they wanted to say.

'I think it would be easier because you're just telling them what you want but then it might not be so good because they might write down something false, that you didn't really say.'

Young person, Year 8, C2DE, Glasgow

Hardly any young people expressed a preference for interviewer-administered surveys, although one particularly confident year 10 boy from London did not have a preference between the two, even for personal questions, and suggested that an interviewer might be able to put answers into better words than he could.

Interviewers provide key reassurance to young people

It is clearly important to give young people an opportunity to self-complete questions where possible, especially those of a personal nature. Where interviewer administration is required, however, young people stated that they wanted time to consider answers and not feel rushed or pressured. For example, some young people registered nervousness at the beginning of these interviews, and were worried about getting answers wrong, or not knowing how to respond to the questions they were asked. It was clear therefore that an interviewer has a key role to play in reassuring young people that there are no right or wrong answers, that no special knowledge is required and that 'don't know' is an acceptable answer²⁰, and overall in creating an open and relaxed environment.

Different tasks involved in research

Height and weight measurements

Parents generally comfortable with height measurements

Many parents were comfortable with their child's height being measured as part of a longitudinal study and quickly grasped why this information would be useful to researchers. A few parents wanted more detailed information about the purpose and what the data would be used for before granting consent. These parents also felt that their children would be comfortable with the idea, partly because they would be 'used to it' from past experiences of height measurement at the doctor or school, but also because they thought that it did not feel too personal or intrusive.

Reassurance about height measurements required by some young people

In line with these parental assumptions, many young people were comfortable with height measurements. However, a few demonstrated some unease about the idea. The reasons for this unease were:

- Needing to know the purpose of collecting this data;
- Lack of understanding about how this data would be linked; and,
- Personal sensitivities (especially notable amongst young people who were taller or shorter than average).

'I would like to know the reason, the company, before they measure me'

Young person, Year 8, C2DE, Bridgend

'[Feel] a bit uncomfortable [about height being measured]...because I don't see a need of having to measure the height for something.'

Young person, Year 9, ABC1, Bridgend

²⁰ Reeves, A., Bryson, C., Ormston, R. and White, C. 'Children's perspectives on participating in survey research', National Centre for Social Research, November 2007

'I don't know. I guess if you were conscious, if you're really tall or really small then I guess maybe they'd feel a bit [uncomfortable].'

Young person, Year 9, ABC1, Long Eaton

This underlines the importance of keeping young people and their parents informed about the purpose and value of research, explaining concepts such as data linkage thoroughly, and of the interviewer's role in creating a comfortable and safe environment at home in which to take these measurements.

Parents concerned about young peoples' reactions to being weighed

Whilst some parents were comfortable with their child's weight being measured, they were concerned as to what they – or young people in general – would think about the process. Parents were worried that the measurement could impact negatively on self-esteem, and discourage them from participating in research. Further, some parents suggested that girls and older children would be less likely to agree to this than boys and younger children, although many suggested that sensitivity about body shape depended on the individual and so the decision to participate in this aspect should therefore be up to them.

'It depends on your child, doesn't it? If you've got a child who's already got weight issues, well then maybe they might not want to stand on the scales.'

Parent of Year 9 young person, ABC1, Liverpool

Young people need reassurance and a considerate setting for weight measurements

As the parents suspected, many young people expressed varying levels of discomfort about the idea of their weight being measured. As with height, lack of understanding about how this data could be useful lead to some unease, although self-consciousness was a far greater driver of young peoples' initial discomfort. Whereas sensitivity about height was mainly expressed by those who lay outside the average, self-consciousness about weight measurement was expressed by many more young people, regardless of body shape. These feelings and concerns were raised by girls and boys of all ages, although the strength of feeling was greater amongst girls. Furthermore, a girl in year 7 and a boy in year 8, both from London and neither visibly overweight, expressed concern that friends might discover their weight and that they would be made fun of as a result. Other young people spontaneously added that they did not want their weight to be measured in front of friends.

'I think if it was for something you knew was going to be important then I guess I wouldn't mind. But I know that for a lot of people it's quite personal, especially if you're insecure about yourself. I think it's too much to ask someone to do that.'

Young person, Year 9, ABC1, Long Eaton

'Because everyone feels uncomfortable [about having their weight measured]...people will be looking at it.'

Young person, Year 10, ABC1, Bridgend

Interestingly, concerns about weight measurement were greater amongst parents and young people who participated in group settings, compared to those who were interviewed in a parent-child pair at home. Although similar concerns were raised during the paired in-home interviews, the strength of concern expressed was lower and more parents and young people said that they would agree to the weight measurements.

Despite these sensitivities, most young people said that they would be willing to have their weight measured especially in a considerate setting like home.

'If it has to be given then I would do so, but I would not feel comfortable with it,'

Young person, Year 10, ABC1, Bridgend

'[I would feel] a bit uncomfortable [about having weight measured]...it depends on the circumstances, I don't think I would do it at school. If I was at home it would be [ok].'

Young person, Year 9, C2DE, London

Many younger participants in years 6 and 7 particularly also said that they would want a parent to be with them. Other information linked to greater likelihood to consent was understanding the purpose of the measurement, as well as the knowledge that they could opt-out if they wanted to. Reassurances about anonymity and confidentiality were also key, indicating that although many parents and older children appeared to understand that physical measurements formed part of a larger data set for trend analysis, it was difficult for some to see past the individual measurement.

Optional sensitive reporting of individual physical measurements should be offered

Opinion about whether young people should be informed about their physical measurements was mixed, with some parents and young people wanting to be told, whilst a few preferred not to know. There were four instances described by parents where prior negative direct or indirect experiences of reporting of weight impacted on their views. In each case, a young person had been weighed at school, and had a letter sent home reporting that they were overweight. These parents felt that this had been inappropriate and impacted on the young person's self-esteem. For these parents then, reassurance about sensitive reporting of individual results was key to them granting consent.

Interviewer key to provide reassurance about physical measurements

The views expressed here by many parents and young people suggest that sensitivity about physical measurements, and especially weight, could impact on engagement and participation in longitudinal research. It is, therefore, important for interviewers to be aware of such feelings and to handle measurements sensitively and according to the preferences of each young person involved. Recruitment for projects involving these type of measurements could take place in-home once rapport has been established and once participants felt comfortable with an interviewer. Explanation about the purpose of this type of data collection and what the data would be used for is essential, as well as reassurances about confidentiality and the ability to opt-out. Whilst all of the above could mitigate the negative perceptions of physical measurements, it is important to note that for some parents and young people, this type of data collection was still too personal for them to imagine agreeing to it.

Researchers must ensure that the purpose of physical measurements is understood

An important finding in this research was that some young people agreed that they would go ahead with the physical measurements, despite not understanding or misunderstanding the purpose. This lack of understanding was either admitted by some young people, or demonstrated by an incorrect interpretation about the purpose. One example of this was a Year 7 girl in Long Eaton who thought that the measurements were to identify which young people needed to take more exercise. This highlights the need for research organisations to

not only explain, but to ensure understanding amongst young participants when seeking informed consent.

Cognitive assessments

Cognitive assessments widely acceptable to parents

Many parents were comfortable with their children completing cognitive assessments as part of a longitudinal study. These felt familiar to them, and most felt that this type of assessment would be familiar to and appropriate for their children. Some parents equated cognitive assessments to what young people might undertake in school, and so it would be important to ensure that both parents and young people understood what this type of assessment involved, before consent was sought.

Some reassurance about cognitive assessments required, especially for girls

A few parents did, however, express concerns that cognitive assessments would put their children under pressure because it would feel too much like a test. A related view was expressed amongst many of the girls who participated. Although some were happy to take part in cognitive testing, a significant proportion of girls across all school years were put off because they thought the assessments felt too much like being tested, and were worried and embarrassed about getting the answers wrong. These young participants were clearly concerned about the perception interviewers and researchers had about them, and as with physical measurements, struggled to see past individual results to the wider picture.

'If it was like a really easy game and I got something really silly wrong, and they put that down that was what I done and didn't look at other stuff I did, and just took the first answer I had, and don't look at the rest of what I had done, so I would sort of feel like they would think I was someone who messes up on an easy mistake.'

Young person, Year 7, C2DE, London

'I would feel embarrassed if I got them wrong.'

Young person, Year 10, ABC1, Bridgend

In contrast, many boys were comfortable with cognitive assessments. Although some again likened them to tests, they were more inclined to see these as a positive challenge that they might enjoy undertaking. As with other data collection methods, many young people, regardless of gender, wanted to understand the purpose of taking part in cognitive assessments before agreeing.

In order to ensure that concerns about cognitive assessments did not affect the engagement of some parents and young girls, it would be important to give detailed explanations about the purpose of collecting this type of data, and about how researchers would look at the wider data set and not individual results. Reminders about confidentiality and anonymity would be important, along with reassurance either that there are no right or wrong answers if appropriate, or at least the lack of consequence should an answer be incorrect. As with physical measurements, the interviewer's role in making young people feel comfortable during cognitive assessments would be essential to encourage young people to take part more than once.

DNA sample

DNA extraction from saliva samples was controversial

In line with findings from the CLS Cohort Studies report²¹, the topic of collecting saliva samples for DNA extraction was the most controversial of all those broached amongst parents. It proved very difficult to focus them on the data collection method itself, as many were quickly caught up in discussion about their feelings about the idea in general. There were three distinct reactions amongst parents.

It would be challenging to convince some parents to consent to DNA samples

Some parents reacted strongly against the idea initially, and even with further explanation²² and discussion, their view remained the same. Their concerns were driven by fears that their child's DNA could be manipulated (one parent even mentioned cloning) and in some cases this was exacerbated by an unknown fear about what researchers and scientists might be able to do with DNA in the future. Others were more concerned about who might have access to the samples and how safely they would be stored. In line with a group of parents who refused to give saliva samples in the Millennium Cohort Study 5th sweep, these parents would not accept guarantees about data security and assurances that data would not end up on police, government and insurance databases. The story about the CIA whistleblower Edward Snowden was on the mind of some parents during these discussions, as well as media stories about government organisations leaving unencrypted personal data in public places. Another area of concern was that DNA was considered to be traceable back to the individual. For these parents, unlike giving an opinion which could be kept anonymous, DNA never could be separated from its owner. Amongst these parents, there were a few who suggested that they would be happy for their child to be tested for a certain medical condition and so could see a benefit to them and their child, but were not happy for DNA samples to be submitted for general research.

'DNA's part of your make-up. You hear so many different things about what has happened...it is a case of human error. I have seen it happen when I was a social worker and the police mixed up DNA once.'

Parent of Year 8 young person, C2DE, Glasgow

'Because it is unique, how could it not possibly be traced back to you? So much information can go astray. But this is not just information, this is your print, it could be manipulated.'

Parent of Year 9 young person, ABC1, Glasgow

Some parents more open to DNA samples but need considerable reassurance

Whilst other parents articulated similar concerns to the view described above, their initial reaction was one of discomfort or unease rather than antagonism. In contrast to the view

²¹ Calderwood, L, McArdle, W., Ring, S. and Rose, N. (2013) 'Collecting saliva samples for DNA extraction from children and parents: Evidence from the UK Millennium Cohort Study', CLS Working Paper 2013/3, London: Centre for Longitudinal Studies.

²² The following explanation about how saliva samples would be used was given to participants:

- Researchers will be able to use the DNA sample to look at whether you have certain types of genes. This can help researchers understand better differences in children's development, health, behaviour, growth and learning.
- Researchers might look at specific genes which have been shown to influence children's growth and learning.
- It will not be tested for the HIV (AIDS) virus and will not be available for police records (or insurance companies when you are older).

above, the explanation about what would and would not happen to their child's DNA sample reassured these parents and with further discussion they became more open to the idea. However, all were clear that they would need further information about the organisation conducting the research, what the data would be used for, how the samples would be stored and when the data would be destroyed. A few of these parents wanted the data to be destroyed immediately once it had been tested in order to give their consent. One parent became more open to the idea once she knew the DNA would not be subject to a paternity test.

A few parents were open-minded about the topic when it was first mentioned and remained comfortable with the idea as discussion progressed. Again, these parents all still wanted further information and reassurance, but their attitude indicated that they expected to feel the same way and to give consent once they received this. A couple of parents were open to the idea, despite being unsure how useful the data would be. Another parent was generally comfortable as long as he was convinced there was some benefit to society. A couple more were happy as long as they knew who the data was being collected for, whilst another parent was comfortable as long as a blood sample was not taken.

