



Ethics in Social Research: the views of research participants

Technical Report

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 $\label{eq:APPENDIX} \textit{F. Thematic Framework} - \textit{matrix headings}$



Research Methods

This appendix provides further information about the conduct of the study 'Ethics in Social Research - the views of research participants'. The study findings are published separately by GSRU. The study aimed to explore ethics from the perspective of people who have taken part in social research, and to understand their ethical requirements through exploring their experience of research. The study involved 50 in-depth interviews with people who had recently taken part in an interview-based study, either a survey or qualitative research. This appendix provides further information about the conduct of the research and explains key decisions taken in relation to the design of the study. Study documents can be found in the following appendices.

Scope for other methods

We used in-depth interviews because we wanted to capture a detailed account of each individual participant's experience of the interview. However, other research methods would also have had useful roles to play.

There might have been value in bringing together groups of people who had participated in interviews, since hearing about different experiences and views might have stimulated discussion and insight. However, it would have been difficult to do this within two weeks of the main study interviews, some people would have been unwilling or unable to participate, and the potential sample was sometimes very dispersed geographically.

There might also have been value in research with people who had not taken part in an interview, particularly for example using a video of an interview to stimulate discussion in groups. However, we felt the topic of research and ethics was a fairly abstract one anyway, and would have been more remote and abstract to people who had not participated. We suspected this approach would not have been particularly attractive to all potential participants.

Finally, there would be great value in research with people who have taken part in several research studies – for example people with particular disabilities or medical conditions who are repeatedly approached. Whilst research with this more 'expert' group would be of great value, we felt it was important in this initial exploratory study to focus on a more general population.

Selecting the studies for follow-up

A key decision in the study design was the selection of studies which were followed up. These are referred to here as the 'main studies' and the interviews that took place on them as 'main interviews'. Criteria were developed to guide the selection of studies for follow up:

- It was decided that the Ethics in Social Research study should follow-up studies in a broad range of substantive areas. The literature review indicated that much of the existing research on research participants' views of ethics has involved following up single studies particularly in sensitive research areas. There was therefore value in a design which could look across different substantive areas, including ones which might be seen as less sensitive.
- It was decided to follow up only studies that used face-to-face interview methods. This is the main method used in government research. It would be interesting and helpful to conduct further research following up focus groups, telephone surveys and observational methods, for example. However, it was likely that these methods would raise different ethical issues, and that including them would limit the depth with which face-to-face interview-based methods could be explored. Similarly, studies with additional components to interviews, such as diary keeping or medical tests, were not included.

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- The main studies included only adult participants. The ethical issues surrounding research with children and young people are important, but are likely to differ from those with adults, and so deserve separate and focused enquiry.
- Longitudinal studies were only considered for inclusion where there were at least 8 months since the last interview or would be at least 8 months before the next. Again, longitudinal studies would offer a different set of issues for consideration, and would arguably offer a more 'expert' group of participants. However, we were keen to avoid overburdening participants and having a negative effect on other studies' participation rates. It was anticipated that study funders and main study research teams would have concerns around this issue.
- Studies were not included if a member of the Ethics in Social Research study team was involved with a potential main study, since confidentiality between the two studies could not then be assured.
- Studies were also excluded where ethical approval was required by the NHS Research Ethics Committees (RECs), as it was felt that the follow up would have potential consequences for the REC's decision making on ethical approval about the main study.

All studies eligible for follow-up were discussed with GSRU and the Advisory Group to the study, and decisions made as to which to include.

Once preferred studies had been selected, the main study teams at NatCen were approached for their agreement in principle. The main study sponsors were then approached by GSRU and their permission sought to follow up their study. In all cases where this was sought, permission was granted. The methods and approaches used in each main study are summarised in Appendix B.

The Ethics in Social Research study followed up five studies conducted by NatCen. There would have been benefits in being able to follow up research conducted by a wider range of organisations but the potential difficulties and implications outweighed this. Accessing research participants through another organisation would have presented a more complex transferral of confidential information; it is likely some potential participants would have refused consent to passing their details to another organisation. There would also have been less scope for controlling which participants interviewers invited to take part, and there would have been commercial sensitivities in following up research conducted by another organisation.

Generating the sample from main studies

The sample frame was generated by main study interviewers. In qualitative studies all interviewers were included and in surveys between four and six interviewers were selected to approach their interviewees. The number of survey interviewers included for follow-up in each main study was determined by the size of the sample issued per interviewer and the overall expected response rate on a study. The sample issued ranged from twenty five to fifty addresses per interviewer depending on the study. Survey interviewers were selected to represent a broad range in the geographical location of interviews, the demographic profile of the postcode or area in which they were interviewing, their level of experience , age and gender. It was initially intended to include a diverse range of ethnicity among the survey interviewers. However, this proved impossible as it would have compromised the ability to meet other sampling criteria.

