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Understanding
Participation:
Being part of the 1958
National Child
Development Study
from birth to age 50

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October 2010

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Abstract

At a time when there is increased acceptance and understanding of the value of longitudinal research, it has become increasingly difficult to recruit and, more importantly, retain participants in a longitudinal study. However, little has been researched into the reasons why respondents have remained, or not, in a study and what strategies help improve retention. This article presents findings from a study based on qualitative interviews with 170 men and women who have participated in the longitudinal 1958 National Child Development Study for half a century. Reflections on the experiences of study members are particularly pertinent in light of recent substantial investments in longitudinal research¹. Many of the complex relationships between circumstances and experiences over the lifecourse can only be understood by longitudinal data. Recruiting and retaining participants in these studies is vital if the questions posed by society are to be answered.

Key words

Participation, longitudinal, retention

¹Examples of notable recent funding pledged to longitudinal research. A) 'Understanding Society', a study of the socio-economic circumstances and attitudes of 100,000 individuals in 40,000 British households. It is funded by the Economic and Social Research Council (ESRC) and run by the Institute for Social and Economic Research (ISER). For further details see <http://www.understandingsociety.org.uk>. B) Although not yet confirmed, there are plans for a Birth cohort study 2012.

Introduction

At a time when there is increased acceptance and understanding of the value of longitudinal research, it has become increasingly difficult to recruit and, more importantly, retain participants in a longitudinal study (Tinker et al, 2009; Adamson et al, 2007; Philips et al, 2002). The 1958 National Child Development Study (NCDS) is one of Britain's four longitudinal birth cohort studies² which follow the same group of people from birth into and through adulthood, thus giving a picture of whole generations. They are one of the richest resources for the study of human development, covering all aspects of life. All longitudinal studies 'lose' participants over the years due to migration out of the country, due to death, out of date contact details, unavailability at time of interview and unwillingness to remain involved, etc (Elliott & Shepherd, 2006), and an increasing vast body of literature is available that demonstrates the impact that attrition can have on the representativeness of longitudinal data (Hawkes & Plewis, 2006; Goldstein, 2009; Rubin, 1987). However, little has been researched into the reasons why respondents have remained, or not, in a study and what strategies help improve retention (Philips et al, 2002; Robert et al, 2002; Adamson & Chojenta, 2007). It is therefore pertinent to learn what we can from those who have participated in a study for half a century. Although initially it was their mother who agreed to participate in the study on their behalf³, once cohort members became independent, young adults it became solely their decision to remain part of the study.

The NCDS initially collected information on more than 17,000 babies born in one week in 1958 to examine the social and obstetric factors associated with stillbirth and death in early infancy. Additional funding meant the same families were re-contacted seven years later in 1965, and then subsequently in 1969, 1974, 1981, 1991, 2000, 2004 and most recently in 2008. Apart from cohort members' themselves, information has been collected from their parent(s), teachers, and health professionals. During childhood the cohort members took part in a variety of assessments and examinations. These are summarised in Figure A. The latest round of data collection was carried out between 11th August 2008 and 18th May 2009, when they were age 50 in the vast majority of cases. 9,790⁴ were interviewed and more than 12,000 are still in contact with the study team.

² The four surveys are: 1946 National Survey of Health and Development (NSHD); 1958 National Child Development Study (NCDS); 1970 British Cohort Study (BCS70); Millennium Cohort Study (MCS), which began in 2000.

³ Midwives attending the birth gained consent and recorded medical details about the child and additional information from the mother.

⁴ 364 (4%) were interviewed after their 51st birthday.

Figure A: Childhood assessments and examinations

Age 7	Age 11	Age 16
Height/weight measured	Height/weight measured	Height/weight measured
Vision/hearing/speech assessment	Vision/hearing/speech assessment	Vision/hearing/speech assessment
Medical examination	Medical examination	Medical examination
Un/descended testes	Pubertal assessment	Pubertal assessment
<u>Laterality tests</u>	<u>Laterality tests</u>	<u>Laterality tests</u>
Throw/kick crumpled paper ball	Throw, catch/bounce a tennis ball	Catch/bounce a tennis ball
Draw a cross	Kick a ball	
Hop on one leg	Look through paper tube	
Look through paper tube / hole in a card		
	<u>Motor co-ordination tests</u>	<u>Motor co-ordination tests</u>
	Walk backwards along a line	Hopping between lines
	Stand on right/left foot	Stand heel to toe
	Stand heel to toes	
	Time taken to pick up 20 matches	
<u>Educational assessment</u>	<u>Educational assessment</u>	<u>Educational assessment</u>
Reading, arithmetic tests	Reading, arithmetic, general ability tests	Reading, arithmetic tests

In recent years social participation has become a topic of great interest to commentators, politicians and researchers (Putnam, 1995, 2000; Li et al, 2008). Concerns about a possible decline in social unity and changes in British society have raised questions about the role and importance of people's involvement (Halpern, 2005; Pattie, 2004). Information collected from cohort study members has been used to look at levels of social attitudes and social participation across different education and socio-demographic groups (Bynner & Ashford, 1994; Wiggins et al, 1997; Schoon et al, 2010; Deary, 2008). Cross cohort comparisons have also highlighted changing formal participation levels among men and women born at different times in the 20th Century (Paterson, 2008; Bynner & Parsons, 2003; Parsons & Bynner, 2002). The age 50 survey included questions on social participation activities, frequency of activities, political interest and voting in an election to facilitate the continuity of research in this area of interest⁵. To complement this information and enrich understanding of the social activities people engage in and why some people are more socially active and involved than others in-depth conversations with a sub-sample of cohort members have been carried out (Elliott et al, 2010)⁶. At the end of the interview, specific questions (see Figure B) on membership of the NCDS were asked⁷. Questions within this section were directed at finding out what cohort members felt about being part of the NCDS. In examining both positive and negative

⁵ For full details of questions see <http://www.cls.ioe.ac.uk/studies.asp?section=00010002000300180002>.