'I suppose...if it's to change something for the better, then... or to find something out for the better, then I suppose it would be beneficial.'

Parent of Year 6 young person, ABC1, Liverpool

As with weight measurement, concerns about collecting saliva samples for DNA extraction were greater amongst parents who participated in group settings where participants sometimes took on the concerns expressed by others, compared to those who were interviewed at home.

Many young people felt uneasy about DNA samples

Many of the young people that took part in this research did not fully understand the purpose of collecting their DNA and struggled to articulate their feelings about it. This was noted across all age groups, but most particularly amongst young people in years 8 and below. Despite this, the pattern of reactions were very similar to those of the parents. A few young people remained firmly against the idea even after discussion. Lack of understanding and confusion, as well as feeling 'weird' about someone having their saliva predominantly drove their concerns.

'I feel uncomfortable about it because I would feel a bit awkward. It would feel weird for other people to have my saliva. But if I have to do it, I probably would...if the research included a test like this, I may not be keen to do it again...I don't know why I would feel uncomfortable. I suppose because it's your body and stuff.'

Young person, Year 9, ABC1, Bridgend

Many young people demonstrated varying levels of unease initially, but with more explanation and discussion became more open to the idea, even if some remained wary. For some, initial unease focused on the saliva collection methods which were 'yucky' and unhygienic, although not all young people agreed with this. One boy had seen this on the television programme *CSI* which helped him understand the process and feel comfortable with it. For others, concern focused around who would collect the sample from them and a couple of young people suggested that they would want this to be done by a doctor or nurse, or someone that they knew and trusted.

'I'd only do it if I had to go to the doctors or the hospital. Like I wouldn't do it if it was somebody who just came up to your door, knock, knock, can you give me a saliva. I wouldn't like that.'

Young person, Year 6, C2DE, Long Eaton

The primary driver of concern in this group again appeared to be lack of comprehension about why researchers would collect these samples and what they would do with them. Whilst the explanation given and further discussion gave some reassurance and discouraged them from 'refusing' to provide a sample in the hypothetical scenario, many remained uneasy. An exception to this was a group of Year 9 boys in Portadown who despite initially disliking the data collection method, came round to the idea as 'cool' and exciting and enjoyed the idea of being involved in a sophisticated type of research which might help to understand humans.

A few young people did react positively about the saliva samples straight away. It was not clear that these young people fully understood the concept, they just seemed to instinctively trust that the idea was acceptable, possibly because the person asking was an interviewer that their parent had already 'ok'd'. During the in-home depth interviews, the concept of DNA data collection was introduced to the child first, and then the parent was brought into the discussion. Unsurprisingly, several young people who had initially been comfortable with the idea, became uneasy as their parent began to raise their concerns. This was especially noticeable amongst younger participants in years 6 and 7.

Young people want their parents to be involved in consent to give DNA samples

Most young people said that they would want to check with their parent about this type of data collection, and this was evident even amongst older, more mature young people where the balance of consent power for other types of data collection had shifted in favour of the young person. An example of this was a boy in year 10 who was very active in household decision-making and felt that he did not really need his parent's say to take part in research, who admitted that although he was comfortable with saliva sample collection, would still want to check this with his parents.

Reassurance and comfortable surroundings key to gaining consent to take DNA

It is clear that collection of saliva samples for DNA extraction is a challenging topic for many parents and young people to contemplate, and as such, is likely to have an impact on engagement and participation in research that involves this. It would be important to ensure that detailed information about the research organisation and purpose of data collection are given, along with reassurances about data security, storage and destruction, and details about who would have access to the data when consent is sought. Although it appears that some parents and young people are unlikely to be convinced, many might be willing to take part if fully informed and reassured. The fact that more openness to the idea was observed during in-home interviews suggests that this would be the most appropriate setting in which to approach parents and young people about this. As noted in the CLS Cohort Studies report, the interviewer role in establishing rapport and creating a comfortable setting for participants is also highly likely to encourage participation.

Researchers must ensure that the purpose of collecting DNA samples is understood

Further, as discussed in the physical measurements section, the evidence suggested that some young people were inclined to give consent to give a DNA sample despite the fact they did not understand what they were being asked, simply because they trusted the person

asking. Again, this highlights the need for organisations to ensure that young people fully comprehend what they are being asked to consent to before data collection begins.

Views on data linkage and consent

The rest of this chapter looks at views of how data which is collected as part of research may be used and the implications of this on participants' future engagement. It is important to understand how research participants reacted to possible uses and means of storing data collected as part of the research as these views often played a role in the overall decision about whether to take part in research. Furthermore, parents often drew a link between these issues and consenting to their child taking part. For some parents, these issues emerged as particular areas of concern for anything involving their children since young people were seen as being more vulnerable given their lower awareness of how data might be used. Many parents therefore saw their role as 'gate-keepers' as particularly important where issues of data linkage were concerned.

In general, young people tended to be less concerned about data linkage as a topic and rarely discussed it as a factor that would impact their willingness to participate in research. However, some more mature young people viewed the idea of data linkage positively because it reassured them that their participation would be worthwhile and that they were contributing to an important cause. This view was further reflected by many parents who felt that data linkage – provided it was done credibly and they were given sufficient information about it upfront – added value to the research and would motivate them to encourage their child to take part.

During discussions, parents and young people were introduced to the idea that data collected as part of a research study might be linked up with data that is collected by other organisations. The following real-life examples were used to illustrate this and facilitate discussion among participants (see Appendix for full discussion guide):

- (A research company) might link your information to other information the Department for Education holds about you. This might be information about the school as well as your exam results.
- (A research company) might link your information to your health records such as any hospital visits you made, why you went and how long you stayed for.

This concept of data linkage was generally accepted amongst parents. Whilst some appeared to accept data linkage unconditionally, others added caveats which included reassurances about confidentiality, data security and up-front consent. However, even parents with these concerns were confident that if the proper reassurances were received they would be happy giving consent for their child to take part in research.

Some parents were keen to know what was being linked exactly. It also seemed that the more they were told about what was being linked in the examples above and why it might be linked, the more they wanted to know about the specifics such as which variables they were linking from each dataset.

'Would want to know what they're linking, but wouldn't be worried ... Would they be well informed beforehand? The level of what's being linked is questionable.'

Parent of Year 8 young person, ABC1, Liverpool

Another concern was the anonymity of the data linking. Although not spontaneously mentioned, when they were told that once the data is linked, personal details are not held, they seemed to be happier for the data linking to take place. This view was reflected in

discussions with young people as well. There were a few parents who remained sceptical about whether or not the data would be held securely or anonymously and for them, consenting to data linking, particularly where their child was concerned, was out of the question.

Overall, the concept of data linkage in the hypothetical study did not appear to be particularly controversial amongst most parents. It is possible that parents would have more concerns if faced with a real decision, but the findings here indicate that with the right reassurances, many would give consent and data linkage would have minimal negative impact on research engagement and participation. Indeed, several parents thought that the concept of data linkage and the subsequent insights that it could lead to were a fundamentally positive output of research and they therefore appreciated that it was a worthwhile activity. Furthermore, they often said they felt encouraged by the prospect of data linkage if it was made clear that it was for a good cause or would help to understand young people.

The parents who *were* concerned about data linkage were even more concerned about the age of consent being 16 years old. They felt that at 16, the young person would not understand the implications of data linking and that the age should be at least 18 years old. The implication for these parents is one of mistrust with the agency and whoever has commissioned the research.

'I would be absolutely furious with whoever it is that's conducting the research if only he is asked when he turns 16.'

Parent of Year 10 young person, ABC1, Long Eaton

'I think at the age of 16 it would still be a good idea to ask the parent for consent. It'd be better at 18 or older.'

Parent of Year 6 young person, C2DE, London

Tate, Calderwood et al.²³ discovered that consent for data linkage for the Millennium Cohort Study was notably lower amongst mothers living in Northern Ireland and mothers from ethnic minority groups, which is supported by *Understanding Society* records that also show lower consent for data linkage amongst parents living in Northern Ireland. Although this was not evident in this current research, it is interesting to note that the few parents requiring more specific information about what data would be linked with what, were mostly mothers from ethnic minority backgrounds. In discussions about 16 as the age of consent for data linkage, almost every mother from an ethnic minority background who took part in a depth interview felt strongly against this, and thought that 18 was more appropriate. This view was driven by concerns that young people were still too young at 16 and so would not understand the concept. Whilst similar concerns were observed in parents from white backgrounds, the proportion was notably higher amongst parents from ethnic minority backgrounds and is an example of how cultural differences impact approaches to parenting and household decision-making.

For those parents who thought that age 16 was appropriate, their judgement tended to rest on whether they felt the 16 year old in question had the capacity to understand the concept of data linkage. A couple of parents admitted that they only felt comfortable with the age of 16, because they knew their child would check with them first. This demonstrates how the maturity of the young person and individual relationship between a parent and child are key factors affecting consent to data linkage (and research in general).

²³ Tate, A. R., L. Calderwood, et al. (2005). "Mother's consent to linkage of survey data with her child's birth registration records in a multi-ethnic national cohort study." *International Journal of Epidemiology*.

'At 16 he's old enough and it's OK because he'll probably ask my opinion anyway.'

Parent of Year 7 young person, C2DE, Portadown

Most young people did not understand what data-linkage meant at first as it was not a concept they were familiar with. However, when explained fully using examples they quickly grasped the concept and often found it interesting. Many liked the idea that you might be able to find out richer information by linking it to other existing information and recent news headlines, such as the link between when the child is born and their exam grades²⁴ enforced this.

However, they too had concerns about what was being linked and why those commissioning the research might be doing this. Many said that they would therefore need to know upfront what the purpose of linking one set of data about them up with another was. Furthermore, many spontaneously said that they would envisage checking with a parent before they felt comfortable about it.

'Depends what they're linking. If they're linking two things you're OK with then this is fine. I'd want to know why they're linking it too.'

Young person, Year 7, C2DE, Liverpool

Some young people were especially concerned about some of the more sensitive aspects in the research being linked. For example, one young person was particularly concerned about weight being used as one of the variables because she felt that this was highly personal and something she was sensitive about.

'I wouldn't want them to look at something like weight. It feels more personal. If you tell people about what your results are in a test that's OK but not weight... it's more sensitive.'

Young person, Year 8, C2DE, Liverpool

After explanation and further consideration, many younger people, in particular those who were older and/ or more mature, expressed genuine interest in the prospect of data linkage and acknowledged that it would be useful. There was also some enthusiasm among younger age groups towards the idea that through data linkage they might find out something new and interesting that was directly relevant to their lives. In all cases, young people, similar to parents, stressed they would want to be fully informed of the purpose of the data linkage in order to agree to it taking place.

'I would feel ok if I understood why they were doing it. It would be interesting to know why short people get A+!'

Young person, Year 8, C2DE, Bridgend

The same unease about data linkage was not so evident amongst young people that took part in depth interviews with their parents. Although lack of understanding was still apparent amongst many, they seemed to be reassured by their parent's comfort and understanding of the concept, which they were able to provide during the interview itself.

Most young people said they would be happy to give consent to data linkage at the age of 16, mainly because they thought they would understand the concept by then. However,

²⁴ https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/182664/DFE-RR017.pdf

most still emphasised that they would want to involve their parents in a discussion about it as they trusted their parents' advice and judgement on an issue like this.

'No I'd be like 'can you explain what it means?' I might know obviously when I was 16, but I wouldn't know now.'

Young person, Year 8, C2DE, Liverpool

'I would say it's appropriate but I would personally still ask my parents.'