Main study interviewers were briefed by the Ethics in Social Research study team and were asked to discuss the study with participants at the end of the main study interview. Although ethical arguments could be made for participants being told about the Ethics in Social Research study at the consent stage in the main study, it was felt that this could affect participation rates in the main study, and the conduct and experiences of the main study interview itself. Interviewers were asked to:

- Approach all participants about the follow-up, except where the interviewer felt the
 participant would not be able to make an informed decision about participation,
 or where they were particularly agitated by participation in their main interview and
 further requests to take part in research were likely to increase their agitation.
- Briefly explain the Ethics in Social Research study approach, and leave a leaflet with each participant (see Appendix C for a copy of this leaflet).
- Stress that the main study team and the Ethics in Social Research study team were separate; that main study interviewers would not know who the Ethics in Social Research team actually interview and that Ethics in Social Research team members would not have access to the main interview data.
- Seek consent for the Ethics in Social Research study team to contact participants. Main study interviewers were briefed to stress that participants were not consenting to participation and were free to decline participation if they were to be contacted by the Ethics in Social Research study team at a later date.
- Complete a form for each participant (Appendix D). This provided contact details where participants had consented to have their contact details passed on. Where participants had either declined or the main study interviewer had decided not to approach the participants section B of this form was completed. This gave demographic information and the reasons for refusal or non-approach. In this way information was collected about each participant the main study interviewer had interviewed and could be monitored to ensure that potential participants were not being excluded inappropriately.

Main study interviewers then phoned in details for those participants who had consented to be contacted by the Ethics in Social Research study team, within 24 hours of the interview, leaving contact details at a dedicated and secure voicemail address. All participant forms were mailed in to the Ethics in Social Research study team within 3 days of the main interview. This ensured that the sample frame generated by main study interviewers was delivered in sufficient time to allow follow-up interviews to take place within two weeks of the main study interview.

This approach had several advantages. It offered an account for each participant interviewed by the main study interviewers and so deterred interviewers from excluding participants where they felt their interview had been less successful. The approach also ensured that the introduction of the Ethics in Social Research study did not have any effect on the conduct of the main interview, on the part of participants. It also ensured that consent was explicitly sought from each participant about being contacted by the Ethics in Social Research Study team.

There is clearly scope for bias in the potential sample frame against people who had a particularly negative experience of their main interview, since they were approached by the main interviewer and might be more likely to refuse permission for their contact details to be passed on. However, it would have been difficult in practical terms to use another method without building in delay between the first interview and the second. It is perhaps reassuring that a range of positive and negative experiences were described in the Ethics in Social Research interviews, and as Table 2 shows only 4 potential participants refused permission for contact details to be passed on on the grounds that their experience of the main interview had been negative.

Approaching participants

As the contact details were phoned in for participants willing to be contacted, the Ethics in Social Research study team kept a detailed log of potential participants. People were selected from this log to be approached in order to ensure diversity among participants in gender, age, ethnicity and regional location. As selections were made participants were approached by telephone to be invited to participate in an Ethics in Social Research interview. These calls

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were made at least 24 hours after the main interview had taken place, in order to allow participants time to think about their willingness to take part in a follow-up study. Telephone calls to participants stressed that participation in a follow-up interview was voluntary. The purpose and coverage of the Ethics in Social Research research was explained to people. The tape recording of interviews and the £20 thank you payment were also explained. People were then invited to either take part, decline participation, or arrange a time for the Ethics in Social Research researcher to call back if they were unsure of their decision.

Once appointments had been made a confirmation letter was sent to participants, reminding them of the appointment time, date, the name of the interviewer and again stressing the voluntary nature of participation. Contact telephone numbers were included in the letter in case any participant should change their mind about taking part.

Overall consent and refusal rates

The table below details response to the consent process. The first row shows the number of eligible interviews across the 5 main studies – that is, those where the participant was to be approached about the Ethics in Social Research study. The second row shows the number not approached, and the third the number who were approached. The fourth row shows the numbers of participants who consented to having their contact details passed on to the Ethics in Social Research study team. As the table shows, overall 94% of eligible participants were approached, and 84% of those approached consented to contact details being passed on.

Table 1: Approach rates

	People, Families and Communities Survey	Learning for Life and Leisure Survey	Child Maintenance Payments Survey	Child Maintenance Payments qualitative	Transport and Travel in Later Life qualitative	Total
Total eligible interviews	65	57	84	57	41	304
Number not approached	8	5	5	1	0	19
Number approached	57	52	79	56	41	285
Number consenting to pass contact details	45	38	67	52	37	239
% of eligible participants approached	88	91	94	98	100	94
% of approached participants consenting	79	73	84	93	90	84

The reasons for declining to pass on contact details are shown in Table 2.

Table 2: Reasons for refusal among participants who declined to pass contact details to the Ethics in Social Research study team

Reason	People, Families and Communities Survey	Learning for Life and Leisure Survey	Child Maintenance Payments Survey	Child Maintenance Payments qualitative	Transport and Travel in Later Life qualitative	Total
Lack of time/ already done enough	5	4	9	2	2	22
Away during follow-up period	4	1	1	1	1	7
Not interested in follow-up	1	7	1	1	0	10
Negative experience of main study	1	1	1	0	1	4
No reason given/other	1	2	0	0	0	3
Total refusals	12	14	12	4	4	46

The participants who had been approached and consented to pass on their contact details to the Ethics in Social Research study team made up the sample frame for the study. From this frame individual participants were selected to be invited to take part in a follow-up interview.

Table 3 details the outcome of approaches to potential participants. The reasons given for refusal to participate were lack of time or already having done enough to help, or a lack of interest in the subject of the Ethics in Social Research interviews. In some cases no reason was offered. Those who were away during the follow-up period of two weeks from their main interview often expressed willingness to participate.

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Among potential participants who agreed but where an interview did not take place, this was generally because the participant was not at home at the agreed interview time. Where this happened the participant was telephoned and, if there was sufficient time in the two week follow-up period offered another appointment, or the opportunity to leave it there. Where time did not permit letters were sent to participants thanking them for their willingness to take part and explaining that there was not time enough to re-arrange the interview. In other cases participants informed the study team of sudden illness or family emergencies that prevented them keeping an appointment within the follow-up time frame.