⁶ This research was funded by ESRC, RES-503-25-0001 - Social Participation and Identity: combining quantitative longitudinal data with a qualitative interview.

⁷ The interview lasted an average of 90 minutes. The topics covered included 'Neighbourhood and belonging', 'Participation', 'Friendships', 'Life stories & trajectories', 'Identities' and 'Membership of the NCDS'. See Elliott et al (2010) for full interview schedule including example diagrams that cohort members were asked to complete.

responses we hope to learn more about what those involved in running a longitudinal study could do to improve the experience of being a survey member and maximise participation in future rounds of data collection in NCDS, and perhaps more importantly, in younger birth cohorts. These insights are particularly pertinent in light of the recent substantial investments that have been pledged to 'Understanding Society', a study of the socio-economic circumstances and attitudes of 100,000 individuals in 40,000 British households, and potentially, a new birth cohort in 2012.

Figure B: Membership of NCDS

Finally, we'd like to find out more about what it has been like for you to be a member of the NCDS - whether it's been a good and interesting experience, how it might have been improved, whether we've been asking the right types of questions, and so on.

- Do you have any memories of being in the study as a child?
 - What? Whether unsettling or enjoyable, etc
- As an adult there has been the opportunity to be interviewed 6 times between age 23 and 50. Can you recall any occasions on which you didn't take part and what the reasons for this were?
- Have you ever thought of dropping out?
 - Why/Why not? When?
 - What have been the most frustrating aspects of being a cohort member?
 - What would improve the experience of being a panel member?
- Has being part of the NCDS had any impact on your life?
 - Whether it makes them feel somehow different from other people
 - Do you ever talk about being a panel member with anyone? Who? In what context?
 - Does the experience of being a panel member ever encourage you to reflect on your own life and experiences?

Methods and sample

All cohort members selected into the qualitative ESRC funded 'Social Participation' study⁸ had taken part in the main quantitative study, with the qualitative interviews taking place within six months of an individual's main age 50 interview. The qualitative interviews were carried out between November 2008 and August 2009. The sample was selected on two main criteria: geographic location and social mobility. 180 cohort members were to be interviewed living in selected locations within three geographic regions across Great Britain, namely the North West and South East of England and also within Scotland⁹. 60 interviews would take place in each region.

⁸ The research reported here was funded by the ESRC Research Resources Board. The main aim of the overall project was to better understand social participation and how this relates to social mobility and to create a resource at the UK Data Archive for use by other research teams.

⁹ 890 cohort members interviewed at age 50 lived in the selected locations within the three geographic areas. Additional funding from The Welsh Assembly has completed the British profile for the study. 60 interviews will be carried out in selected areas of Wales during the first half of 2010.

In total, 238 cohort members were contacted and 170 interviews were completed (86 men and 84 women), resulting in an overall response rate of 71%. 17% refused (including those who initially agreed but then cancelled or were not in at time of interview) and 12% were not contactable – either they had very recently moved, the phone numbers were not valid or the interviewer only left messages and never actually spoke to the cohort member.

Those interviewed had a more complete record of participation when compared to the 9,790 who were interviewed at age 50. Two-thirds (67.1%) of the participants in the qualitative study had been interviewed in every round of NCDS collection from birth to age 50 (nine in total), 26.5% had missed one interview, 6.5% two or three interviews. The comparable figures for the full sample are 53.4%, 26.6% and 20% respectively. In other words, the qualitative sample over represents those with a complete participation record.

The vast majority of interviews were undertaken in the individual's home. The interviews were guided using a semi-structured schedule but the aim was to encourage a conversation. Interviews were undertaken by seven interviewers, two of whom were part of the funded project team. Notes on the atmosphere of the interview and the physical environment were written up immediately following interviews. The recorded interviews were transcribed verbatim and checked by interviewers before being imported into NVivo 8¹⁰ to facilitate analysis. Initial coding was undertaken by research support staff at the question level before being developed thematically by members of the research team.

Findings

Four main themes emerged from the responses cohort members gave to the questions about their participation in the study. Firstly, memories they had of their involvement as a child, particularly the physical tests and educational assessments. Secondly, reasons for their continued participation which encompass feeling 'special' to just doing it because they are asked to. Thirdly, accounts of why they had not participated at an earlier time together with thoughts on what may lead to future non-participation. Finally, what they would like changed to improve their own experience and involvement. These reflections in particular will help guide research teams involved with longitudinal study to maximise future participation rates.

Each of these themes is explored in more detail below, with quotations taken from the interviews to illustrate cohort members' views. As the sample size is relatively large for a qualitative study, a few descriptive statistics have also been included.

¹⁰ For further details on NVivo8 see <http://www.qsrinternational.com/products.aspx>

Childhood memories

During childhood cohort members completed a variety of educational and medical assessments, which are summarised in Figure A. The medical assessments generally took place in a medical centre with the child's parent or guardian present. The educational assessments were carried out in school, as part of the school day. Well over 90% of participants held early memories of the interviews and assessments they completed, with a mixed bag of experiences and emotions being remembered. Very few could not remember their early involvement – *Not a great-, no, I haven't got a great deal of memory of being in the study as a child [P046]. ... only the vaguest of memories [P072].* Many mentioned being told they were or felt 'special' or 'important', a theme that is returned to later on, whereas for others it was fun – *I just thought it was a bit of a gas, you know [P078].* However, some children did not like the feeling of being 'singled out' or identified as 'different' from other children. Feeling singled out was sometimes tempered if there were other children in the school involved in the study, or for one individual interviewed who had a twin.