Young person, Year 8, ABC1, Liverpool

Implications for engagement

- The study findings suggest that data collection methods have a significant impact on young people's survey experience and engagement. Common concerns among all age groups and related to all methods of data collection included: ability to answer the questions, ability to amend answers, having enough time to reflect and/ or discuss responses with others they trusted. Young people want to feel in control of their responses and at ease when giving them; therefore any engagement materials should emphasise that the method of data collection will provide this opportunity.
- Surveys via pen and paper, computers, laptops or tablets were generally found acceptable, given the right reassurances and adequate information being provided to both young people and their parents upfront. Telephone and mobile (as a CATI device) were widely rejected as data collection tools – in some cases to the extent that using these methods would discourage participation – as young people felt this would put them on the spot.
- Linked to the point that young people want to feel control over their responses, many demonstrated a preference for self-completion surveys. It was felt these were beneficial as they gave them more time to think (young people would not feel pressured because an interviewer was waiting for an answer). Self-completion was considered preferable for personal questions so that they could keep their responses private. Additionally self-completion was a way of being sure their responses were an accurate reflection of that they wanted to say rather than relying on an interviewer to accurately record responses. If surveys are not self-completion, possible engagement strategies could still build on these findings – for instance by interviewers reassuring young people that they can take their time, that their responses will be recorded verbatim and that any responses will be anonymous.
- To engage young people in – as well as reassure parents about - height and weight measurements, providing an understanding of the purpose of these measurements and how data will be used is key. For weight measurement especially – which was seen as a more sensitive measure – confidentiality is important; girls particularly required reassurances that others would not be told the outcome and that these are conducted in a private setting. The interviewer approach must be sensitive to the fact that some young people feel self-conscious about these measures.
- Whilst generally participants were receptive to cognitive assessments, some parents and young people – particularly girls, had reservations based on these measurements being an assessment of an individual's performance. To overcome these, it would be important to give detailed explanations about the purpose of collecting this type of data, and about how researchers would look at the wider data set and not individual results. Reminders about confidentiality and anonymity would be beneficial, along with reassurance either that there are no right or wrong answers if appropriate, or at least the lack of consequence should an answer be incorrect.

- Collecting saliva samples for DNA extraction was the most controversial topic of all those broached amongst parents and young people. Some parents were firmly against the concept of DNA samples and would not change views. For others, explanation about what would and would not happen to their child's DNA sample reassured them and with further discussion they became more open to the idea; it is amongst these parents that information materials providing explanation would play a role in encouraging engagement/ willingness to participate in DNA extraction. Many young people struggled to fully understand the purpose of DNA extraction and how DNA would be used. Whilst providing appropriate information – especially reassurances of what it will *not* be used for – would be beneficial, the fact that not all young people could comprehend DNA extraction should be borne in mind when considering informed consent. Reflecting unease often felt around collecting saliva samples, young people want their parents to be involved in consent to give DNA samples.
- Lack of understanding amongst young people was clearly a concern surrounding data linkage and consent and therefore research organisations need to ensure understanding upfront both by the parent and the young person.
- The findings suggest that whilst some parents and young people felt comfortable with consent at 16, the concerns of others, along with young peoples' comments suggesting that they would still check with a parent, indicate that it might be prudent for research organisations to seek consent for data linkage up to 18 to mitigate the risk of alienating any participants.
- Since parents find data linking to different data sets interesting and most are happy for it to happen because they wish for the research and themselves to be as useful as possible, it is important to stress this when discussing the research. Although it may not always be possible to give as much detail as parents sometimes expect the usefulness of data linking could be an important aspect to stress to parents to encourage them to consent.
- Although most young people did not appear to be knowledgeable to begin with about data linking, once explained they seemed more at ease with it. Therefore, a full explanation would perhaps be a useful tool in gaining consent. However, examples need to be used carefully as we say in this research that young people tend to take them literally and it can be difficult to shift their initial views.

Implications and recommendations

Implications and recommendations

Given the role this study will play in the future development of engagement approaches for MCS and Understanding Society, this closing chapter provides a summary of the most far-reaching implications that emerged from the research and highlights areas for further consideration. It is worth noting that these are recommendations of the research team based on analysis of qualitative data and go beyond the suggestions of participants themselves.

Research overview

Ipsos MORI carried out research with young people aged 10-15 and parents of this age group to inform participant engagement approaches on the Age 14 Survey of the UK Millennium Cohort Study (MCS)²⁵ and the youth panel of *Understanding Society: The UK Household Longitudinal Study* (UKHLS).²⁶ **Fieldwork** was carried out between 3rd June and 28th June 2013 and comprised 10 discussion groups with young people, 7 discussion groups with parents and 22 in-home depth interviews with young people and their parents. Fieldwork was conducted in a mix of urban and rural areas across England, Wales, Scotland and Northern Ireland.²⁷

Key topics covered by the research were:

- Young peoples' attitudes to research and their role in it;
- Young peoples' understanding of the consent process, both for participation generally and for data linkage;
- Young peoples' responses to the collection of biomarkers and their use in research;
- The role of parents as gatekeepers and how the decision-making process works between parent and child;
- Young peoples' and parents' engagement with particular modes of data collection;
- Young peoples' and parents' preferences in terms of direct communication throughout the research process; and,
- The suitability of different materials and survey approaches for young people.

Discussion guides containing key questions and prompts were used by researchers to facilitate discussion during both groups and in-home interviews. Discussion guides were designed in conjunction with the Centre for Longitudinal Studies, the Institute for Social and Economic Research and NCB.

Analysis of findings across interviews and groups was conducted throughout the fieldwork period through the collation of moderators' field notes, coded analysis in Excel spreadsheets and in regular analysis sessions with the interview team. Initial hypotheses were developed, discussed and tested throughout. Following an initial pilot stage research materials were revised.

²⁵ The Millennium Cohort Study is run by the Centre for Longitudinal Studies (CLS) at the Institute of Education.

²⁶ The *Understanding Society* survey is run by Institute for Social and Economic Research, University of Essex.

²⁷ When conducting research with young people and parents about their likelihood to participate and engage in research, we were speaking to an already engaged audience. The views of harder to reach audiences who may present more of a challenge to engagement are thus not covered and further research would be needed to understand their views and the implications for engaging with these groups.

Key recommendations

It is important to provide sufficient information upfront outlining what the research is for, what it entails and what the intended outputs are. It is also important to give feedback on what is being done with the results.

The purpose, subject matter and perceived value of a piece of research are often key factors used by young people and their parents to initially assess a study's worth. Therefore highlighting this information to potential participants could be a good way of prompting engagement.

Young people also often want to feel that they have some control over the process in order to feel more comfortable participating and key to this is providing them with an understanding of, and reassurance about, the process.

Similarly parents want reassurance, not just about the process but also about the legitimacy of the organisation and the interviewer and engagement tools which provide this will work well to ensure parents view the research positively and are more likely to actively encourage their children to take part.

These considerations are even more key for encouraging participation in longitudinal research given the perception that more of a contribution is required. For engaging participants in longitudinal research it is vital to explain the commitment required upfront and rationale for the increased frequency of visits. Building rapport with the interviewer could also be key to this and therefore anything that can be done to provide young people with a sense of familiarity with the interviewer before the visit would be beneficial.

Future engagement exercises with parents and young people could give greater emphasis to the fact young peoples' opinions will be listened to in the research; this would provide a 'hook' and warm young people and their parents to the idea of participation.

Young people and parents can often feel that the views of young people are not always given a platform for being voiced or heard. The prospect that a research organisation, potentially working in collaboration with a Government or other official body, may be interested in collecting first-hand the opinion of young people could be a powerful way of attracting the attention of both younger and older participants and potentially motivate them to take part in research.

In order to engage participants in research which includes topics or methods of data collection that are potentially sensitive it is particularly important to give upfront information and transparency about what the research entails and what the data will be used for.

A clear example of this is for research involving height and weight measurements. It is important to provide clear explanations of the purpose of taking these in order to engage young people and reassure parents that the research is appropriate for their child. For example, it will be important that engagement tools stress the fact personal data of this kind is analysed on an *aggregate* basis rather than being looked at in isolation. This kind of information will communicate a message to young people and their parents that the young person's participation has wider significance, adding to a body of knowledge that experts analyse. This sense of *contribution* and taking part in a *valuable study* can have a powerful motivating effect on young people.

It is particularly important that reassurances are given around the practicalities of how *weight* measurements are carried out; participants (especially some girls) need reassurance that others would not be told the outcome and that the measurements will be taken in a domestic setting where they will feel comfortable. Likewise it will be key for interviewers to adopt a sensitive approach during the administration of this part of the interview.

Engagement approaches need to take into account the wide variation in maturity of young people of the same age as well as wide variation in parental perceptions of what is appropriate for their child(ren). Care therefore needs to be taken and the risks of a taking a blanket approach to engagement processes should be considered.

Age is rarely the key factor driving the degree of autonomy young people exercise in household decisions. Instead there are many individual and contextual factors at play and it will be important for engagement materials to take these into account when looking at how to engage young people within a given age group.

Individual factors such as gender and the child's placement relative to other siblings in the household can often play a significant role in parental perceptions of their child's capability to make good independent decisions and in turn their willingness to grant them autonomy to do so.

Given the extent to which household dynamics have a role to play in decisions it is also important that engagement materials appeal to both young people and their parents, taking into account that both are likely to be involved to varying degrees in the decision to participate.

It is important that engagement processes take account of the fact older and/or more 'independent' children can also feel reassured by a certain level of involvement from their parents during decision-making and the consent process.

Many young people of all ages opt to involve parents in their decisions, even when they are of an age or maturity when their parents are happy to grant them more autonomy. This suggests that the engagement process should ideally be designed to ensure young people and parents having the time and the information they require to be able to have informed discussions about participation, wherein they can weigh up potential risks and benefits.

This underlines the vital role played by clear and upfront communications about the scope and outputs of the research. Direct mailings and information provided well in advance of the interviewer's visit could also be key to ensuring young people and parents can have these relaxed discussions and that the young person does not feel pressurised in to making an on-the-spot decision or simply doing what they think is the *ought* to do..

Engagement materials should emphasise that the methods of data collection will provide young people with a degree of control over their responses and will be in an easy to use format.

In keeping with the need for reassurances about the scope and outputs of the research in general, there is a clear need for clear and upfront communication about how exactly a young person will be asked to provide their responses: How much time will they have? What format will the survey take (Online? Face-to-face?) What type of questions or subject matter will be covered (Multiple choice? Personal / academic?)

Providing as much information as possible about the nature of the data collection method and survey will ensure participants can prepare themselves psychologically, putting them at ease and more likely to give honest, thoughtful answers.

Even where surveys are not self-completion, possible engagement strategies could still build on these findings – for instance by interviewers reassuring young people that they can take their time, that their responses will be recorded as verbatim and that any responses will be anonymous. Reminders about confidentiality and anonymity are especially beneficial and many participants of this research stressed that they would want these reassurances before even agreeing to take part.

Similarly, many young people want to know that there are no right or wrong answers or at least that there is no negative consequence to missing a question out or not providing the right ‘type’ of answer.

It is important that engagement materials are transparent about how personal contact data about young people is stored and specifically how long it is stored for.

Parents can be particularly sensitive to issues of data security given wider awareness of data leakage scandals and they can be especially concerned about the potential risk of contact data that relates to their children being shared. In order to allay parents’ fears engagement materials should clearly show that the risks have been considered and should explain how data is kept secure and the length of time it is kept for.

Reassurances relating to data security are particularly key for securing and sustaining engagement in longitudinal research given the extended amount of time that the child’s data will potentially be ‘exposed’ for (in the parents’ eyes).

Engagement materials should provide sufficient information about the process of collecting and intended use of DNA samples. This will allow parents and young people to discuss this aspect of the research and familiarise themselves with what is to many, particularly young people, a strange concept.

Many young people can struggle to fully understand the purpose of DNA sampling and how their DNA can be useful to researchers. Emphasising the usefulness of DNA analysis and potentially data linkage in this area could be an effective way of putting young people at ease and encouraging them to give consent.

Furthermore, given the low awareness and sometimes confusion young people (of all ages) have surrounding DNA sampling, encouraging an informed discussion between parents and young people is an important part of guaranteeing an appropriate consent process. Engagement materials which give clear examples of what a participant’s DNA will, and *will not*, be used for in future will greatly help these discussions.

Appendices

Appendices

Appendix A: Discussion guides

MCS6 Engagement study Young People Groups Guide (06/06/13)

Background to the research

The research was commissioned by the Centre for Longitudinal Studies (CLS) who run the Millennium Cohort Study (MCS) and the Institute for Social and Economic Research at the University of Essex, who run Understanding Society: two longitudinal studies in the UK which allow researchers to analyse how complex social, economic, cultural and biological factors interact to contribute to people's life outcomes.

In order to ensure that this research is providing them with the highest quality data possible, it is extremely important for both studies to ensure an effective long term engagement of their panel members.