The final row of the table shows the number of potential participants who were selected, but where no contact was made despite repeated attempts at different times of day over a period of several days.

Table 3: Outcomes of approaches to participants by the Ethics in Social Research study team

	People, Families and Communities Survey	Learning for Life and Leisure Survey	Child Maintenance Payments Survey	Child Maintenance Payments qualitative	Transport and Travel in Later Life qualitative	Total
Number approached	17	15	15	11	20	78
Agreed and participated	10	10	10	10	10	50
Refused when contacted	3	3	3	0	4	13
Away/ unavailable during follow up period	1	0	0	1	4	6
Agreed but interview did not take place	2	2	0	0	1	5
No contact made	1	0	2	0	1	4

Conduct of the interviews

Interviews took place within two weeks of the main interview. They were in-depth interviews and lasted between an hour and an hour and a half. Most interviews were conducted in people's homes, although alternative locations were arranged where this was preferred by participants.

Ethics in Social Research interviewers used a topic guide which was designed in collaboration with GSRU and the Advisory Group. This was designed to list the key themes to be covered during the interviews, but was used with flexibility and interviews were responsive to the emphases placed by participants on key areas for discussion. The topic guide is replicated in Appendix E. All of the interviews were tape or digitally recorded, with participants' permission, and transcribed verbatim.

Interviewers on the Ethics in Social Research study faced some challenges in the conduct of depth interviews.

Firstly, participants sometimes seemed to see the Ethics in Social Research interview as 'checking up' on their main study interviewer. People were quick to point out and re-iterate that their interviewer had 'done a good job'. This was coupled with a reluctance to offer anything sounding like criticism about main study interviewers. Ethics in Social Research interviewers emphasised again the confidentiality between the main study and the follow up, and underlined the purposes of the research as looking at research conduct and experiences in the wider sense, and not as an evaluation of the performance of individual interviewers.

Second, where people had not found the main study interview a particularly significant event, and particularly if it had been unproblematic, they seemed to feel that they had 'nothing to say' and it could be difficult to encourage them to talk in depth. Some commented on how strange it was to be 'interviewed about an interview'.

The third challenge in conducting Ethics in Social Research interviews was a feeling of a 'hall of mirrors'. Participants were often discussing and commenting on the same processes or approaches as those used by Ethics in Social Research interviewers in the interview. They sometimes draw explicit comparisons between the two interviews. It was impossible to avoid a sense that both participant and interviewer were aware that what was said about the main study interview also applied to the Ethics in Social Research interview being conducted. The conduct of the Ethics in Social Research interview thus became part of the commentary on the main interview, and the commentary on the main interview in turn influenced the conduct of the Ethics in Social Research interview. For example when participants described interviewer behaviour they either welcomed or did not welcome, interviewers became very conscious of their own related behaviour. We felt we ought to moderate our behaviour accordingly to avoid practices people had found unhelpful, but we tried not to do so too obviously. We sometimes felt that participants too were conscious of these dynamics and found them challenging.

Analysis

Verbatim transcripts of the 50 interviews were analysed using 'Framework', a method developed by the Qualitative Research Unit at NatCen (Ritchie, Spencer & O'Connor, 2003). The first stage involves familiarisation with the transcribed data and identification of emerging issues to inform the development of a thematic framework. This is a series of thematic matrices or charts each chart representing one key theme. The structure of the thematic matrices used in this study is replicated in Appendix F. The column headings on each theme chart relate to key sub-topics and the rows to individual respondents. Data from each case is then summarised in the relevant cell. The context of the information is retained and the page of the transcript from which it comes is noted so that it is possible to return to a transcript to explore a point in more detail or extract verbatim quotation.

This approach ensures that the analysis is comprehensive, consistent and that links with the verbatim data are retained. Organising the data in this way enables views and experiences

to be compared and contrasted and for patterns and themes to be identified and explored within a common analytical framework which is both grounded in and driven by respondents' own accounts. The charted data were then studied in detail, carrying out classificatory and interpretative analysis of the charted data in order to identify patterns, explanations and hypotheses.

The use of quotations in the report

The report used verbatim extracts taken from the transcripts of interviews. The intention in using quotations has been to convey to the reader something of the flavour of the primary data and how participants constructed their accounts. Quotations are used to illustrate analysis, to convey the language, emphasis and strength of feeling demonstrated by research participants. In selecting individual quotations, the researchers reviewed a selection of transcripts in which the relevant point was made and selected the one which best illustrated the point, avoiding extracts which, taken out of context, might misrepresent the content or tenor of the interview. The research team monitored the selection of quotations to avoid over-reliance on individual participants. No more than three quotes are used from any individual participant.

The methods and approaches in the main studies

People, Families and Communities Survey (2005).

This was the third wave of this time-series survey, funded by the Home Office. Previous waves have been conducted by other research organisations in 2001 and 2003. The study interviews different participants at each wave, keeping changes in questions to a minimum in order to analyse trends. Fieldwork for the study was conducted between March and September 2005. Approximately 14,000 interviews were conducted in England and Wales. Ethics in Social Research interviews followed up participants who were interviewed in July and August 2005. All Ethics in Social Research interviews took place shortly after the bombings of the London Underground in July 2005. Given that the survey asks questions about participants' perceptions of discrimination toward different ethnic groups by various public bodies it is likely that the proximity of the survey to the London bombings explains the high level of recall and some sensitivity about these particular questions.