Oh yeah, yeah, fantastic. I felt really important, I remember as a kid I was asked to come out of the class and everybody was jealous, all the kids were jealous...[P566]

I remember at infants school being taken out of class with definitely one other boy who was in it, I think there was two, I know xxxxx,we didn't have to do the normal stuff, got away from maths, [P361]

...there was another girl, ...me and xxxxx used to be pulled out, and did feel a bit special for that [P351]

Reflecting the very different legislative guidelines that operated in the 1960s and 1970s, participants' spoke of how uninformed they felt about why or what they were doing – *I remember being hoicked out of class with another girl and not quite understanding why and being asked to do sort of weird tasks, like drawing circles and stuff like that [P057].* There was also recognition that their parent(s) had also not fully understand their involvement and had just agreed when asked to be involved... *she [mother] just said it was something which happened or...when she was asked to get involved in, she said yes..... and that was it.. [P154].*

Since the late 1980s there has been an increased importance attached to the ethical considerations of conducting social research with children (Morrow & Richards, 1996; Alderson, 2004; Farrell, 2005). A variety of ethical guidelines began to emerge in the 1990s and have continued to evolve (e.g. British Educational Research Association, Social Research Association). In the Millennium Cohort Study (MCS) parents are asked to give written consent for each type of information or task that their child is asked to complete (Gray et al, 2010)¹¹. Once old enough, they are also given an age-appropriate information sheet and an opportunity to ask questions and ultimately to refuse to participate.

¹¹ This technical report and accompanying appendices refers specifically to MCS4, carried out when children were age 7. For others, see <http://www.cls.ioe.ac.uk/studies.asp?section=000100020001> and follow links.

The medical and educational tests or particular aspects of them – were the most vividly remembered by cohort members, *Oh gosh, I remember being measured and weighed and remember all the cold tape measures and things as a little girl, I think I was seven [P115] or I remember..... having to strip down to my pants and walk in a line! [laughs] [P696].* Some reflected on how they had wanted to do well in the tests, how they worried about their performance afterwards and also the frustration of not knowing how they did or what was being measured. This theme of feedback is returned to under ‘Improving the experience’.

I remember thinking that I wanted to do really well and I wanted to be really smart and really clever and knowing later that I could have done better.....thinking, I could have done that better, they'll think I'm one of the stupid ones now. I remember worrying about things like that.....[P238].

All through childhood children will have been assessed educationally and medically. Memories of the age and frequency of participation in NCDS was often very ‘blurred’, with most ages in early childhood being cited. Activities or other visits to medical centres, a doctor, education specialists, or general testing in school had been inaccurately filed away under ‘experiences of being part of NCDS’.

I can't remember how old I'd be, probably about eight, nine, ten or something like that. [P1090]

... my memory is that I was forever having tests...[P441]

...used to be every year and then it went to every few year and then, I don't know, [P244]

...I don't know, they get--, all the childhood memories get jumbled.....I don't know, there's like some of them might be--, I don't know if there are other studies or whatever, you know. [P168]

Reasons for continued participation

In the discussions, cohort members expressed reasons for their participation in terms of ‘personal fulfilment’, the ‘greater good’, ‘obligation’ and also an understanding of the ‘longitudinal’ aspect of the study.

‘Personal fulfilment’ was expressed in a variety of ways, from feeling proud of their involvement, feeling special, part of something or part of a special group to having interest in and enjoyment from being part of the study. Feeling ‘special’ was mentioned in 80 (47%) interviews and by more women (44, 52%) than men (36, 42%). Those with a more consistent participation record were no more likely to report they felt special than those who had missed a few rounds of data collection.

*I feel very privileged. I feel dead special, do you know what I mean? [P025]
I actually feel--, oh right, I actually feel quite proud to have been part of this and if.... [P043]*

Participants also spoke of getting enjoyment from the interviews – ...*So it's quite fun, you know* [P696] –, mentioning the experience holding 'interest' 'excitement' and being 'different' together with having a sense that their opinions were valued.

I find it interesting doing it, people asking your opinion on things. It's not often you get the chance to voice your opinion on things and your thoughts on stuff. [P149]

I actually look forward to it, because every time someone phones me up, I'm like, what's coming next, because each time it's been something quite different. [P190]

There was also a sense of the study holding more importance and interest as the participants have become older. This was expressed in an increased interest in the topics and questions that the survey has covered at different times reflecting the journey over the lifecourse, though of course the change in focus of questions can focus attention on ageing itself.

You know, obviously as I've got older and understood it more. I've found it really quite interesting. [P417]

...There were questions [in the latest sweep] there about are you able to dress yourself, you know, can you--, do you need help getting up in the morning and can you walk, and have you got chest pains and all those sorts of things. And I must admit I found some of that was bloody depressing 'cause you think, Christ, I'm only 50! [both laugh] But you realise how important those questions are, 'cause clearly they wouldn't be asking them if they didn't relate to people of our age, so there is an element of thinking, wow, there but for the grace of God go I. [P161]

Respondents also placed emphasis on their involvement in the study being for the 'greater good'. They spoke of being happy to take part if it was of use to wider society and could be a help to others in the future.

...and if it's going to help someone in the future or if it's going to give them an idea of why something's happened or why something could possibly happen in the future, I think it's great..... If I can just be a very small part of that then brilliant. [P130]

Well to me, I know it sounds weird.....I mean, you know, it doesn't affect me in a sense where I did do it or I didn't, but I think it would affect a lot of other people if I didn't...[P344]

Along with voicing their involvement in terms of the 'greater good', there was a sense that it was not that much to ask of them as individuals. It did not take up a great deal of their time, with a couple highlighting that it took far less than the time that has been put into the survey by those involved in running the study.