Structure of this guide

Section 1: Motivations to participate in research

Section 2: Information gathering habits

Section 3: General views on research

Section 4: Views on data collection

Section 5: Views on consent

PLEASE NOTE, FROM SECTION 4 ONWARDS WE ARE INTERESTED IN THEIR INITIAL REACTIONS TO EACH METHOD (I.E. WHAT KIND OF RESEARCH IT CONJURES UP FOR THEM, THEIR EXPERIENCES OF THAT METHOD, ETC. BUT WE ALSO WANT TO UNDERSTAND WHAT THEY THINK OF THE METHOD IN THE CONTEXT OF: SOCIAL RESEARCH (IF NOT ALREADY MENTIONED), ONE-OFF SURVEYS, LONGITUDINAL SURVEYS. SO PLEASE KEEP PROMPTING TO ASCERTAIN WHETHER THE RESEARCH DESIGN CHANGES THEIR OPINIONS OF THE DATA CAPTURE METHOD.

Activities / aims	Key Questions	Materials needed
Introduction and explanation of the purpose of the session (5 minutes)		
	<ul style="list-style-type: none"> • Introduce self and Ipsos MORI as an independent research company • Thank participants for taking part • Explain it is an informal chat lasting an hour and a half • Explain we're going to be talking about research and all the things that might be involved in this. This is because government departments are interested in conducting research with young people your age to help understand how people your age are developing and growing, and to understand what services and support you might need. • No right or wrong answers and not a Q&A- we want to hear what they have to say • If you don't agree with something then we want to hear your point of view too, or if you have more to add to something someone else has said please do! • Feel free to let me know if you don't understand anything or if we're going too fast • Anonymity of participants and MRS (Market Research Society) code of conduct • Permission to audio record – only so we don't have to take down loads of notes, won't be able to tell who said what but that we'll need them to only talk one at a time or the audio recorder won't be able to pick up what they're saying • Ask them to go round in a circle introducing their friend with their name and telling us something their friend likes to do 	
Section 1: Motivations to participate in research (5 minutes)		
	<ul style="list-style-type: none"> • Why did you take part in the research today? <ul style="list-style-type: none"> ○ Interested? Sounded fun? Felt pressured? ○ What sorts of things went through your mind? ○ Were you excited about taking part? ○ Were you nervous at all? ○ Did you have any questions about it? ○ Did you feel you could say no? 	
Section 2: Information gathering habits (5 minutes)		

Activities / aims	Key Questions	Materials needed
	<ul style="list-style-type: none"> • If you want to find out something, where do you normally go to find it out? <ul style="list-style-type: none"> ○ What sorts of things do you need to find out? <ul style="list-style-type: none"> ▪ Personal interests or reasons? ▪ Something for school? ▪ For friends? ▪ For family? ○ Are you usually good at being able to find the information you are looking for? ○ Do you go to different places to find out different things or is it normally the same place? ○ Are there places you trust or believe information from more than others? <ul style="list-style-type: none"> ▪ For example, would you believe information from the TV more or less than information from the internet? <div data-bbox="584 687 1850 831"> <p>Further questions for research on research group:</p> <ul style="list-style-type: none"> • When you were researching “research” where were you going to find out this information? <ul style="list-style-type: none"> ○ Was it anywhere different to where you’d normally look? </div>	
Section 3: General views on research (10 minutes)		
Write up their ideas on flipcharts	<p>Turn to your friend and discuss in pairs what you think the word “research” means.</p> <p><i>Get them to tell you their descriptions and write them on large flipchart paper in front of them (not on wall) as a diagram. Make links across what they are saying as they are talking.</i></p> <ul style="list-style-type: none"> • How would you describe it to someone? <ul style="list-style-type: none"> ○ What else do you think it is? ○ What does it include? What does it not include? • What sorts of things might doing research involve? <ul style="list-style-type: none"> ○ If I told you I was doing research, what sorts of things might I be doing? • Why might someone want to do some research? <ul style="list-style-type: none"> ○ What sorts of things might they be trying to find out about? • What sorts of organisations might do research? <ul style="list-style-type: none"> ○ An academic organisation such as a university 	Flipchart Research examples

Activities / aims	Key Questions	Materials needed
	<ul style="list-style-type: none"> ○ An agency that does research on behalf of lots of different organisations e.g. Ipsos MORI ○ A scientific organisation that is researching things such as disease ○ Government ○ A brand ○ Any others? • Have you ever done any types of research? <ul style="list-style-type: none"> ○ If so, what did you do for it? ○ How did you find it? • Do you think research is a good thing? Is it ever a bad thing? <ul style="list-style-type: none"> ○ What should people be doing research in? ○ What should they be using research for? • How important do you think it is? <div style="border: 1px solid black; padding: 5px; margin-top: 10px;"> <p>Further questions for research on research group:</p> <ul style="list-style-type: none"> • Did you find any research projects when you were exploring that were particularly interesting? • Was there anything that surprised you? </div> <p>There are lots of different types of research and it is normally based on trying to find information or facts about something. Today, we are mainly going to be talking about research where we are talking to people and finding out what they do, think or their habits and behaviour.</p>	
Section 4: Views on data collection (50 minutes)		
Introducing questionnaires	<p>We've talked a bit about how some people might do research. Now we're going to talk a bit more specifically about the different ways in which research might be done.</p> <ul style="list-style-type: none"> • Has anyone heard of a survey or a questionnaire? <ul style="list-style-type: none"> ○ What do you know about them? <p>When research needs to be done with a lot of people, surveys, using questionnaires, are a way of collecting this information.</p>	

Activities / aims	Key Questions	Materials needed
	<ul style="list-style-type: none"> Has anyone ever done a type of survey? If so, how did you do it? What was it for? How did you find taking part? Why did you decide to take part? <div data-bbox="582 440 1850 539" style="border: 1px solid black; padding: 5px;"> <p>Further questions for research on research group:</p> <ul style="list-style-type: none"> Is this something you came across when doing your research? Were there other types of research? How were they different? </div>	
Introducing different modes of collection and longitudinal surveys	<p>For the next part, you're going to imagine you've been asked to take part in a research project. The research project wants to talk to and follow young people and their families throughout their lives. This means that interviewers will come to the homes of young people regularly, such as every year. As part of this research they will be asked to fill in a questionnaire, and their parents will too, and they may be asked to do a variety of tasks to find out more about themselves and their lives. The research hopes to gain a better understanding of what it is like to be a young person today; and what happens to them as they grow up and become adults. This is to make sure services and their policies are able to give young people the best start in life and to support them to make the most of their adult lives. PLEASE NOTE – IT WILL BE IMPORTANT TO KEEP REITERATING THIS EXAMPLE DURING THE SUBSEQUENT DISCUSSIONS</p> <p><u>Moderator note: throughout this section ask participants to keep comparing one method against the other – what are the advantages/disadvantages of each, how do views change as discussion moves on</u></p> <p>The information for this research project can be collected in a number of different ways:</p> <ul style="list-style-type: none"> Has anyone ever heard of a paper questionnaire? <ul style="list-style-type: none"> What do you know about them? <p><i>Hold up picture of someone doing a paper questionnaire.</i></p> <p>Questionnaires can be done on paper which you can either do yourself, and mark the questionnaire with your answers, or an interviewer could ask you a series of questions and take down your answers.</p> <ul style="list-style-type: none"> Has anyone ever done anything like this? <ul style="list-style-type: none"> At the doctor's, dentist's, on the street, at school 	Pictures of example questionnaire modes

Activities / aims	Key Questions	Materials needed
	<ul style="list-style-type: none"> • Is this something you would be comfortable doing or not? Why? 	
	<ul style="list-style-type: none"> • Has anyone ever heard of doing a survey with a tablet computer? <ul style="list-style-type: none"> ○ What do you know about them? <p><i>Hold up picture of someone doing a questionnaire on a tablet computer</i></p> <p>Questionnaires can also be done using a tablet computer which you can also do either yourself or with an interviewer.</p> <ul style="list-style-type: none"> • Has anyone ever done anything like this? <ul style="list-style-type: none"> ○ In your home? In a shop? • Is this something you would be comfortable doing or not? Why? 	
	<ul style="list-style-type: none"> • Has anyone ever heard of doing a survey online? <ul style="list-style-type: none"> ○ What do you know about them? <p><i>Hold up picture of someone doing a questionnaire online</i></p> <p>Questionnaires can also be done online which you can do yourself</p> <ul style="list-style-type: none"> • Has anyone ever done anything like this? <ul style="list-style-type: none"> ○ On a website? Through a panel • Is this something you would be comfortable doing or not? Why? 	
	<ul style="list-style-type: none"> • Has anyone ever heard of doing a survey by telephone? <ul style="list-style-type: none"> ○ What do you know about them? <p><i>Hold up picture of someone doing a questionnaire on the phone</i></p> <p>Questionnaires can also be done over the phone and are led by an interviewer</p> <ul style="list-style-type: none"> • Has anyone ever done anything like this? <ul style="list-style-type: none"> ○ Were you called up out of the blue? • Is this something you would be comfortable doing or not? Why? 	

Activities / aims	Key Questions	Materials needed
	<ul style="list-style-type: none"> Has anyone ever heard of doing a survey on a mobile phone? <ul style="list-style-type: none"> What do you know about them? <p><i>Hold up picture of someone doing a questionnaire on a mobile phone</i></p> <p>Questionnaires can also be done by you using your mobile phone</p> <ul style="list-style-type: none"> Has anyone ever done anything like this? <ul style="list-style-type: none"> Were you called up out of the blue? Is this something you would be comfortable doing or not? Why? <hr/> <p><i>Place all of the pictures out on the table in front of them.</i></p> <ul style="list-style-type: none"> Out of all of these different ways, which would you feel most comfortable doing and which would you feel least comfortable doing? <p><i>Get them to rank the pictures in order from most to least comfortable doing</i></p> <ul style="list-style-type: none"> Does it make a difference if you are the one filling it out or an interviewer? <ul style="list-style-type: none"> Why might it make a difference? Do you think there are things you might put down yourself in a survey that you wouldn't tell an interviewer when doing a survey? If the research was asking you about bullying, would this change what your preferences are for how you do a questionnaire and how comfortable you are? If the research was asking you about your local area, would this change what your preferences are for how you do a questionnaire and how comfortable you are? 	
Doing physical measurements for research	<p>For the research project, they might want to take recordings of your height using a height measure.</p> <p><i>Show picture of child being measured</i></p> <ul style="list-style-type: none"> How would you feel about being measured? Have you had this done before? Would you feel comfortable with this? <ul style="list-style-type: none"> If not, what would make you feel more comfortable? 	Pictures of different measuring equipments

Activities / aims	Key Questions	Materials needed
	<ul style="list-style-type: none"> What do you think it might be used for? Why might it be useful? <p>For the research project, they might want to take recordings of your weight using scales. <i>Show picture of child being weighed on scales</i></p> <ul style="list-style-type: none"> How would you feel about being weighed? Have you had this done before? Would you feel comfortable with this? <ul style="list-style-type: none"> If not, what would make you feel more comfortable? What do you think it might be used for? Why might it be useful? 	
Doing cognitive assessments for research	<p>They might also want to do tasks that look at your abilities in lots of different areas. These can be a task on your speaking skills, your memory or how you think about things. <i>Show picture/video of child doing a cognitive assessment. Explain this is only an example and there are lots of different ways of doing this.</i></p> <ul style="list-style-type: none"> Have you ever done anything like this before? <ul style="list-style-type: none"> When? Do you know why you were asked to do it? How do you feel about doing these sorts of exercises? <ul style="list-style-type: none"> Would you feel that you are being tested? Would that make you more or less likely to want to take part? What do you think it might be used for? Why might it be useful? 	Example video of cognitive assessments
Collecting biomarker data for research	<p>They might also want to look at your DNA; this can be done by collecting saliva (spit) samples. <i>Show picture of child giving saliva sample</i> <i>If don't know what DNA is: Your saliva contains something called genes. Genes are part of you and are like recipes for what people are like. The way children grow and think is decided in part by their genes.</i></p> <ul style="list-style-type: none"> Have you ever done anything like this before? <ul style="list-style-type: none"> When? How do you feel about this sort of information about you being collected? Would you feel comfortable doing it? What do you think about the way it is collected? PROBE FULLY. Is that what you'd expect? What do you think it might be used for? Why might it be useful? 	Example pictures