The People, Families and Communities Survey used the Postcode Address File (PAF) to sample addresses; a list was generated of selected random post-code code areas, and specific post codes within areas. These post codes were distributed to survey interviewers. Interviewers sent an advance letter to each selected address informing them of the research and their household's selection in the study. It gave contact details for potential respondents to ask for any further information and informed household members that a survey interviewer would shortly be calling at their address to explain the study further and seek their participation. Advance letters were sent out in envelopes marked 'On Her Majesty's Service' in an attempt to distinguish the letter from junk-mail. When survey interviewers made contact with someone in each selected household they asked for a list of the household members over the age of 18. This is known as a household grid. Interviewers work with randomly pre-selected allocations on the household grid, and seek to interview that member of the household. So, if for example, there are 3 adult members in a selected address and the household grid allocation is 2, survey interviewers will request an interview with the member of the household whose name is second in alphabetic order. In addition, a technique called focused remuneration was also employed in order to boost the sample of minority ethnic participants. This involves asking participants selected via the PAF whether any of their immediate neighbours are from minority ethnic groups. Survey interviewers then approached neighbours from minority ethnic groups and sought their participation in the survey in addition to the originally selected household.

Survey interviewers call at addresses on numerous occasions to seek contact with the relevant household member. They then explain the research further, seek the participant's consent to take part and either interview at that time or arrange a later time and date to return and conduct the interview.

Learning for Life and Leisure (2005).

This was the fifth wave of this time-series study, funded by the Department for Education and Skills (DfES). DfES use this survey to monitor the effectiveness of their adult learning policies and to measure trends in adult learning over time. Like the People, Families and Communities survey, changes to questions are kept to a minimum, although new areas of enquiry are added. The study conducted around 6,000 interviews with participants in England, Wales and for the first time in 2005, Scotland. Survey interviews took place between October 2005 and January 2006. The Ethics in Social Research study followed up interviews conducted in December 2005 and January 2006.

This survey also sampled households via a random list generated from the PAF, and employed a household grid in the selection of a household member to interview. Again, advance letters were sent to each address in the sample giving information about the study, the household's selection, contact details for further information and informed households that a survey interviewer would be calling at their address soon. All approaches to potential participants are made by survey interviewers in person at the selected address.

Improving Child Maintenance Payments Survey.

This survey took place after the qualitative research study from the same research programme (described below). This study was commissioned by the Department for Work and Pensions, which oversees the Child Support Agency. The study was an in-depth investigation of the payment methods used by parents, and their experiences of payment and issues such as child contact. The study looked at differences between parents using Maintenance Direct (direct payment between parents) and the CSA's collection service.

The sample for the study was selected from the Department's administrative records of parents who have had contact with the Child Support Agency. The Department wrote to selected parents, informing them of the study, their selection and that a research organisation wished to interview them. Potential participants were given two weeks to opt out – i.e. to inform NatCen that they did not want to participate in the research. After the opt-out period had elapsed interviewers called at household addresses, seeking contact with the individual named on the CSA records. Potential participants were randomly selected from the administrative records, but only one person in each case was approached. That is, if a mother had been selected to participate then the father was automatically removed from the list of potential participants. This was done in order to reduce concerns about confidentiality and privacy. The study sought to interview equal numbers of people paying and receiving child maintenance.

Interviews on the study took place between April and July 2006. Around 1,500 parents were interviewed in England. Follow-up interviews for the Ethics in Social Research study were conducted in April and May, 2006.

Improving Child Maintenance Payments; qualitative study.

This study took place as part of the same programme of research as the survey. The qualitative work was conducted before the survey and informed the survey design. The main aims of the work included exploring what shaped decisions to use different payment options, and what hindered and facilitated parents' use of Maintenance Direct. The study also looked at parents' experiences of different payment methods.

Letters were sent to selected couples from the CSA's administrative data base, informing potential participants about the research and giving them a two-week opt-out period if they did not want to be contacted by the main study research team. After this period people were screened via telephone calls to establish whether potential participants would be willing in principle to participate, and willing if their ex-partner was also interviewed by the research team. From this screening exercise a sample frame was generated from which the main study participants were selected.

Because the study sought to interview ex-partners from the same CSA case procedures were put in place to minimise any potential anxieties on the part of participants. At the telephone screening stage, the research team explained that they would like to interview ex-partners, but that no information would be given to either partner about the other's interview, including whether they had taken part or not. In addition the study team explained that ex-partners would be interviewed by different researchers, in order to maintain absolute confidentiality between the two interviews. Once these procedures were explained potential participants were asked whether they would still be willing to be interviewed on this basis.

Once a sample frame had been constructed potential participants were selected to represent diversity in terms of their gender, type of payment method, timing of their CSA assessment, payment level and geographical locations. Participants were telephoned again and interviews were arranged. 60 in-depth interviews were conducted in May and June 2005, including 19 matched 'pairs' and 22 unmatched interviews.

The Ethics in Social Research follow up interviews took place in May and June 2005. It would have been difficult to ensure, as the main study had, that different interviewers were used for ex-partners within a former couple, and it was felt that including both partners in the follow up study might cause unnecessary discomfort to participants. It was therefore decided to follow up only one partner in each ex-couple.

Transport and Travel in Later Life; qualitative study.