...it's not a difficult thing to do or it's not like it's every year or, you know, you're not sort of thinking, oh here we go again, type thing. No it's been fine. [P562]

No, it's not really infringed in my life at all, I mean it's a couple of hours every three or four years, is nothing really. [P220]

.... they're spending a lot more time than I'm actually spending at it, why should I say no...[P344]

Participants revealed an understanding of the 'longitudinal' nature of their involvement, with 20 (12%) talking about this aspect of the study in their discussions and that they were ultimately irreplaceable. This was more likely to be mentioned by men and those with a complete participation record. Others grasped how representative the study was and that it was important to cover all people in society.

...and being part of this, you know, longitudinal survey it has to be important and I do hope that it's starting to, you know, define some policies and that there's something more than just a--, a, you know, wodge of information. [P061]

I'm quite proud to be part of the study and, you know, I think it's a great idea, they've tracked people for 50 years and I think it's the longest serving study in the world--, longest serving--, longest running study. [P440]

No, I think it's a good, worthwhile study and it also seems to be from the cradle to the grave, so...[P218]

...Yeah, because I suppose you must talk to people from a wide range of backgrounds, from--, what I would say, you know, sort of like you've got your posh and you've got your middle and then you've got your rough and ready. So I suppose you cover that whole spectrum. [P430]

This understanding of the longitudinal nature of the study evoked a sense of commitment to the study, of feeling obligated but also of wanting to see it through to the end and that it had become part of their life. Dropping out of the study in the foreseeable future was not something this group of respondents were considering now that they had invested so much of themselves to the study.

'it's an obligation now, I mean, Christ, I've come this far!' [laughs] [P046]

...I don't want to overstate it, but I felt a sense of obligation really to do it [P057]

I wouldn't knock it on the head I'll be honest with you. If I was going to knock it on the head I'd have knocked it on the head a long time ago ...so I think to myself well I've gone this long, you know, I suppose I do it 'til I drop dead, or 'til they send me a card one day and I ain't here no more...[P344]

... what's the point of doing it for 20, 30 years and then dropping out? What a waste of time that would be. [P238]

... it's not so much it's part of my life, but it is in a sense, goes back a long time and so drop out now I would just feel, you know, crikey. [P566]

A commitment to NCDS was also expressed through a willingness to stay with this study, but not become involved with other research requests. In a way recognising that the study was very different from the other surveys that people are increasingly asked to participate in over the telephone, online, etc. They spoke of feeling their

decision to participate or not was respected, that they were not badgered into participation by the study team or interviewers.

...anyone else does now and it's no, go away. I don't do anything, I will not answer anything. No, because I'm well aware that it's just someone making money somewhere. If you want to pay to get my opinion I'll give it. You lot can have it for free! [laughs] [P140]

I mean you get people in the shopping centre trying to impose themselves on you, you get people ringing you up on the phone and not wanting to get off. Whereas I've always been given the option in the NCDS, you know. [P078]

However, as much as being part of NCDS was important for some, it also had no discernible impact on the lives of many respondents, it was just something they did when they were asked to do it, their involvement only ever being something they thought about when they received communication from the study team.

...Just part of my life line, it just happens. [P025]

I think I've probably just done them and--, and just got on with it I suppose and then just forget about it. [P357]

Reasons for non-participation: past and future

The NCDS study team has made consistent attempts to contact all cohort members on an annual basis, despite big gaps between some of the earlier interviews. Between 1981 and 2000 the interviews were roughly a decade apart. Although two-thirds of this group of respondents have participated in all previous NCDS interviews, it is understandable that recall of individual involvement is somewhat vague. Many did not know if they had missed an opportunity to be interviewed, with as many of those who had missed a sweep thinking they had participated in all possible interviews as vice versa.

I don't think I've missed one... can't recall that I have, but I might have done....[P130]

To enhance the limited body of knowledge on non-participation, we asked respondents to recall reasons behind any non-participation in a survey, including reasons for non-completion of a section of the interview. Within this sample, reasons cited for 'missing' a sweep of data collection were usually to do with general life as opposed to the survey. A few mentioned that they had not participated due to a fairly major life event occurring at the time they were contacted, for example death of a family member or being in the middle of a divorce, but for the majority it was far more day-to-day experiences. For example if they had [temporarily] emigrated, were travelling around with work, away on holiday or in the process of moving house.

I think I slipped through the net a couple of times when I've been moving from place to place, but I think I've done most of the studies and most of the surveys actually, to be honest. [P078]

*I think I did miss a bit 'cause I've moved around a bit... [P052]
...I may have cancelled a couple of times but that was just for something that happened on the day. There's no reason why I don't want to do them. [P268]*

It could even just be something that cropped up on the day that meant the interview had to be cancelled and for whatever reason did not get successfully rearranged. Often it was a case of life being a bit too busy and so it was easier to say no than yes at the time they were contacted. Among the 40 who were contacted for the study but did not take part on this occasion, 43% cited being too busy as the reason for their refusal (Elliott et al, 2010). In terms of future participation, some accounts suggested that a vast increase in the frequency of interviews could impact on participation, and that willingness to participate could be tempered if they led more busy lives and/or they had to take time off work to fit the interview in.

No, it's, you know, every now and again you don't mind do you? I mean if it was every six months or something it might be a bit different but I mean every couple of years. [P441]

Sometimes you think, oh, well that's a bit of a bind to have to do that, and then I think, well, you've been in all this long, it's only an hour or two, whateverI mean obviously if I was busier and I worked 'til six or seven o'clock at night I perhaps would have a different attitude towards it, but because I have time it doesn't matter. [P1094]

Historically, information collected from NCDS cohort members has involved a face-to-face interview¹². The interview is now routinely carried out using a computer instead of being paper-based – whether the interviewer is asking the questions (Computer Assisted Personal Interview – CAPI) or the cohort member is answering a self-completion questionnaire (Computer Assisted Self Completion Interview – CASI). However, with rising costs and technological advancements interviews have also been carried out over the telephone and parts of the interview have been collected from self-completion postal questionnaires. Online questionnaires are increasingly used in other studies and may be an option for future NCDS surveys. In the conversations for this project, some respondents indicated a dislike for the telephone interview and in the main accounts gave a sense that the 'personal touch' was appreciated.