Activities / aims	Key Questions	Materials needed
	<p>Examples of how saliva samples will/will not be used:</p> <ul style="list-style-type: none"> • Researchers will be able to use the DNA sample to look at whether you have certain types of genes. This can help researchers understand better differences in children's development, health, behaviour, growth and learning • Researchers might look at specific genes which have been shown to influence children's growth and learning. • It will not be tested for the HIV (AIDS) virus and will not be available for police records (or insurance companies when you are older) 	
Views and concerns about data collection	<p><i>Lay out all of the modes of surveys and types of data collection on the table.</i></p> <ul style="list-style-type: none"> • Would you want anyone to be with you when you are doing these types of research? <ul style="list-style-type: none"> ○ Just you ○ A parent ○ A friend ○ A teacher • Are there any here where you would want them there for more than others? <ul style="list-style-type: none"> ○ Which ones would you want them there for? ○ Which ones would you not want them there for? • Does it make a difference if they were there while you were being interviewed by an interviewer and so saying the answers out loud or if you were doing it yourself? • Do you think the information you have given in the research will be seen by anyone other than the researchers or interviewer? <ul style="list-style-type: none"> ○ Do you think people, other than those doing the research, will be able to tell that you have taken part and what you've said? • Would you expect your parents to be able to see what you've said? <ul style="list-style-type: none"> ○ If yes, how would that make you feel? 	Views and concerns about data collection
Views on data linkage	<p>They might want to “link” what you’ve told them as part of the research to other information about you that might exist.</p> <p><i>Use at least one example from the below. If time, use both examples.</i></p> <p>Example 1: For example, they might link your information to other information the Department for Education holds about you. This might be information about the school as well as your exam results.</p>	Diagram of two different data sources and linking of fields

Activities / aims	Key Questions	Materials needed
	<p>Example 2: For example, they might link your information to your health records such as any hospital visits you made, why you went and how long you stayed for. <i>Show diagram of two different data sources and linking of fields.</i></p> <ul style="list-style-type: none"> • How do you feel about this sort of data linking happening with your information? <p>Before they do this though, they need to ask your parent's or your permission.</p> <ul style="list-style-type: none"> • How would you feel if your parents are asked permission first for your data to be linked? • If your parents are asked permission first, do you think when you are 16 this will change? i.e. you are asked instead? • What do you think they might do this for? • Would you have any concerns about it? <ul style="list-style-type: none"> ○ What sorts of concerns? ○ What would have to happen to stop you feeling worried? ○ Would you want to know more about this data linking before you say that it's ok to do it? ○ <i>(If concerned about anonymity assure participants it would be anonymous)</i> Does this make you feel differently? 	
Views on data preservation	<p>After the research has happened, your personal information might be stored somewhere after the research has been conducted. Personal information might include your name and contact details. This information will be stored separately from the information collected from you for research purposes and are only kept so that the researchers can come back to interview you at a later date. The information that is collected for research is looked at anonymously so no-one will know that the information is about you.</p> <ul style="list-style-type: none"> • How do you feel about that? • Would you expect them to hold this information forever or destroy it after a certain amount of time? <p>As part of the research project, they would like to come back and visit you in your home at regular intervals throughout your life.</p> <ul style="list-style-type: none"> • How would you feel about that? • Would you feel happy agreeing to that? • What sorts of things would make you not want to agree? • What do you think it might be used for? Why might it be useful? <p>As you get older the researchers may want to come back to visit you when you are no longer considered a</p>	Picture of two databases: one with contact details and another with research data

Activities / aims	Key Questions	Materials needed
	<p>'child' anymore i.e. when you are 16 or older.</p> <ul style="list-style-type: none"> • How do you feel about this? • Would you feel comfortable with them interviewing you at 16 without your parent's permission being asked first? • Would you still ask permission from your parent first or would you feel comfortable making this decision yourself? 	
Section 5: Views on consent (15 minutes)		
	<p>Before you were asked to attend today's session, your parent was asked if it was okay for us to talk to you.</p> <ul style="list-style-type: none"> • How do you feel about this? • Do you think they should be asked first? • Would you expect them to be able to find out what you have told us? <ul style="list-style-type: none"> ○ Can you think of any situations where it would make sense for them to find out? • How old do you think you need to be to agree to do today's session without your parent's being asked first? <ul style="list-style-type: none"> ○ How about when you are 16? • How much say do they normally have in decisions about your life and what you're going to do in it? • What sorts of decisions are you able to make about your own life and what you do compared with your parent's decisions? <ul style="list-style-type: none"> ○ Do you have to get permission for most things? ○ Is there anything you can do without your parents saying whether you're allowed to do them or not? • For this research your parents were approached, and had to give their permission for us to ask you if you wanted to do it. Is this right? Do you think your parents should have been asked or not? Or just been told that that was going to happen? Did you ask their advice as to whether you should take part or not? Why/why not? What sorts of things did you ask them? • How would you feel if we just approached you and not your parents? • Should you and your parents be approached at the same time or one after the other, and if one after the other in what order? <p>We then asked you if you wanted to take part in the research.</p> <ul style="list-style-type: none"> • How did you feel about being asked yourself? 	<p>Stimulus of current MCS consent forms or mock versions without the MCS logo</p>

Activities / aims	Key Questions	Materials needed
	<ul style="list-style-type: none"> • Would your parent normally make these sorts of decisions for you on your behalf? • Would your parent normally consult you as well? • Was there anything that you wanted to know before you said yes to doing the research? <ul style="list-style-type: none"> ○ What sorts of things did you want to know? <ul style="list-style-type: none"> ▪ What the research is about? ▪ Who you will be talking to (age, sex etc) ▪ How long it will take ▪ Where it will be ▪ What if you don't want to do it? • Did you feel like you understood what you were going to do? <ul style="list-style-type: none"> ○ Were you given enough information? • What would have made you not want to do the research? <p>Once you agreed to take part you had to sign a piece of paper and give your contact details.</p> <ul style="list-style-type: none"> • How did you feel about signing it? • Have you had to sign many things before? • Was there anything you felt nervous about when signing? • What about giving your contact details to the recruiter? <ul style="list-style-type: none"> ○ Was this something you felt comfortable doing? ○ Was there anything you were unsure of? ○ Did you need or want to ask your parents about any of it? <p>We talked earlier in the imaginary research project about agreeing to do research without needing your parent's permission.</p> <ul style="list-style-type: none"> • Do you feel the same about other types of research? For example, a piece of research like today's rather than one that you'd do lots of times? PROBE AGAIN FOR MARKETING, SOCIAL, ONE-OFF, LONGITUDINAL • Do you think you'd feel old enough to make that decision? Do you feel you'd be ready now? <p>IF NEEDED, use stimulus with examples of how consent is asked for MCS as an aid to discussion</p>	
Summary and wrap up (5 minutes)		

Activities / aims	Key Questions	Materials needed
	<ul style="list-style-type: none"> • What sorts of things make you more or less likely to want to take part? • How did you find doing this research for us? • Does it make you more or less interested in research? • Does it make you want to take part in more research? Is it something you might think about doing... <ul style="list-style-type: none"> ○ Another time? ○ Another way? ○ If yes: <ul style="list-style-type: none"> ▪ Why would you want to do more of this sort of thing? ▪ Do you think it's worth doing? ○ If no: <ul style="list-style-type: none"> ▪ Why not? ▪ Is it from how this session has gone or is it from finding out more about this research? • Do you feel like you understand what research is about more? • Do you have any questions? • Is there anything else you'd like to tell us about your experiences? 	

MCS6 Engagement study Parents' Groups Guide (06/06/13)

Background to the research

The research was commissioned by the Centre for Longitudinal Studies (CLS) who run the Millennium Cohort Study (MCS) and the Institute for Social and Economic Research at the University of Essex, who run Understanding Society: two longitudinal studies in the UK which allow researchers to analyse how complex social, economic, cultural and biological factors interact to contribute to people's life outcomes.

In order to ensure that this research is providing them with the highest quality data possible, it is extremely important for both studies to ensure an effective long term engagement of their panel members.

Structure of this guide

Section 1: General views on research

Section 2: General perceptions of a mock study involving children

Section 3: Views on specifics of research process itself

Section 4: Views on decision-making and children's input into decisions about research

Section 5: Views on giving parental consent

PLEASE NOTE, WE ARE INTERESTED IN THEIR INITIAL REACTIONS TO EACH METHOD (I.E. WHAT KIND OF RESEARCH IT CONJURES UP FOR THEM, THEIR EXPERIENCES OF THAT METHOD, ETC. BUT WE ALSO WANT TO UNDERSTAND WHAT THEY THINK OF THE METHOD IN THE CONTEXT OF: SOCIAL RESEARCH (IF NOT ALREADY MENTIONED), ONE-OFF SURVEYS, LONGITUDINAL SURVEYS. SO PLEASE KEEP PROMPTING TO ASCERTAIN WHETHER THE RESEARCH DESIGN CHANGES THEIR OPINIONS OF THE DATA CAPTURE METHOD.

Key Questions	Materials needed
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	Key Questions	Materials needed
Introduction and explanation of the purpose of the session 5 minutes	<ul style="list-style-type: none"> • Introduce self and Ipsos MORI as an independent research company • Thank participants for taking part • Explain it is an informal discussion lasting an hour and a half • Anonymity of participants and MRS (Market Research Society) code of conduct • Permission to audio record – only for analysis, no attribution of comments • Explain purpose of tonight's discussion – to find out a bit about their views of research, the process and role of research and hear their ideas about what makes them more/less likely to get involved – we'll also be talking a bit about them as parents – no right or wrong answers – but don't all talk at once please <p>Group introductions: ask participants to introduce themselves to the person on their right, then go round in a group and ask everyone to introduce the person next to them</p>	
Section 1: General views on research		
10 minutes	<p>Thinking very generally, remember there are no rights or wrongs, can I ask...</p> <ul style="list-style-type: none"> • Why did you agree to come tonight? DISCUSS <ul style="list-style-type: none"> ○ What was your first thought when you were asked to take part? Shout out anything that comes to mind.... ○ Did you have any worries? What? ○ Were you excited? Why? • What do you think the point of taking part is? <ul style="list-style-type: none"> ○ PROBE FULLY for associations and feelings about taking part in research • How do your views differ depending on the subject being researched? • IF NEEDED use examples of market and social research e.g. asking consumers about their choice of energy tariff / use of supermarkets / perceptions of GPs / purpose of A-levels • Can you sum-up what you think the point of research is for me in three words? WRITE DOWN <ul style="list-style-type: none"> ○ Go round group asking what they wrote down and DISCUSS. ○ Why do you think it is / is not important? ○ What ways do you use research at home? Personally? With your family? PROBE online surveys, 	Plain paper for 'the point of research' exercise

	Key Questions	Materials needed
	<p>feedback on websites, pop-up questionnaires</p> <ul style="list-style-type: none"> • Does your view change if I say research <i>with</i> children? Why? <ul style="list-style-type: none"> ○ What kind of research relating to children do you think is useful? ○ What do you think about research that involves children? ○ Would you be happy for your child to take part in research? Why / why not? ○ Is the age of the child relevant? Why? How young is too young? ○ What concerns do you have about children taking part? • Overall, do you think involving children in research is a good or bad thing? Why? 	
Section 2: Views on decision-making and children's input into decisions		
10 minutes	<p>I'd like to talk now about how you decide on things at home, are the kids involved, if so, when, what types of decisions are they involved in....remember we don't have to agree, I expect you're all pretty different in this respect!</p> <ul style="list-style-type: none"> ○ Firstly, overall, how involved / not involved would you say your children are in household decisions? PROBE very / not very / sometimes / more than I'd like them to be / it's out of my hands etc. DISCUSS ○ How does this differ depending on the decision? PROBE holidays, school (learning, trips), health, free time, food, shopping, money ○ When is it appropriate to give them more autonomy? Why? ○ When do you like to retain input? Final say? ○ How does this / is this expected to change over time? 	
Section 3: General perceptions of a mock study involving children		
10 minutes	<p>We've talked a bit about research in general and your views on research that involves children. For the next part, you're going to imagine you've been asked to take part in a research project. The research project wants to talk to and follow young people and their families throughout their lives. This means that interviewers will come to the homes of young people regularly, such as every year. As part of this research</p>	