This study was commissioned by the Department for Transport and was a follow-up study to the National Travel Survey (conducted by NatCen for DfT). The study sought to map participants experiences of transport in later life, understand changing needs through and after retirement and to explore future travel aspirations.

Participants were drawn from the National Travel Survey sample. At the end of the survey participants had been asked whether they would be willing to be contacted about future research. The qualitative study composed a sample frame made up of participants in the right age groups (those over 50), in clustered locations, whose survey interview had happened at least six months previously, and who had given consent to be contacted again in the future at the time of their survey participation. An advance letter was sent to these participants about the qualitative follow-up and a two-week opt out period ensued for participants who did not want to be contacted about the follow-up work.

After the opt-out period telephone calls were made to participants to seek their willingness to participate in principle and to collect additional screening information as required. Participants were selected to represent range across four age groups (50-59 years old, 60-69 years old and 70-70 years old and 80 years old and over) and diversity in their gender, economic activity, household income and whether anyone in their household drove a car. Initially 55 in-depth interviews were conducted (it was these interviews that the Ethics in Social Research study followed up). Later an additional 10 interviews were added to the main study to include participants in particularly rural areas. The initial 55 interviews took place in February and March 2006, and the additional 10 interviews were conducted in May. Ethics in Social Research follow-up interviews took place in March 2006.

Participant information leaflet

PARTICIPANT INFORMATION LEAFLET

Experiences of taking part in research



Tell us what it's like to take part in research......

We want to talk to people who have taken part in our research studies about what it is like to be interviewed. The study is funded by several government departments. The government commissions organisations like us to carry out lots of research. We need to know whether the way in which we go about research is sensitive, professional and ethical, and whether people are happy with what it involves for them. It will help us, and other research organisations, to improve the way research is carried out.

The National Centre for Social Research is conducting the research on behalf of the Cabinet Office, which is part of the UK government. This leaflet gives you more information about the study.

Our responsibilities to you:

We guard your privacy: your participation will be treated in strict confidence in accordance with the Data Protection Act. Your contribution will be used for research purposes only. Individuals will not be identified in the final report.

We respect your wishes: participation in the study is voluntary. If you do not want to take part, just let the research team know when they contact you.

We answer you questions: we will be happy to answer any questions you may about the research.

Contact the research team:

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Why do you want to interview me again?

The government commissions NatCen and other organisations to carry out lots of research. But we know very little about what it's like to take part in a research study. We need to know whether the way we go about research is sensitive, professional and ethical. The best way to find out is to ask people who have recently helped us by being interviewed for one of our research studies. We would like to talk to you about that experience and find out what it was like from your point of view. We hope the research will help us and other research organisations to improve the way we carry out our research.

What sorts of things would we talk about?

The kinds of issues we would like to talk to you about are:

- What was it like being interviewed?
- Was anything particularly important to you about the way the research was carried out?
- Why did you decide to take part? Did you know enough beforehand about what it would involve?

 What did you think about the kinds of things you were asked
- about? Were you comfortable talking about them?
- Was the interview what you expected or was anything different?
- Did you have any views about what would happen to the information you gave?
- How can we do research that is sensitive and respectful?

Who will interview me on the second occasion and what will the interview be like?

The second interviewer will be a different person. The person who already interviewed you will never see any information from the second interview and won't know who we interview. We will not see any information from your first interview either. The interviewer for

the second study will want to hear about your experiences of taking part in research. They will have a list of topics they want to ask you about, but will want to hear from you in your own words. The interview will take an hour to an hour and a half. The interview will come to your home, or somewhere else if you prefer, at a time that suits you. Everyone who takes part in a second interview will receive £20 as a thank you for their time

What will happen to the information I give?

The information that you give will be drawn together with what other people in the study tell us, in a report. This will be published by the Cabinet Office, and used so that people who do research can improve the way they work. You will not be identified in the report. We will send a copy of the findings to everyone who takes part in the study, if they would like to see them.

How will we arrange the second interview?

One of the research team may call you by telephone over the next few days to ask whether you are willing to be interviewed again. Taking part is completely voluntary, and if you have any questions please do ask them

If you are willing to take part, they will arrange a time for the interview that is convenient for you.

Will I definitely receive a phone call?

No. We can only conduct a limited number of interviews. We aim to talk to a broad range of people, and it may be that we have enough people and so don't contact you. If you haven't heard from us in 3 weeks, that means we won't be able to include you in the second study. If we don't call you, we'd like you to know we're grateful to you for your interest so far.

Participant form

National Centre for Social Research

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National Centre for Social Research

PARTICIPANT FORM

Responde	nt serial number:				
	main study:				
ir	terviewer name:				
date	/_/_				
 Section 	WER: please complete: n 1; if the respondent did not wish to be contacted about the study n 2; if you did not ask the respondent about being contacted n 3; for all				
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responder	t (tick one):				
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Topic guide

P6124 **Ethics in Social Research**

Introduction to the topic guide

As this is an exploratory study, we wish to encourage participants to discuss their views, experiences and practices in an open way without excluding issues which may be of importance. This topic guide aims to find a balance between exploring participants' spontaneous views, understanding, framing and requirements of ethical issues, and their views and experiences of ethical issues as researchers define them.

The interview will begin with a discussion of previous research experience and will invite any initial thoughts participants may have on defining ethics.