I always took part, I think--, what was it, there was--, oh no, tell a lie, yeah I did, they wanted to do it on the phone and I just thought no, I'm no doing it on the phone because:.... I just felt no, I'm not prepared to do it on the phone... [P566]

...so maybe yes, the telephone one isn't a good idea, yeah.....It goes a lot quicker but on the phone it was hard... [P684]

Throughout any interview, cohort members are assured that they do not have to answer any question or set of questions they do not want to. The questions that are deemed too personal, sensitive or intrusive differ from one individual to another. For

¹²Although interviews at age 23, 33, 42 and 50 were face-to-face there was also an additional self-completion module. These were paper-based at age 23 and age 33, computer-assisted at age 42 and age 50. The age 46 interview was conducted over the telephone.

some it will be questions on employment or finances, for others it might be personal relationships or health concerns. By looking at response rates to different questions within any survey, it is clear that the option of refusing to answer certain questions is taken up. For example, of the 9,790 taking part in the NCDS survey at age 50 9,762 (99.7%) gave a personal assessment of their current financial situation to the interviewer and 9,599 (98.0%) answered who they would vote for in the next General Election. Within this much smaller qualitative sample, a few participants mentioned they had opted out of questions [in previous interviews] due to feeling uncomfortable with the topic.

...I think the last interview with the guy, yeah he was asking a lot of personal questions.... really, really personal questions about finances and different things like that and I was a wee bit uncomfortable. [P566]

Perhaps of more concern for those involved with running longitudinal research was the refusal to some questions due to the answer categories available. Cohort members take their involvement in the study seriously. As such if they could not 'fit' their answers to the pre-coded answers then they would not complete the questions as the response would not provide a true picture of them.

I'm not capable of saying, "Okay, this is as close as I'll get to my answer," I kind of have to always say that, like, "I'm sorry that's not really--, I can't answer that question."..... I don't answer them--, I mean, yeah a lot of the time, I don't say, "Don't know," 'cause I don't know 'cause that's the only choice you've got, you know. [P168] I found some of the questioning frustrating..... the questions were, you had, what was it--, agree, disagree, strongly, something like that. But some of them you cannot--, some of the questions you cannot answer with that sort of answer.....that's not just with your study that's with any study or any questionnaire, I found that really frustrating because you cannot answer that question at all. [P676]

For others, although they did complete the questions there was much concern about what the researchers would think of them from the answers if they forced their answers into the available categories. Although it is the 'collective answer' that is of most importance to quantitative researchers, it is important for the study teams to realise that for some of the individuals involved, giving an accurate picture is of vital importance.

I don't know if I answered quite rightly, 'cause really it's not black and white sometimes, there's an awful lot in-between. [P351]

I think sometimes the questions weren't open-ended enough.... In the last one there was a question about how often do you see your children, ...I had to put like I only saw him three times a year or something, which it was wrong, because I see him for long times when I see him....he's at university but the form wouldn't allow that. And I feel quite upset about it really though.... [laughs]There's some researcher thinking, my God, she only sees him three times a year! [P351]

Improving the experience and maximising future participation

Respondents were asked what would improve the experience of being a part of NCDS. By far the most mentioned 'topic' in the individual discussions was 'feedback'. Many wanted more feedback about their own answers and performance in tests and assessments, whereas others placed importance on hearing more about the study in wider society and the media. Other aspects mentioned were knowing more about the purpose of the questions being asked, meeting other study members, the interviewer and rewards and remuneration.

'Feedback' was not a direct question or prompt in the topic guide¹³, but was discussed in nearly half of all 170 interviews (49%) and more so by men than women (54% to 44%). Respondents who had missed two or more previous interviews were less likely to mention feedback (4 of 11, or 36%) than those with a complete or near complete participation record.

The accounts reflected that feedback had improved in recent years and there was some recognition that this obviously reflected improved, or at least more consistent, funding.

I think the one thing as a child that I always used to be frustrated with was there was never any--, we didn't get any feedback... [P440]

I liked the idea that there was feedback, I thought there was not enough feedback in the early years.....I get the impression, 'cause obviously a lot of it comes down to funding and the like, is that the powers that be are looking kindly upon it...and I've noticed just recently that you've been offering that kind of information and more information. [P149]

Providing the right amount of feedback is of course difficult, if not impossible, trying to successfully strike a balance between keeping members informed, interested but not overwhelmed with details. Within this sample, individual responses ranged from wanting more to [a few] wanting less, but encouragingly, in the interviews where feedback was raised, half wanted more feedback and half thought it was essentially pitched about right as they would not have time, or interest to read more. Around a third of all respondents wanted more feedback, although there was no difference by gender or previous participation record in NCDS surveys.

...we don't get to see the feedback.....none of the reports which are written by it are visible, and they'll be quite interesting to have a look at. [P394]

I think they've done a good--, they've kept an even keel ... I think they've kept it right, at the right level really. [P023]

I don't think I would make a lot of use of a lot more feedback to be perfectly honest, you know. Hmmm, I think most people nowadays actually suffer from information overload...[P487]

¹³ It was raised in as few as 5% of interviews by one interviewer to 90% of interviews by another

In some discussions the request, or desire, for more feedback was sometimes associated with feelings that information was being 'sucked out of them' and not enough came back. This in turn was often related to not knowing what the information has been used for and what, if any, policy impact there has been. Fourteen people in the sample specifically talked about the relationship between the information they give and 'policy' formation.