	Key Questions	Materials needed
	<p>the young person will be asked to fill in a questionnaire, and their parents will too, and they may be asked to do a variety of tasks to find out more about themselves and their lives. The research hopes to gain a better understanding of what it is like to be a young person today; and what happens to them as they grow up and become adults. This is to make sure services and their policies are able to give young people the best start in life and to support them to make the most of their adult lives. PLEASE NOTE – IT WILL BE IMPORTANT TO KEEP REITERATING THIS EXAMPLE DURING THE SUBSEQUENT DISCUSSIONS</p> <p>What are your first thoughts about this? What else?</p> <ul style="list-style-type: none"> • What is good about this study? FLIPCHART 'Pros' • What is not so good? FLIPCHART 'Cons' • Do you have any concerns? What? Why? • Would you want any reassurances from the people running the research? What? Why? • Would you be happy for your child to take part? <p>Now imagine that you have been approached by someone (similar to how you were approached to take part in tonight's group) and they explained to you a bit about this study and what would be involved....</p> <ul style="list-style-type: none"> • Quick show of hands, who would say yes? We don't have to agree on this. • Who would say no? • DISCUSS reasons for and against • Of everything we've just seen, what is the one thing that would make you want to take part? Why? • What is the one thing you think would make your child want to take part? Why? <p>Now imagine that you were telling your child about this - take a minute and individually write down what you'd say to get them involved.</p> <p><i>Present back ideas if people feel comfortable or collect up.</i></p>	

	Key Questions	Materials needed
Section 4: Views on giving parental consent		
10 minutes	<p>Thinking about how you decide whether your child is going to take part in a research study like this one...</p> <ul style="list-style-type: none"> ○ Would you want to be involved in decisions about your child taking part in research? Why? ○ Is there a cut-off age after which you'd be happy for your child to make their own decision? When? ○ Would you encourage your child to take part or not? PROBE FULLY type of research topic, research process/method, who the research is for ○ Does it make a difference what the research is about? Why? PROBE FULLY ○ Does it make a difference what the process involves? PROBE survey, physical measurements, interview at home / school ○ Does it make a difference who the research is for? Why? PROBE government, private company, charity ○ Would the decision to take part be the kind of thing you would let your child be involved in? Why? ○ Who would have a discussion about it? ○ Imagine you were having the discussion, how would it go? ○ Who would make the final decision? <p>How important / not do you think it is to involve children in a decision like this? Why? FLIPCHART</p> <ul style="list-style-type: none"> ○ Thinking of all the information you've seen tonight, how much of this would you want to know before you feel comfortable giving consent for your child to take part in a study of this sort? ○ Can you think of similar scenarios where you asked to give consent on behalf of your child, what seems like a good comparison here? PROBE school trips, medical tests, social activities, anything educational ○ To what extent are you happy to just be 'in the know' about what your child is doing? ○ When is it appropriate to give formal consent? And verbal? PROBE for examples ○ If your child was 16 would you be happy for them to consent to take part in a study like this themselves? Why / why not? ○ What are your concerns over letting your child give their own consent for something like this? ○ What about issues relating to how the data might be shared with another organisation or used for research purposes...would your child understand about this? To what extent do you think you would still need to be involved in giving consent? ○ What suggestions do you have for how best to get the 'OK' from your child as well as you? 	

	Key Questions	Materials needed
Section 5: Views on specifics of research process itself 45 minutes		
Introducing different modes of collection	<p><u>Moderator note: throughout this section ask participants to keep comparing one method against the other – what are the advantages/disadvantages of each, how do views change as discussion moves on. Probe throughout on consent.</u></p> <p>We're now going to talk a bit more about different ways in which the research project might be carried out.</p> <ul style="list-style-type: none"> ○ Have you heard of a survey or questionnaire? What do you know about them? <p>Surveys, using questionnaires are used to conduct research with a lot of people in a structured way. The information for this research project could be collected in a number of different ways: <i>WORK THROUGH EACH METHOD IN TURN. Hold up pictures of each questionnaire mode as talking about it and then lay them out on the table.</i></p> <ul style="list-style-type: none"> • What are your first thoughts? • How appropriate do you think this is for conducting research with you/your child? Why/why not? • How happy would you be to participate in this? How happy do you think your child would be? • Is anything worrying? Why? What would make you less concerned? 	Stimulus slides detailing individual stages of the model research process
	<p>Now you know a bit more about it, would you want your child to take part? How likely / unlikely would you be to encourage them to get involved? Why? Can you see any problems? Reasons why you would not want your child to take part / why your child would not want to take part? Why?</p> <ul style="list-style-type: none"> ○ What would you want the data to be used for? ○ What do you think about the possibility of this kind of data being used by different organisations as a resource? REASSURE RE ANONYMITY ○ What about how the data is stored...are you interested in this? ○ What issues might there be about how the data collected by the research is stored? Where does this concern come from? Word of mouth? Past experience? General fear? Media? 	

	Key Questions	Materials needed
Doing physical measurements for research	<p>For the research project, they might want to take recordings of your child's height using a height measure. <i>Show picture of child being measured.</i></p> <ul style="list-style-type: none"> • What are your first thoughts? • Why do you think they might want to do this? • How happy would you be for your child to participate in this? How happy do you think your child would be? • Is anything concerning? Why? What would make you less concerned? • Can you imagine how this would work practically? Does it look easy / difficult? 	
	<p>They might want to take recordings of your child's weight using scales. <i>Show picture of child being weighed on scales.</i></p> <ul style="list-style-type: none"> • What are your first thoughts? • Why do you think they might want to do this? • How happy would you be for your child to participate in this? How happy do you think your child would be? • Is anything worrying? Why? What would make you less concerned? • Can you imagine how this would work practically? Does it look easy / difficult? 	
Collecting biomarker data for research	<p>They might also want to look at your child's DNA; this can be done by collecting saliva samples. <i>Show picture of child giving saliva sample</i></p> <ul style="list-style-type: none"> • What are your first thoughts? • How appropriate do you think this is for conducting research with you/your child? Why/why not? • How happy would you be to participate in this? How happy do you think your child would be? • Is anything concerning? Why? What would make you less concerned? • What do you think about the way it is collected? PROBE FULLY. Is that what you'd expect? • What do you think it might be used for? Why might it be useful? <p>Examples of how saliva samples will/will not be used:</p> <ul style="list-style-type: none"> • Researchers will be able to use the DNA sample to look at whether you have certain types of genes. This can help researchers understand better differences in children's development, health, behaviour, growth and learning • Researchers might look at specific genes which have been shown to influence children's growth and learning. 	

	Key Questions	Materials needed
	<ul style="list-style-type: none"> It will not be tested for the HIV (AIDS) virus and will not be available for police records (or insurance companies when you are older) 	
Views on data linkage	<p>They might want to “link” the data collected as part of the research to other information about you or your child that might exist. <i>Use at least one example from the below. If time, use both examples.</i> Example 1: For example, they might link the results from the research to other information the Department for Education holds about your child. This might be information about the school as well as their exam results. Example 2: For example, they might link the results from the research to your child’s health records such as any hospital visits they made, why they went and how long they stayed for. <i>Show diagram of two different data sources and linking of fields.</i> Before they do this though, they will ask either your or your child’s permission.</p> <ul style="list-style-type: none"> How do you feel about this sort of data linking happening with your child’s information? Would you feel comfortable if you were to give consent on behalf of your child? <ul style="list-style-type: none"> Would this be appropriate? Do you think a child under 16 can make their own decision? If you were not asked, would you feel comfortable for your child (under 16) to give consent instead of you? <p>When a child turns 16 they will only be asked themselves</p> <ul style="list-style-type: none"> Is this an appropriate age? If not, when is appropriate? What do you think they might do this for? Would you have any concerns about it? <ul style="list-style-type: none"> What sorts of concerns? Would you feel confident your child would understand what this was if they were to agree to it? <i>(If concerned about anonymity assure participants it would be anonymous)</i> Does this make you feel differently? 	

	Key Questions	Materials needed
Views on data preservation	<p>After the research has happened, yours/your child's personal information might be stored somewhere after the research has been conducted. Personal information might include name and contact details. This information will be stored separately from the information collected from the research. They are only kept so that the researchers can come back to your household at a later date. The information that is collected for research is looked at anonymously so no-one will know that the information is about you/your child.</p> <ul style="list-style-type: none"> • How do you feel about that? Why? • Are you interested in how the data is stored? Why? • Would you expect them to hold this information indefinitely or destroy it after a certain amount of time? • What issues might there be about how the data collected by the research is stored? Where does this concern come from? Word of mouth? Past experience? General fear? Media? 	
Views on longitudinal research	<p>As part of the research project, they would like to come back to visit you and your household at regular intervals throughout your lives.</p> <ul style="list-style-type: none"> • What are your first thoughts? • How appropriate do you think this is for conducting research with you/your child? Why/why not? • How happy do you think your child would be to participate in this? <p>As your child gets older the researchers may want to come back once your child is no longer considered a 'child' anymore i.e. when they are 16 or older.</p> <ul style="list-style-type: none"> • How do you feel about this? • Would you feel comfortable with them interviewing your child at 16 without your permission being asked first? • Would your child still ask permission from you, do you think, or would they feel comfortable making this decision themselves? 	

	Key Questions	Materials needed
Sorting exercise	<p>Now in groups of 3-4, take about 5-10 minutes and look at all of the showcards. Thinking about what we've discussed and imagining that this was actually happening to your family, I'd like you to sort these elements of the research in to groups –</p> <ol style="list-style-type: none"> 1. Acceptable / I would be happy about this 2. Not sure / I have some concerns about this 3. Not acceptable / I would not be happy about this <p>Feedback to the group.</p> <ul style="list-style-type: none"> • Now you know a bit more about it, would you want your child to take part? How likely / unlikely would you be to encourage them to get involved? Why? • Can you see any problems? Reasons why you would not want your child to take part / why your child would not want to take part? Why? <p>Finally, thinking about the data that would be collected....</p> <ul style="list-style-type: none"> • What would you want the data to be used for? Why? • Who would be the ideal 'organisation' that used the data from the research? Why? • What do you think about the possibility of this kind of data being used by other organisations as a resource? <p>REASSURE RE ANONYMITY</p>	
Summary and wrap up		

	Key Questions	Materials needed
5 minutes	<p>Thank you so much for taking part tonight. Before we go, I want to make sure I have understood what's most important to you....</p> <ul style="list-style-type: none"> • So what do you think are the key messages from tonight? • Has there been anything surprising / worrying / particularly interesting? • What's your final message to people who run studies like this one we've been looking at? How would you get people engaged? <p>Thank and close. Handout incentives.</p>	

MCS6 Engagement study Household Interviews Guide (06/06/13)

Background to the research

The research was commissioned by the Centre for Longitudinal Studies (CLS) who run the Millennium Cohort Study (MCS) and the Institute for Social and Economic Research at the University of Essex, who run Understanding Society: two longitudinal studies in the UK which allow researchers to analyse how complex social, economic, cultural and biological factors interact to contribute to people's life outcomes.

In order to ensure that this research is providing them with the highest quality data possible, it is extremely important for both studies to ensure an effective long term engagement of their panel members.

PLEASE NOTE, WE ARE INTERESTED IN PARTICIPANTS' INITIAL REACTIONS TO EACH METHOD (I.E. WHAT KIND OF RESEARCH IT CONJURES UP FOR THEM, THEIR EXPERIENCES OF THAT METHOD, ETC. BUT WE ALSO WANT TO UNDERSTAND WHAT THEY THINK OF THE METHOD IN THE CONTEXT OF: SOCIAL RESEARCH (IF NOT ALREADY MENTIONED), ONE-OFF SURVEYS, LONGITUDINAL SURVEYS. SO PLEASE KEEP PROMPTING TO ASCERTAIN WHETHER THE RESEARCH DESIGN CHANGES THEIR OPINIONS OF THE DATA CAPTURE METHOD.