A key section of the guide asks participants for a reconstruction of their recent research experience. It then asks participants to highlight the most important aspects of their experience; aspects where it was important that the research team treated them ethically, or 'got things right'. Issues raised spontaneously here will be fully explored at this stage. After this spontaneous exploration the interview moves on to look at the research process from the viewpoint of issues researchers consider to be central to ethics. The introduction to this section will emphasise that these issues are researchers' concerns, and that it is important to understand where these are and are not shared by participants.

After these sections the interview will return to the question of defining ethics and its meaning in a research context. We have deliberately avoided offering any kind of definition until this stage (and what is offered is as broad as possible).

The guide does not contain pre-set questions but rather lists the key themes and subthemes to be explored with each participant. It does not include follow-up questions like 'why', 'when', 'how', etc. as participants' contributions will be fully explored throughout in order to understand how and why views and experiences have arisen. The amount of time spent on different themes will vary in practice to reflect the participants' own priorities and emphases on the different issues.

(NB- text in italics throughout the guide indicates instructions or aids to *interviewers*)

Aims of interviews:

- Understand research participants' requirements of ethical practice through exploring their experience of participating in research
- Exploring the theoretical principles of research ethics from the perspective of research participants particularly:
- informed consent;
- avoiding undue intrusion;
- protecting the interests of participants;
- power dynamic in interviews;
- enabling participation; and
- Confidentiality and disclosure.

1. Introduction

- Introduce yourself, NatCen.
- Introduce the study: i.e. about participants' experiences of research, how researchers can improve they way they do things – particularly interested in what researchers call research ethics.
- Funded by a range of Government departments: Cabinet Office, Inland Revenue, Dept. for Transport, Office of the Deputy Prime Minister (regions, local govt) and Scottish Executive as well as by Joseph Rowntree Foundation – who give grants for social research. All of these organisations/Departments fund research and so want to understand more about the experiences of people who take part in research to try and improve the way researchers do things.
- Reassure re confidentiality & anonymity
- between their 'main' study and this interview (that we do not see the information they gave in their first interview, and that their interviewer will not hear anything from this interview and won't know who we've talked to either).
- to the study team for this research when the research is written up no individual can be identified – and the report pulls together the findings from all participants to this study.
- Explain that this is an exploratory study, that there are no wrong or right answers, we're just interested in their opinion and experiences. We're interviewing different people who haven taken part in a range of original studies. Explain that if they don't want to answer a question at any point that they don't need to, and they should let you know if they'd like to take a break during the interview, or stop at any point – their taking part is entirely voluntary.
- (If appropriate) Explain why carrying out interview in pairs.
- Remind on length of interview -1.5 hours.
- Introduce tape recorder and explain transcription, data storage and destruction (post publication of findings).
- Check if participant has any questions at all.
- Check if still happy to participate in research.
- Thank person for their agreement to participate.

2. Background

- Household/ family make-up
- Daily activities (e.g. employment, caring responsibilities etc.)

3. <u>Definitions and experiences - general</u>

- Prior experiences of research (e.g. reading about it, taking part in it, what is research and what isn't research)
- Interest in research
- Meaning, if has any, of **ethics** (reassure participant that we'll come back to this later, but helpful to hear any initial thoughts they may have on it)
 - generally (if helpful, explore scenario of doctor acting unethically)
 - in research context

(If has no meaning to participant: 'ethics in research is something researchers think about when they plan and do research. It's to do with doing research well, e.g. treating people who participate in research well)

4. The 'main' interview (KEY SECTION – UNPROMPTED/SPONTANEOUS VIEWS)

Explain that we'd like to start the main part of the interview by hearing from them about what it was like to take part in research and the parts of research that mattered more to them, or were more important for the research team to get right.

- Outline the experience of research from start to end what happened in detail (encourage a detailed overview of their experience, unprompted, from where the participant sees the research experience as starting and ending)
- What research experience was like, overall
 - Comparison of overall experiences and expectations
 - Anything that seemed particularly memorable or significant
- Two (or more) aspects of research experience that felt were done particularly well
 - way in which done well
 - importance of doing it well
 - impact/effect of doing it well
- Two (or more) aspects of research experience that felt were not done well or left participant feeling uncomfortable
 - ways in which not done well
 - importance of not having done it well
 - impact/effect of not doing it well
 - how should be done

- Important aspects of the research experience to 'get right'/ take care over
 - reasons for importance
 - how each aspect was conducted in main study experience
 - impact/effect of how aspect conducted
 - preferred way important aspects should be handled
- (Only where any definition of ethics was given in section 3) Relation of any of these to earlier consideration/definition of ethics or of how people taking part in research should be treated 'ethically'

5. Participants' experiences of researchers' ethical concerns (KEY SECTION) (NB – Do not repeat anything in this section already covered in section 4.)