...cause I always wondered where, you know--, there's all this input going and there must be some output somewhere, so. [P367]

The only problem I find with them is--, with the whole thing is not really knowing what any of the information's being used for....."Yeah thanks for doing this, we now know that--," you know,." [P168]

...and this is how we shaped government policy if that's what it's for or shaped health policy or whatever, you know, to show the cause and effect as it were, yeah. [P675]

A request for accessible, relatively basic, feedback was a common theme. How many were actually still involved in the study, simple percentages of how many were married, divorced, working, etc. There was a sense that some wanted to place themselves, to see how they compare to their peers.

I'd like to know if like--, how average I am or how above average or how below average, I would like some sort of feedback on that. Because there must be statistics which show like above the line, below the line, I'd like to see that. But on a personal level, not just everybody, myself. But I think that's a vanity thing, you know, and I'm quite honest about it. I think it's a vanity thing. But I think secretly everybody would like that. Just to see, you know? [P238]

Some of this information has been sent out to cohort members over the years – ...it's been interesting to read all the studies afterwards and seeing what my peer group are all doing and what directions that they've gone into and what proportion are male or female, etc.... [P115] – with some publications and information being available on the website specifically for NCDS cohort members. An important feature of these discussions was the distinct lack of knowledge among survey members about what information is readily available about the study, and increasingly so online. Although the website address is featured on all correspondence with cohort members', this is obviously overlooked by many. When new information has been placed on the website[s] or research findings have been promoted across the national media it may be worth doing a specific mail out, or highlighting the availability of online information or findings when sending out the annual birthday card.

...It would be nice to know, and maybe--, I'm quite simplistic, but to have a graph on how many people own their own home out of this group of people, how many people are married, how many people have got children, how many are divorced, you know, those simple statistics, I would love to see that...[P148]

You'd like to see a decent report or have access to an on-line.... the stuff which is being written...they should be stuck on an on-line database that people have got access to read it. [P394]

There was interest in receiving information in a 'magazine' style, with the content including individual stories or case stories of those involved¹⁴. This seems to reflect that as the information they give is on an individual basis, there is an interest in hearing information back at the individual and not just at the group level.

Maybe in magazine form, to look at articles about different people and what they're doing....you know, this one's a rocket scientist and, you know, this one's a lonely dustman ...[P115]

I think most of the feedback that comes back is very, very generic which--, I tend to get bored halfway through reading so I don't bother..... a much wider range of feedback.....maybe some examples, some, I don't know, common case studies, stories, that sort of stuff would make it more interesting and I'd read it then. [P239]

Some placed an emphasis on feedback in hard copy not email format. However, this was not to suggest that cohort members were against receiving information over the internet - *It would be great to get an email every now and then to say, you know, the study is doing this and if you want to find out more about it, go to this link or, you know...* [P217] – but that mail received through the post seems more personal and shows 'more effort' on behalf of the sender, in this case the study team.

*...but written, yeah. Yeah, just sent, a little booklet or something. [P351]
...Probably sent, I prefer things to be sent so I just think picking a website is an easy opt out to be honest with you. [P367]*

...I got the book [now we are 50] through the last time but it kind of danced around a lot things, you know, it didn't really give me the nuts and bolts or anything...[P234]

Each year a birthday card is sent out to all c12,000 cohort members held on the address data base. Some basic figures and statistics are included with the card, together with a change of details card which they are asked to return along with any new details. The 'birthday card' was mentioned in 70 of the 170 interviews (41%), with men and women raising it with equal frequency. Those who had missed one previous interview were the least likely to raise it in discussions (33%).

The conversations revealed a love-hate relationship with the card, though comments were generally positive and reflected the larger 'love' camp. Respondents spoke of 'always guaranteed one card a year' and that it often sparked a conversation about the study when friends or family looked at birthday cards.

... it is quite good how they've managed to keep track of you, I've always thought that [laughs], you know, they keep sending this card every year don't they? [P414]

...and I get a birthday card, it's great, love that! [P130]

¹⁴ In 2005 all cohort members were sent a magazine 'Changing Lives' which gave some basic findings from the 2004 survey, comparing NCDS with the younger 1970 British Cohort Study (BCS70). A follow-up telephone interview with 99 NCDS members revealed that although 42% could not remember being sent the magazine, of those that did 94% said they would like to receive similar information in the future.

'Cause like, obviously I get the birthday card every year.....I mean it's something and nothing but I think it's a nice touch, yeah. [P019]

Linked to the emphasis on feedback in many of the discussions was a feeling, perhaps even a sense of disappointment, that the study was not better known amongst wider society. Cohort members spoke of how it very rare to have known anyone who had ever heard of it, and that they themselves did not often hear it mentioned in the media which was something appreciated or looked forward to *and it's great in the newspapers when you read about studies because they often quote this study in the newspapers and say, you know, people who have been tracked since 1958 have found... [P440].* The lack of attention the study got did not seem to back up that they are part of an immensely important study.

I mean it's certainly not known nationwide apart from the people that attend it, I mean it's not something that's--, nobody else knows about it do they? [P378]

...used to have articles in The Observer and stuff which used to get the centre page, you don't get that now.... [P394]

and people are saying, "What's that all about?"..... No-one's heard of it. [P161]

Confidentiality and the anonymity of cohort members are central to the running of a longitudinal study. This was recognised – *'cause I know it's confidential [P268]* – but some spoke of wanting to meet up with others, or at least to have the opportunity of meeting up with others. Although most knew someone else when they were at school, unless they had remained living near their childhood home, they now do not. Although they feel part of a group and, as discussed earlier, had a sense of belonging to something, the difference in being part of this group, is that they do not [generally] know anyone else who is involved. Even if they did not want to meet them, knowing more about them was also mentioned.