Activities / aims	Key Questions	Materials needed
Introduction and explanation of the purpose of the session – This to be given at start of parent i/v and repeated at start of child i/v		
5 minutes	<ul style="list-style-type: none"> • Introduce self and Ipsos MORI as an independent research company. Thank participants for taking part • Explain it is an informal discussion. • Explain we're going to be talking about research and all the things that might be involved in this. This is because government departments are interested in conducting research with young people your age to help understand how people your age are developing and growing, and to understand what services and support you might need. • No right or wrong answers and not a Q&A - we want to hear what they have to say • Feel free to let me know if you don't understand anything or if we're going too fast • Anonymity of participants and MRS (Market Research Society) code of conduct • Permission to audio record – only so we don't have to take down loads of notes, won't be able to tell who said what but that we'll need them to only talk one at a time or the audio recorder won't be able to pick up what 	

Activities / aims	Key Questions	Materials needed
	<p>they're saying</p> <ul style="list-style-type: none"> • Ask them to introduce themselves • Explain order of interview: speak to parent first, then young person, then both together, ideally speak to each without the other being in the same room 	
Interview with parent (20 minutes)		
Section 1: General views on research (10 minutes)		
	<p>Thinking very generally, recap on introduction (background to research, confidentiality, MRS code of conduct), remember there are no rights or wrongs, can I ask...</p> <ul style="list-style-type: none"> • Why did you agree to take part in this interview? <ul style="list-style-type: none"> ○ What was your first thought when you were asked to take part? ○ Did you have any worries? What? Were you excited? Why? • What do you think the point of taking part is? <ul style="list-style-type: none"> ○ PROBE FULLY for associations and feelings about taking part in research • Would your views differ depending on the subject being researched? • IF NEEDED use examples of market and social research e.g. asking consumers about their choice of energy tariff / use of supermarkets / perceptions of GPs / purpose of A-levels • Can you sum-up what you think research is in three words? <ul style="list-style-type: none"> ○ Do you think it is important? Why? ○ What ways do you use research at home? Personally? With your family? PROBE online surveys, feedback on websites, pop-up questionnaires • Does your view change if I say research <i>with</i> children? Why? <ul style="list-style-type: none"> ○ What kind of research relating to children do you think is useful? ○ What do you think about research that involves children? ○ Would you be happy for your child to take part in research? Why / why not? ○ Is the age of the child relevant? Why? How young is too young? ○ What concerns do you have about children taking part? • Overall, do you think involving children in research is a good or bad thing? Why? 	

Activities / aims	Key Questions	Materials needed
Section 2: Views on decision-making and children's input into decisions about research (5 minutes)		
	<p>I'd like to talk now about how you decide on things at home, are the kids involved?</p> <ul style="list-style-type: none"> ○ Firstly, overall, how involved / not involved would you say your children are in household decisions? PROBE very / not very / sometimes / more than I'd like them to be / it's out of my hands etc. ○ How does this differ depending on the decision? PROBE holidays, school (learning, trips), health, free time, food, shopping, money ○ When is it appropriate to give them more autonomy? Why? ○ When do you like to retain input? Final say? ○ How does this / is this expected to change over time? 	
Section 3: Views on giving parental consent (5 minutes)		
	<p>Thinking about how you decide whether your child is going to take part in a research study like this...</p> <ul style="list-style-type: none"> ○ Would you want to be involved in decisions about your child taking part in research? Why? ○ Is there a cut-off age after which you'd be happy for your child to make their own decision? When? ○ Can you imagine encouraging your child to take part? PROBE FULLY type of research topic, research process/method, who the research is for ○ Does it make a difference what the research is about? Why? PROBE FULLY ○ Does it make a difference what the process involves? PROBE survey, physical measurements, interview at home / school ○ Does it make a difference who the research is for? Why? PROBE government, private company, charity ○ Would the decision to take part be the kind of thing you would let your child be involved in? Why? ○ Who would have a discussion about it? ○ Imagine you were having the discussion, how would it go? ○ Who would make the final decision? <p>How important / not do you think it is to involve children in a decision like this? Why?</p> <ul style="list-style-type: none"> ○ How much would you want to know before you feel comfortable giving consent for your child to take part in a study of this sort? ○ Can you think of similar scenarios where you asked to give consent on behalf of your child, what seems like a good comparison here? PROBE school trips, medical tests, social activities, anything educational 	

Activities / aims	Key Questions	Materials needed
	<ul style="list-style-type: none"> ○ To what extent are you happy to just be 'in the know' about what your child is doing? ○ When is it appropriate to give formal consent? And verbal? ○ If your child was 16 would you be happy for them to consent to take part in a study like this themselves? Why / why not? ○ What about issues relating to how the data might be shared with another organisation or used for research purposes...would your child understand about this? To what extent do you think you would still need to be involved in giving consent? ○ What suggestions do you have for how best to get the 'OK' from your child as well as you? 	
Interview with young person (17 minutes)		
Section 1: Motivations to participate in research (2 minutes)		
	<ul style="list-style-type: none"> ● Why did you take part in the research today? <ul style="list-style-type: none"> ○ Interested? Sounded fun? Felt pressured? ○ What sorts of things went through your mind? ○ Were you excited about taking part? ○ Were you nervous at all? ○ Did you have any questions about it? ○ Did you feel you could say no? 	
Section 2: Information gathering habits (5 minutes)		
	<ul style="list-style-type: none"> ● If you want to find out something, where do you normally go to find it out? <ul style="list-style-type: none"> ○ What sorts of things do you need to find out? <ul style="list-style-type: none"> ▪ Personal interests or reasons? ▪ Something for school? ▪ For friends? ▪ For family? ▪ Can you show me some examples of what you have looked up? ○ Are you usually good at being able to find the information you are looking for? 	

Activities / aims	Key Questions	Materials needed
	<ul style="list-style-type: none"> ○ Do you go to different places to find out different things or is it normally the same place? ○ Are there places you trust or believe information from more than others? <ul style="list-style-type: none"> ▪ For example, would you believe information from the TV more or less than information from the internet? ▪ Can you show me? 	
Section 3: General views on research (5 minutes)		
	<p>What you think the word “research” means?</p> <ul style="list-style-type: none"> • How would you describe it to someone? <ul style="list-style-type: none"> ○ What does it include? What does it not include? ○ If I told you I was doing research, what sorts of things might I be doing? ○ Why might someone want to do some research? What sorts of things might they be trying to find out about? • What sorts of organisations might do research? <ul style="list-style-type: none"> ○ An academic organisation such as a university ○ An agency that does research on behalf of lots of different organisations e.g. Ipsos MORI ○ A scientific organisation that is researching things such as disease ○ Government ○ A brand ○ Any others? • Have you ever done any types of research? <ul style="list-style-type: none"> ○ If so, what did you do for it? How did you find it? • Do you think research is a good thing? Is it ever a bad thing? <ul style="list-style-type: none"> ○ What should people be doing research in? • How important do you think it is? <p>There are lots of different types of research and it is normally based on trying to find information or facts about something.</p> <p>Today, we are mainly going to be talking about research where we are talking to people and finding out what they do, think or their habits and behaviour.</p>	<p>Flipchart</p> <p>Research examples</p>

Activities / aims	Key Questions	Materials needed
Section 4: Views on consent (5 mins)		
	<p>Before you were asked to take part in this interview, your parent was asked if it was okay for us to talk to you.</p> <ul style="list-style-type: none"> • How do you feel about this? Do you think they should be asked first? • How much say do they normally have in decisions about your life and what you're going to do in it? • What sorts of decisions are you able to make about your own life and what you do compared with your parent's decisions? <ul style="list-style-type: none"> ○ Do you have to get permission for most things? ○ Is there anything you can do without your parents saying whether you're allowed to do them or not? • For this research your parents were approached, and had to give their permission for us to ask you if you wanted to do it. Is this right? Do you think your parents should have been asked or not? Or just been told that that was going to happen? Did you ask their advice as to whether you should take part or not? Why/why not? What sorts of things did you ask them? • How would you feel if we just approached you and not your parents? • Should you and your parents be approached at the same time or one after the other, and if one after the other in what order? <p>We then asked you if you wanted to take part in the research.</p> <ul style="list-style-type: none"> • How did you feel about being asked yourself? • Would your parent normally make these sorts of decisions for you on your behalf? • Would your parent normally consult you as well? • Was there anything that you wanted to know before you said yes to doing the research? <ul style="list-style-type: none"> ○ What sorts of things did you want to know? <ul style="list-style-type: none"> ▪ What the research is about? ▪ Who you will be talking to (age, sex etc) ▪ How long it will take ▪ Where it will be ▪ What if you don't want to do it? • Did you feel like you understood what you were going to do? <ul style="list-style-type: none"> ○ Were you given enough information? • What would have made you not want to do the research? 	

Activities / aims	Key Questions	Materials needed
	<p>Once you agreed to take part you had to sign a piece of paper and give your contact details.</p> <ul style="list-style-type: none"> • How did you feel about signing it? • Have you had to sign many things before? • Was there anything you felt nervous about when signing? • What about giving your contact details to the recruiter? <ul style="list-style-type: none"> ○ Was this something you felt comfortable doing? ○ Was there anything you were unsure of? ○ Did you need or want to ask your parents about any of it? <p>We talked earlier about the possibility of agreeing to do research without needing your parent's permission.</p> <ul style="list-style-type: none"> • Do you feel the same about other types of research? For example, a piece of research like today's rather than one that you'd do lots of times? PROBE AGAIN FOR MARKETING, SOCIAL, ONE-OFF, LONGITUDINAL • Do you think you'd feel old enough to make that decision? Do you feel you'd be ready now? • How would it make you feel if your parent were asked? And if they weren't? 	
Joint interview: parent and young person (40 minutes)		
Introducing questionnaires	<p><i>Moderator note:</i> throughout this section direct questions initially to young person and bring parent in after young person has given their initial response</p> <p>We've talked a bit about how some people might do research. Now we're going to talk a bit more specifically about the different ways in which research might be done.</p> <ul style="list-style-type: none"> • Have you heard of a survey or a questionnaire? <ul style="list-style-type: none"> ○ What do you know about them? <p>When research needs to be done with a lot of people, surveys, using questionnaires, are a way of collecting this information.</p> <ul style="list-style-type: none"> • Have you ever done a type of survey? If so, how did you do it? What was it for? How did you find taking part? Why did you decide to take part? 	
Introducing different modes of collection and longitudinal	For the next part, you're going to imagine you've been asked to take part in a research project. The research project wants to talk to and follow young people and their families throughout their lives. This means that	Pictures of example

Activities / aims	Key Questions	Materials needed
surveys	<p>interviewers will come to the homes of young people regularly, such as every year. As part of this research they will be asked to fill in a questionnaire, and their parents will too, and they may be asked to do a variety of tasks to find out more about themselves and their lives. The research hopes to gain a better understanding of what it is like to be a young person today; and what happens to them as they grow up and become adults. This is to make sure services and their policies are able to give young people the best start in life and to support them to make the most of their adult lives. PLEASE NOTE – IT WILL BE IMPORTANT TO KEEP REITERATING THIS EXAMPLE DURING THE SUBSEQUENT DISCUSSIONS</p> <p>Moderator note: throughout this section ask participants to keep comparing one method against the other – what are the advantages/disadvantages of each, how do views change as discussion moves on</p> <p>The information for this research project can be collected in a number of different ways:</p> <ul style="list-style-type: none"> Have you ever heard of a <u>paper</u> questionnaire? <ul style="list-style-type: none"> What do you know about them? <p><i>Hold up picture of someone doing a paper questionnaire.</i></p> <p>Questionnaires can be done on paper which you can either do yourself, and mark the questionnaire with your answers, or an interviewer could ask you a series of questions and take down your answers.</p> <ul style="list-style-type: none"> Have you ever done anything like this? At the doctor's, dentist's, on the street, at school Is this something you would be comfortable doing or not? 	questionnaire modes
	<ul style="list-style-type: none"> Have you ever heard of doing a survey with a tablet computer? <ul style="list-style-type: none"> What do you know about them? <p><i>Hold up picture of someone doing a questionnaire on a tablet computer</i></p> <p>Questionnaires can also be done using a tablet computer which you can also do either yourself or with an interviewer.</p> <ul style="list-style-type: none"> Have you ever done anything like this? In your home? In a shop? Is this something you would be comfortable doing or not? 	
	<ul style="list-style-type: none"> Have you heard of doing a survey <u>online</u>? <ul style="list-style-type: none"> What do you know about them? <p><i>Hold up picture of someone doing a questionnaire online</i></p> <p>Questionnaires can also be done online which you can do yourself</p> <ul style="list-style-type: none"> Have you ever done anything like this? 	