"We're going to move on now to talk through the last interview experience you had step by step. I'm going to be asking you specifically about aspects that researchers are commonly concerned with when they think about what is 'good practice' or 'ethical practice' in doing research. It's really important to know where you do not share these concerns, as we want to learn about what people who take part in research consider to be important, rather than what researchers think. So if I ask you about an aspect that wasn't a concern of yours, or didn't matter to you, please do tell me that; it's really important for us to understand..." (Re-iterate throughout section)

Note: throughout, where any problems or poor experiences are identified, explore whether participant wanted to or did take any action, and suggestions for improvement or lessons for researchers

5A - 1st thoughts and reactions to the 'main' research

- Important information when first heard about research (what do they need to know?)
- Understanding of research when first heard about it
 - purpose
 - funder/ who research was for
 - who was conducting research
 - why they were approached to take part
 - how they were selected/identified
 - understanding of what participation involved

5B - Deciding to take part in the research

- How made decision (BROAD first and then prompt)
 - e.g. considered participation when letter arrived, talked to friends/family, researcher etc.
- The decision-making process
 - extent to which felt like a decision
 - period over or point at which decided to take part (e.g. when got first advanced letter, when interviewer called) Explore whether decision was an event or a process
 - did they have enough information at this stage

- Point at which told interviewer / research organisation that would take part
 - whether felt they were committed by doing so, whether felt could change mind
 - any written consent: any impact this would have had on their feelings or experience
- Influences or motivations on/for decision (or barriers or enablers to participation)

Explore for example following, and PROMPT on views about incentives if not mentioned

- perceived benefits of taking part
 - altruism, personal benefits, reciprocity/gift etc
 - Incentives: any role, reaction to it, appropriateness
- perceived disadvantages/ deterrents and risks in taking part
- any concerns about participation
- influence of the research topic
- influence of the research funder
- influence of the recruitment process (letter, person who telephoned/called round)
- influence of what was required/what participation involved

Try to draw out the difference, if any, between influences on decision and enablers/ barriers to participation - e.g. - If X hadn't been the case, would you still have taken part?

- With hindsight, likelihood of making same decision to participate again
- How would have felt if after receiving approach letter had not been contacted to take part in interview
- Suggestions for improving researcher conduct in gaining people's consent to take part

5C – Arranging the interview

- Importance of interview arrangements made
- Timing of interview
 - how agreed
 - freedom of choice
- Location of interview
 - how agreed
 - freedom of choice
- How well arrangements worked out for participant
- Any suggestions for improvement

5D – Anticipating the interview

- Thought given to forthcoming interview in advance of interview
 - any impact of anticipating interview on thinking about interview subject
- Feelings about forthcoming interview
 - (if any concerns) ability/ ease of seeking more information, addressing concerns

(Only ask if participant did think about the interview in advance)

- Desire and ability to withdraw from forthcoming interview
- Any suggestions for improvement

5E - Starting the interview

- Arrival of interviewer
 - feelings at time, anything important to 'get right'
- Events before interview started/introduction to interview
 - recall of what was said
 - new information & feelings about, e.g purpose of study
 - confidentiality and anonymity
 - understanding and views
 - introduction to tape recorder (qual) / laptop (survey interview)
 - reactions/views
 - freedom to say no to any aspect/withdraw consent to take part
- Any questions had for interviewer
 - ease/freedom to ask any questions
- Any reconsideration of participation at this point
 - barriers/enablers to discussing any re-considerations
- Suggestions for improvement for how interviewers start the interview

5F - Answering questions

- Overall view of how interview went
- Kinds of information asked for in interview
 - extent to which met expectations
 - views/feelings about
- Level of detail asked for in interview
 - extent to which met expectations
 - views/feelings about

- Way in which information asked for in interview
 - what type of questions, how researcher got them talking
 - extent to which met expectations
 - views/feelings about
- Length of interview
 - extent to which met expectations
 - views/feelings about
- Fullness of information given during interview
 - withholding information
 - refusing to give information/ answer questions
- (for each) experiences of
- reasons for
- Feelings in self or emotional range experienced during interview (e.g. distressed, upset, angry, relieved, unburdened, bored etc)
 - cause of any feelings
 - response wanted from interviewer
 - how interviewer responded to feelings
 - impact on experience/views of interview
 - if felt fine throughout interview, what see as appropriate response from interviewer if had been distressed
 - balance between distressing people and obtaining research data
- Interviewer responses and reactions during interview describe
 - cues how the interviewer reacted (e.g. non-verbal, verbal)
 - feelings about interviewer responses
 - impact/ effect of responses on interview (if any)
- Pace and structure of interview
 - pace: how felt, whose pace
 - structure: coherence, clarity of direction or coverage
 - any impacts
- Suggestions for improving the experience of answering questions

5G Relationship with the interviewer

- Extent to which (if at all) there was any 'relationship' with interviewer describe
 - significance or meaning of relationship, (if any)
- Control/power
 - what influenced what was talked about, how much time spent on each topic, changes in topics
 - whether able to say as much or as little as they wanted to
 - how the interview moved on to new topics

- Interviewer demographics/characteristics (e.g. gender, age, ethnicity, accent/ regional origin, class, etc) / shared experiences
 - extent to which demographics matter
 - impact/ effect on answering questions
- Interviewer's manner
 - importance of
 - impact/effect on answering questions
- Stability/ accuracy of information given (e.g. if interview had happened on a different day, or had been done by a different interviewer how different responses would be)
- Suggestions for improvements to interviewer conduct/ the research interview 'relationship'

5H – Ending the interview

- How ending came about
 - whether signalled, rushed etc
 - feelings about interview ending and feelings when it ended
- Any interaction with interviewer after interview
- Suggestions for improvements to process of ending interviews

5I - After the interview/ looking back (KEY)

- Feelings after the interview
 - when feelings emerged
 - changes over time
 - negative & positive feelings
 - any support or information needs
- Any feelings around information/responses DID give during interview
- Any feelings around information/responses NOT given during interview
- Whether discussed interview with anyone
 - content of discussions
 - impact on feelings about interview
- Any impact of interview on
 - feelings, self-awareness
 - views
 - behaviour