I think it'd be interesting to meet the--, the locals, because I know certain kids when I was at school, ... it'd be nice to meet them, you know, because--, and to see how things have progressed. [P005]

... I hear that there are some round this area, you know, sort of thing and I sort of think it would be great just to sort of like, you know, meet up. I don't know what we'd talk about [both laugh] because we'd have nothing in common probably apart from this! But there is a sense in which--, again at which you feel like you belong to something... [P696]

Another aspect mentioned in some conversations was the interviewer. Participants in a study essentially welcome a stranger into their home and are asked a lot of questions (Blohm et al, 2007). As these respondents are part of a longitudinal study, the experience is repeated. As many answers could be very personal, it is important for the atmosphere to be as friendly and relaxed as possible. Although quite understandable, some felt the process was too impersonal and also that there was no sense of continuity. The longitudinal participation was only on their side as the

interviewer was rarely the same, again understandably, from one interview to the next. ...*I've had some lovely researchers that have come, but you just--, there's no continuity with it...* This occasionally raised feelings that the interviewers should know more than they did about whom they were interviewing and also about the study itself. Mistakes in information should not be made and the study team has a duty to ensure that all interviewers take their responsibilities seriously and understand the longitudinal nature of the study and how irreplaceable the participants are.

I mean what she [the interviewer] said to me was as well some of the information she gave me wasn't exactly right.....and so she said to me, she said, "Oh no, there's not many of you" she said, "You're just selected." And I said, "No, it is actually all the children that were born in that particular week." She said, "Oh no", she said, "It's not like that." [P690]

Some respondents mentioned they would appreciate having more information about the purpose of the study or the questions being asked 'upfront'. They expressed wanting to know why particular questions were being asked. This lack of understanding prompted different thoughts, from feeling a bit 'panicky' as to how to answer a question, or indeed why are they asking me that, to thinking the questions were pointless as they had not been explained what they were trying to capture.

I'm not saying I'm thick but I'm not educated, and there's times when they've come down and I've had to do certain things with like computers and things like that, I haven't got a clue. [P344]

Payment of some kind is becoming more of an issue in management of a longitudinal study and has been employed to varying success in other studies (Zagorsky & Rhoton, 2008; Kropf & Blair, 2005; Collins et al, 2000). Participants were not directly asked about payment for taking part in the study and very few raised this when asked what would improve the experience of being part of the study. If raised at all, it was often in a 'jokey' way. The longevity of participation without financial gain among this group of respondents surely means that their continued participation will not be greatly influenced by 'presents'. However, among less willing or lapsed participants, younger or newer cohorts this may have a positive effect on attrition. And maybe a bottle of champagne at age 75 isn't such a bad idea after all.

Only if you get paid a pound for every year you--, [both laugh] a pound for every week you've been in it [laughs]. That would be nice. That would be all [laughs]. [P238]

... maybe when we get to 75 we should all have a--, I don't know, a bottle of champagne, which I would appreciate, but some people might notmaybe you do us a wish list, you know, 'Happy 75th birthday. Which of these four things would you like?'.....ticket to a football match, bottle of champagne, hmmm, Clarins voucher or a--, I don't know, a new pair of walking boots. [P061]

Discussion

In examining positive and negative responses to what cohort members felt about being part of the NCDS, we have gained insight into ways the experience of being a survey member can be improved to help maximise participation in future rounds of data collection in NCDS, and perhaps more importantly, in younger or future longitudinal studies and birth cohorts.

In the main, cohort members gave very positive accounts of their involvement in NCDS over the past 50 years. From the questions posed, four main themes emerged: childhood memories, continued participation, improving the experience and maximising future participation, reasons for non-participation: past and future. *Childhood memories* usually made respondents remember they felt special to have been selected to be part of the study and centred on the educational assessments or medical and laterality tests. Memories were often blurred and exact age of assessment often inaccurate, but they were generally remembered with fondness. Any negative reflections were raised among the few cohort members who had been shy children who had not enjoyed the experience of being singled out in a school environment or those who had wished to know how they had scored on the variety of tests they sat. Although the NCDS study team try to accommodate individual requests for personal information, providing individual feedback in the form of scores on an assessment has both time and ethical considerations. There is an acceptance that children need to be better informed and feedback directed specifically at the children involved should be an important part of a study's communication strategy. It should focus on the parts of the study the child was directly involved in – as was recently implemented in the Millennium Cohort Study¹⁵.

The NCDS was set up during a time when the word of people in positions of authority carried more weight and was less questioned than it is today. As such, if a mother who had very recently given birth was asked to participate in a national survey by a nurse or mid-wife they would be highly likely to agree – in fact, not one refused. Although there has been drop-out and refusal over the years¹⁶, the theme of agreement has continued with cohort members *continued participation* being reported as a sense of obligation towards the study and an increased sense of wanting to see it through to the end. Some recognised they were irreplaceable, with the longitudinal nature of the study bringing a sense of commitment and that dropping out would now be pointless. However, continued participation was not just out of a sense of duty. The personal benefits for some were feeling a sense of importance or that they felt special to be part of the study, together with an increased understanding and interest in the study as they themselves have got older. This will be important to track over the coming years given older age has been consistently found to be a risk to retention on longitudinal, although not birth cohort, studies (Jacomb et al, 2002; Rabbitt et al, 2004; Matthews et al, 2006; Tinker et al, 2009). The personal investment made by participants in a birth cohort study should, *ceteris*

¹⁵ This is currently available on the MCS cohort members website and will soon be available to download from the main CLS website.

¹⁶ For further details see <http://www.cls.ioe.ac.uk/studies.asp?section=000100020003>.

paribus, make age less of a risk factor to remaining in the study. Others spoke of their participation in terms of more altruistic feelings, being happy to remain involved for the benefit of wider society.