Activities / aims	Key Questions	Materials needed
	<ul style="list-style-type: none"> ○ On a website? Through a panel • Is this something you would be comfortable doing or not? <hr/> <ul style="list-style-type: none"> • Have you ever heard of doing a survey by telephone? <ul style="list-style-type: none"> ○ What do you know about them? <p><i>Hold up picture of someone doing a questionnaire on the phone</i> Questionnaires can also be done over the phone and led by an interviewer</p> <ul style="list-style-type: none"> • Have you ever done anything like this? Were you called up out of the blue? • Is this something you would be comfortable doing or not? <hr/> <ul style="list-style-type: none"> • Have you ever heard of doing a survey on a mobile phone? <ul style="list-style-type: none"> ○ What do you know about them? Were you called up out of the blue? <p><i>Hold up picture of someone doing a questionnaire on a mobile phone</i> Questionnaires can also be done by you using your mobile phone</p> <ul style="list-style-type: none"> • Have you ever done anything like this? • Is this something you would be comfortable doing or not? <hr/> <p><i>Place all of the pictures out on the table in front of them.</i></p> <ul style="list-style-type: none"> • Out of all of these different ways, which would you feel most comfortable doing and which would you feel least comfortable doing? Get them to rank the pictures in order from most to least comfortable doing • Does it make a difference if you are the one filling it out or an interviewer? <ul style="list-style-type: none"> ○ Why might it make a difference? Do you think there are things you might put down yourself in a survey that you wouldn't tell an interviewer when doing a survey? • If the research was asking you about bullying, would this change what your preferences are for how you do a questionnaire and how comfortable you are? • If the research was asking you about your local area, would this change what your preferences are for how you do a questionnaire and how comfortable you are? 	
Doing physical measurements for research	<p>For the research project, they might want to take recordings of your height using a height measure. <i>Show picture of child being measured</i></p> <ul style="list-style-type: none"> • How would you feel about being measured? Have you had this done before? • Would you feel comfortable with this? 	Pictures of different measuring equipments

Activities / aims	Key Questions	Materials needed
	<ul style="list-style-type: none"> ○ If not, what would make you feel more comfortable? • What do you think it might be used for? Why might it be useful? <p>For the research project, they might want to take recordings of your weight using scales. <i>Show picture of child being weighed on scales</i></p> <ul style="list-style-type: none"> • How would you feel about being weighed? Have you had this done before? • Would you feel comfortable with this? <ul style="list-style-type: none"> ○ If not, what would make you feel more comfortable? • What do you think it might be used for? Why might it be useful? 	
Collecting biomarker data for research	<p>They might also want to look at your DNA; this can be done by collecting saliva (spit) samples. <i>Show picture of child giving saliva sample</i></p> <ul style="list-style-type: none"> • Have you ever done anything like this before? When? • How do you feel about this sort of information about you being collected? • Would you feel comfortable doing it? • What do you think about the way it is collected? PROBE FULLY. Is that what you'd expect? • What do you think it might be used for? Why might it be useful? <p>Examples of how saliva samples will/will not be used:</p> <ul style="list-style-type: none"> • Researchers will be able to use the DNA sample to look at whether you have certain types of genes. This can help researchers understand better differences in children's development, health, behaviour, growth and learning • Researchers might look at specific genes which have been shown to influence children's growth and learning. • It will not be tested for the HIV (AIDS) virus and will not be available for police records (or insurance companies when you are older) 	Example pictures
Views on data linkage	<p>They might want to “link” what you’ve told them as part of the research to other information about you that might exist. <i>Use at least one example from the below. If time, use both examples.</i></p> <p>Example 1: For example, they might link your information to other information the Department for Education holds about you. This might be information about the school as well as your exam results.</p> <p>Example 2: For example, they might link your information to your health records such as any hospital visits</p>	Diagram of two different data sources and linking of fields

Activities / aims	Key Questions	Materials needed
	<p>you made, why you went and how long you stayed for. <i>Show diagram of two different data sources and linking of fields.</i> Before they do this though, you might be asked as a parent to agree to this on behalf of your child or your child might be asked to give consent directly.</p> <ul style="list-style-type: none"> • How do you feel about this sort of data linking happening with your information? • Would you feel comfortable giving this consent on behalf of your child?/ How would you feel if your parents are asked permission first? <ul style="list-style-type: none"> ○ Would this be appropriate? ○ Do you think a child under 16 can make their own decision? • Do you think this will change once a child turns 16? <p>When a child turns 16 they will only be asked themselves</p> <ul style="list-style-type: none"> ○ Is this an appropriate age? If not, when is appropriate? • What do you think they might do this for? • Would you have any concerns about it? What? <ul style="list-style-type: none"> ○ Would you want to know more about this data linking before you say that it's ok to do it? 	
Views on data preservation	<p>After the research has happened, your personal information might be stored somewhere after the research has been conducted. Personal information might include your name and contact details. This information will be stored separately from the information collected from you for research purposes and are only so that the researchers can come back to you at a later date. The information that is collected for research is looked at anonymously so no-one will know that the information is about you.</p> <ul style="list-style-type: none"> • How do you feel about that? • Would you expect them to hold this information forever or destroy it after a certain amount of time? 	Picture of two databases: one with contact details and another with research data
Views on recurring visits	<p>As part of the research project, they would like to come back and visit you in your home at regular intervals throughout your life.</p> <ul style="list-style-type: none"> • How would you feel about that? Would you feel happy agreeing to that? • What sorts of things would make you not want to agree? • What do you think it might be used for? <p>As you get older the researchers may want to come back to visit you when you are no longer considered a 'child' anymore i.e. when you are 16 or older.</p> <ul style="list-style-type: none"> • How do you feel about this? Would you feel comfortable with them interviewing you at 16 without your 	

Activities / aims	Key Questions	Materials needed
	<p>parent's permission being asked first?</p> <ul style="list-style-type: none"> • Would you still ask permission from your parent first or would you feel comfortable making this decision yourself? 	
Views and concerns about data collection	<p><i>Lay out all of the modes of surveys and types of data collection on the table.</i></p> <ul style="list-style-type: none"> • Would you want anyone to be with you when you are doing these types of research? <ul style="list-style-type: none"> ○ Just you ○ A parent ○ A friend ○ A teacher • Are there any here where you would want them there for more than others? <ul style="list-style-type: none"> ○ Which ones would you want them there for? ○ Which ones would you not want them there for? • Does it make a difference if they were there while you were being interviewed by an interviewer and so saying the answers out loud or if you were doing it yourself? • Do you think the information you have given in the research will be seen by anyone other than the researchers or interviewer? <ul style="list-style-type: none"> ○ Do you think people, other than those doing the research, will be able to tell that you have taken part and what you've said? • Would you expect your parents to be able to see what you've said? <ul style="list-style-type: none"> ○ If yes, how would that make you feel? 	
Young person and parent: Summing up and close (3 minutes)		
	<p>Thinking of research overall, what sorts of things make you more or less likely to want to take part?</p> <ul style="list-style-type: none"> • How did you find doing this research for us? Does it make you more or less interested in research? • Does it make you want to take part in more research? Is it something you might think about doing... <ul style="list-style-type: none"> ○ Another time? Another way? <ul style="list-style-type: none"> ▪ <i>If yes:</i> Why would you want to do more of this sort of thing? ▪ Do you think it's worth doing? ▪ <i>If no:</i> Why not? 	

Activities / aims	Key Questions	Materials needed
	<ul style="list-style-type: none"> ▪ Is it from how this session has gone or is it from finding out more about this research? • Do you feel like you understand what research is about more? Do you have any questions? <p>Is there anything else you'd like to tell us about your experiences?</p> <p>Thank you so much for taking part today. Before I go, is there anything either of you wants to add?</p> <ul style="list-style-type: none"> • What do you think are the key messages from the interview? • Has there been anything surprising / worrying / particularly interesting? • What's your final message to people who run studies like this one we've been looking at? How would you recommend they get people like you involved? And keep you involved once you're a participant? <p>Thank and close. Handout incentives.</p>	

Appendix B: Pre-tasks

“Research” Task

- Thank you for taking part in this research
- Before we meet, we’d like you to **look into “research”** and fill in this booklet
- Feel free to stick in images or just use text, whatever you like
- Please remember to bring this to the group
- Any questions just contact Tamsin Maries at tamsin.maries@ipsos.com or 020 7347 3084

Who does research and what sorts of things do they do?



What is research used for?



What research do you use everyday?



Information in your daily life



- Thank you for taking part in this research
- Before we meet, we'd like you to think about **what sort of information** you use in your daily life
- Please remember to bring this to the group
- Any questions just email Tamsin Maries at tamsin.maries@ipsos.com or call on 020 7347 3084

Now over the next week we'd like you to fill in a diary about how you're finding out information. Don't worry if some days are blank. Feel free to stick in images or just use text, whatever you like.



	What information were you looking for?	Where did you go to find it out?
Day One		
Day Two		
Day Three		
Day Four		
Day Five		

Appendix C: Consent forms



PARENT CONSENT FORM

TO GIVE PERMISSION FOR CHILD/YOUNG PERSON TO TAKE PART IN

DISCUSSION GROUPS

Participant Engagement Research
Millennium Cohort Study and Understanding Society

I consent for the named child/young person to participate in Ipsos MORI research on the date agreed, in a discussion group with other children/young people of their age and gender. These discussions will help us to understand what children/ young people think about research, how they might want to get involved with it, and how they would make decisions about getting involved.

I understand that Ipsos MORI's research is anonymous, and that neither I, nor my child will be identified in its findings.

I understand that in order to protect confidentiality, the moderator of the discussion group will need to talk to my child, named below, along with other children of his/her age without parents present.

I understand that an audio recording of the discussion will be made and that these recordings will be anonymous and used only for internal and client analysis purposes. My child will be asked at the beginning of the discussion if they are happy to be recorded and can refuse if they want to.

Name of child (PRINT):

Name of legal guardian (PRINT):

Signed

Date

Telephone contact number.....

YOUNG PERSON CONSENT FORM

TO GIVE THEIR CONSENT TO TAKE PART IN

DISCUSSION GROUPS

Participant Engagement Research
Millennium Cohort Study and Understanding Society

You will be taking part in a group conversation with other people of your age and gender, where we would like to hear your ideas about taking part in research. These discussions will help us to understand what people your age think about research, how they might want to get involved with it, and how they would make decisions about getting involved. The questions are not a test, there are no right or wrong answers, we just want to know what you think.

Everything said in these conversations is anonymous, which means that we will not report your name at any point during this research or tell anyone that you came along.

We will be making a sound recording of the group using a digital recorder so that we can remember what you say. Only the team at Ipsos MORI and our client will have access to this recording – no one else will listen to this or use the recording. We will ask you at the beginning of the discussion if you are happy for us to record the group, and you can let us know if you don't want us to do this.

Even if you agree to take part now, you are allowed to change your mind at any point – if you get there and are not happy, for example.

Please sign below to confirm that you are happy to take part in this discussion:

Name (PRINT):

Signed.....

Date

PARENT CONSENT FORM

TO GIVE PERMISSION FOR CHILD/YOUNG PERSON TO TAKE PART IN AN

IN-DEPTH INTERVIEW

Participant Engagement Research
Millennium Cohort Study and Understanding Society

I consent for the named child/young person to participate in Ipsos MORI research on the date agreed, in an in-depth interview, in which the interviewer will talk to my child on their own, as well as with me. The interviews we are conducting will help us to understand what children/young people think about research, how they might want to get involved with it, and how they would make decisions about getting involved.

I understand that Ipsos MORI's research is anonymous, and that neither I nor my child will be identified in its findings.

I understand that an audio recording of the interview will be made and that these recordings will be anonymous and used only for internal and client analysis purposes. I understand that both me and my child will be asked at the beginning of the interview if we are happy to be recorded and can refuse if we want to.

Name of child (PRINT):

Name of legal guardian (PRINT):

Signed.....

Date

Telephone contact number

YOUNG PERSON CONSENT FORM

TO GIVE THEIR CONSENT TO TAKE PART IN AN **IN-DEPTH INTERVIEW**

Participant Engagement Research
Millennium Cohort Study and Understanding Society

We would like you to take part in an interview, where we will ask you some questions about how you feel about taking part in research. The questions are not a test, there are no right or wrong answers, we just want to know what you think.

In the interview, we would like to talk to together with your parent/carer, and also to ask you some questions on your own. We are carrying out 21 interviews across the country with young people and their parents and these interviews will help us to understand what people your age think about research, how they might want to get involved with it, and how they would make decisions about getting involved.

Everything said in these interviews is anonymous, which means that we will not report your name or anything else that would identify you at any point during this research.

We would like to make a sound recording of the interview using a digital recorder so that we can remember what you say, but please let us know if you do not want us to do this.

Even if you agree to take part now, you can change your mind at any point.

Please sign below to confirm that you are happy to take part in this interview:

Name (PRINT):

Signed.....

Date