- Significance/meaning of interaction in interview
 - similarity to any other situation/ experience
 - significance/importance of interview (if any)
- Withdrawal from research after interview (ask only if express concerns/negative *feelings*)
 - awareness of any rights
 - any feelings of wanting to withdraw
- particular answers/information
- whole interview
- Any views on whether participants should be involved in the research process. (prompt if necessary: for example, designing the research, the questions, giving views on findings)

5J - Information given

- Adequacy of the amount of information given
- Accuracy of information given at outset how close this was to actual experience
- What more/kind of information would like at the outset
- What information did not want/need to know at outset
- Understanding & views of confidentiality and anonymity (also covered in 5E - starting the interview)
 - meaning of confidentiality
 - understanding of arrangements
- Suggestions for improvement in information giving (e.g. level, timing, how conveyed)

5K – Next steps in research process

- Awareness of what happens to information given
 - understanding of how/what may be reported, what report might look like, how their interview might appear in it
 - QUAL ONLY: awareness and views of the use of quotes in reports
 - expectations and whether would have liked more information about next steps
 - general views on next steps
- Hearing the findings from the study took part in
 - interest
 - expectations
 - views

- Understanding of confidentiality
 - meaning
 - confidentiality in storage of or access to interview data
 - confidentiality in use of
 - concerns/ lack of concern

Reassure re NatCen approach to confidentiality and anonymity if appropriate

Suggestions for improving anything related to 'after the interview'

6. Comparing research experiences

- Comparisons between interview and any other research experiences
 - key differences in any aspect of experience (e.g. information about the research, deciding to take part, anticipating the interview, answering questions)
 - significance of any key differences in experiences of taking part
 - key positive differences
 - key negative differences

7. Ethics of research

So, to move back to the question of ethics that we started with:

Any further thoughts on defining ethics in relation to research

(If no definition offered, offer: moral, proper, principled, or seemly behaviour when *conducting research)*

- When doing research the most important things to get right or to do Ask them to relate this to ethics and to their own experiences if appropriate, and any sense of order or priorities if relevant
- What makes research a good experience or a bad experience for the respondent

Ask them to relate this to ethics and to their own experiences if appropriate, and any sense of order or priorities if relevant

Advice to a new researcher about how to do research well, what to pay attention

Ask them to relate this to ethics and to their own experiences if appropriate, and any sense of order or priorities if relevant

8. Final thoughts

- Any final thoughts/comments
- Thank participant for their time and contribution.

- Check if they have any questions about the research.
- **Give £20**.
- Explain intention to send research findings to people who took part (in late 2006) and ask if would like to see findings - will post findings to all who do. If likely to be mobile in housing before late 2006 check if they'd like to give a 'stable' address we can send findings to – e.g. some younger people suggest their parents' address.
- Please record these details in the sample log when back in the office

Thematic framework: matrix headings

1	Background and summary
1.1	Respondent background
1.2	Definitions, experiences and views on research
1.3	Definitions of ethics (if any offered)
1.4	Importance of ethics in research
1.5	Summary of ethical issues in early interview (sections 1-4 inc of topic guide)
1.6	Summary of ethical issues in mid interview (section 5 of topic guide)
1.7	Summary of ethical issues in late interview (sections 6 & 7 of topic guide)
1.8	Interpretative comments on the interview overall
1.9	Other
2	Decisions re participation
2.1	Initial info needs and adequacy
2.2	When, how, who with
2.3	Factors taken into account re the research topic, funder, purpose
2.4	Factors taken into account re the research process/approach
2.5	Other factors taken into account
2.6	Views and experiences of the research approach
2.7	Suggestions for improvements to consent process
2.8	Other
3	Anticipating the interview and the interview (1)
3.1	Feelings anticipating interview
3.2	Behaviours anticipating interview
3.3	Voluntariness and withdrawal
3.4	Suggestions for improvement for after arranging the interview
3.5	Starting the interview
3.6	Location/ setting of interview
3.7	Length of interview
3.8	Other

4	The interview (2)
4.1	Topics & level of detail discussed in interview
4.2	Experience of question and answer style
4.3	Order of topics
4.4	Strategies for withholding info/detail
4.5	Emotional range during interview
4.6	Ending the interview
4.7	Suggestions for improvement to interview
4.8	Other
5	'Relationship' with the interviewer
5.1	Existence of rapport/ relationship
5.2	Characteristics (responses) experienced and desired
5.3	Behaviours (responses) experienced and desired
5.4	Control/ pace of interview
5.5	Socio-demographic characteristics
5.6	Personal information exchange
5.7	Suggestions for improvement
5.8	Other
6	The impact of the interview experience
6.1	Thoughts, feelings, reflections, behaviours and attitudes after the interview
6.2	Looking back on answers/information given in interview
6.3	Assessment of cost vs benefit on reflection.
6.4	'construction' of the interview
6.5	Information needs and adequacy in hindsight
6.6	Suggestions for minimising negative impacts/ maximising positive impacts
6.7	Other

7	Confidentiality, anonymity and next steps in research
7.1	Views and understanding of confidentiality.
7.2	Tape recorder or Laptop (and confidentiality & anonymity)
7.3	Report (anonymity)
7.4	Suggestions for improvement to confidentiality and anonymity
7.5	Understanding of next steps in research
7.6	Views on next steps in research
7.7	Views & expectations on feedback/hearing the findings
7.8	Likelihood of being willing to take part in research again in the future
7.9	Suggested format for feedback/findings
7.10	Other