It is these personal and society level feelings that need to be focused on by birth cohort study teams. Even among respondents who felt the study was such an infrequent part of their lives that it had no discernible impact on them at all, a strong, positive identity with the cohort 'brand' could be the most invaluable ingredient for continued participation. A very simple and effective way of communicating with cohort members is by the birthday card that is sent out to all 12,000 survey members on the database each year. This way of reaching cohort members should not be overlooked in the design of future birth cohort studies. Analytic benefits of selecting participants from births occurring throughout a year (Millennium Cohort Study) need to be weighed against selecting participants from all births within a single week (1946, 1958 and 1970 cohort studies). A future approach could be to select births from a certain number of days in a year, thus only involving 'n' specific mail outs each year making it possible for survey members to receive a birthday card each year from the survey team.

Accounts of *improving the experience and thus helping to maximise future participation* placed quite considerable emphasis on feedback that they have had, or would like to achieve. Regularity of feedback was important together with type of feedback. Respondents wanted to know how the information they have given has been used, for example, the Government policies that have been shaped or changed by the data. Although the study continues to receive attention from the British media, most recently in the form of a BBC Radio 4 documentary series '*When I Grow Up*', there seemed to be a distinct lack of knowledge about this among cohort members. To try to combat this the study team could inform cohort members by including publicity information in a twice yearly mail out, or scanning the article and placing it on the NCDS cohort members' website. This might be an important consideration for retaining participants in newer longitudinal or birth cohort studies. All media attention can help to strengthen the sense of identity and belonging with the study. However, it is often the researcher rather than the data source that is [understandably] mentioned. Perhaps there is a way of making it mandatory for researchers to cite the data source in any publication and resulting media coverage.

Providing feedback to survey members should be incorporated into a survey's 'fixed' and not 'additional' costs. However, sending hard copy feedback to all study members has vast cost implications and in today's economic down turn, it is increasingly not viable. A recent approach used by the NCDS study team was to send a small amount of feedback to all along with an accompanying letter which asked cohort members to get in touch if they would like more comprehensive information (Elliott & Vaitilingam, 2008).

With the ever increasing availability of online information, it is important to make this as accessible as possible to the cohort members who would want more detail than can realistically be provided in printed form. This could include emailing study members, or sending a post card to those with no email address, the details of a new

publication and how to access it online. This would be far more cost effective than having the document published in hard copy. For younger and future cohorts, online communications should decreasingly become a problem. Something of a surprise from the interviews, was the lack of knowledge about the NCDS website. The way cohort members have been informed about online information had obviously not penetrated through to the majority, and this group of respondents could, in the main, be classified among the keen ones.

The last theme that emerged from the data was *reasons for non-participation: past and future*. As discussed, this sample of cohort members was over-represented by those with a complete participation record. However, recall of previous participation or non-participation was often sketchy given the large and varying number of years between earlier rounds of data collection. Many did not know if they had missed an opportunity to be interviewed, with as many of those who had missed a sweep thinking they had participated in all possible interviews as vice versa. What we did learn is that reasons for 'missing' a sweep of data collection were not usually to do with the survey, for example, the content of the interview or not liking being interviewed, but rather to do with major (divorce) or minor (away on holiday) life events. Often it was a case of life being a bit too busy and so it had been easier to say 'no' than 'yes' at the time they were contacted. As people's lives become increasingly complex at all stages of life – from children attending numerous after school clubs, adults juggling work and home and increasingly the demands and diaries of blended families – the ability and willingness to participate, to give up an hour or two of time has become less easy. The need to feel special, to identify closely with the study will become increasingly important for participation and retention.

Taking this notion further is the mode of data collection. It is well known that the refusal rates to surveys are far higher if more impersonal, detached communications are used, for example, telephone, postal or e-surveys. Response rates from NCDS and the 1970 British Cohort Study (BCS70) cohort members have been lower for postal and telephone surveys than for face-to-face interviews¹⁷. Respondents gave clear support for the more personal 'face-to-face' approach, but the conflict between cost effectiveness and the continued use of face-to-face interviews for retention in the study will increasingly be a consideration for those involved in running longitudinal studies. The likely impact on future participation will need to be carefully monitored, particularly among older age groups. This *may* be less the case among younger or future cohorts who are more comfortable with electronic communication media. However, the move to more detached modes of data collection could dilute feeling of being 'important' and 'special' for the individual. If the 'gap' in how NCDS and other [market] research agencies are viewed is diminished, then the willingness to participate may also diminish.

To conclude, the data discussed here provides valuable insights into the positive experiences associated with being part of a longitudinal study and the reflections that could help future retention in both this and other on-going birth cohort and panel

¹⁷ <http://www.cls.ioe.ac.uk/studies.asp?section=000100020003>

surveys. Much of the issues and considerations raised in this paper have been, or are being, considered by those involved in running longitudinal surveys. One of the strongest features of these accounts was the strong sense that being part of a birth cohort study was a unique experience, or that the individuals in the study were themselves unique. This sense of 'specialness' and identity with the study brand must be nurtured and kept at the forefront of planning by all involved with longitudinal research. The less compliant age that we live in and the more complex living arrangements and work patterns that are increasingly the norm to many increase the number of reasons respondents have for saying 'no' rather than 'yes' to freely giving up a few hours of their time every few years.

Limitations of the study

This was a qualitative study based on a relatively large sample (n=170) of 1958 NCDS cohort members who had all participated in the latest round of quantitative data collection at age 50. The paper concentrates on the comments given by respondents about their participation in a longitudinal birth cohort study. The sample was over-represented by those with a complete participation record and positive comments far outweighed negative reflections about the study. Acknowledging that the views expressed are taken from a group who are, by definition of their continued involvement, very willing and committed participants, generalisations to participants in a longitudinal study particularly who have dropped out altogether or to those who have a less consistent participation record would not be appropriate.

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