Understanding Individual Behaviour Exploratory Networks

Investigating the genetic, social and neuropsychological influences on individual differences in memory using a lifecourse approach.

Pilot Study

Technical Report

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1. Introduction

1.1 Investigating the genetic, social and neuropsychological influences on individual differences in memory using a lifecourse approach – the pilot study.

This document describes a pilot study conducted as part of the Understanding Individual Behaviour Exploratory Networks which sought to investigate the potential of conducting neuropsychological assessments with purposive subsamples of the British Birth Cohort Studies.

A sub-sample of 133 National Child Development Study (NCDS) members living in and around Cambridge who achieved a range of scores on the cognitive assessments included in the age 50 survey in 2008 were invited to a research centre at the University of Cambridge to complete a 90 minute testing session involving the repetition of the assessments completed at age 50, a battery of 5 CANTAB (Cambridge Neuropsychological Test Automated Battery) assessments and a short questionnaire. Assessments were conducted with 45 individuals.

This document describes the sample design, the assessments, the fieldwork procedures, the response rate and feedback from participants on their experience of taking part. The document concludes with a discussion of some of the lessons learned which could be applied if a similar study were to be planned for the future.

A fuller discussion of the motivation for conducting the pilot study and its substantive findings can be found in Knight et al. (2010).

1.2 The Understanding Individual Behaviour Exploratory Network

The initial aims of the network were to investigate the genetic, social and neuropsychological influences on: i) individual differences in impulsivity and ii) individual differences in memory using a lifecourse approach. However, the work conducted has focussed primarily on mid-life cognitive function and how this relates to experiences and behaviour earlier in the lifecourse.

The network brought together researchers from a number of disciplines within the social sciences, as well as experts from genetics, neuropsychology and neuroimaging, and those with an established interest in research ethics and sought to apply ideas and techniques at the cutting edge of genetics and to capitalize on the research resource represented by the longitudinal British Birth Cohort Studies.

The network includes researchers from the Centre for Longitudinal Studies (CLS), Institute of Education, University of London, the Department of Experimental Psychology at Cambridge University, the Social, Genetic and Developmental Psychiatry Centre at King's College London and the Institute of Psychiatry at King's College London.

The network is funded by the Economic and Social Research Council, the Medical Research Council and the Biotechnology and Biological Sciences Research Council and ran from July 2009 to September 2010.

2. Sample design

The pilot study aimed to recruit individuals with particular cognitive ability trajectories between childhood and mid-adulthood. Childhood cognitive ability was measured using the General Ability Test (GAT) which was conducted at age 11. Adult cognitive ability was measured using the cognitive assessments conducted at age 50. The pilot study was therefore restricted to those who had participated at age 11 and at age 50 and had completed both sets of assessments.

Study members were required to travel to a research centre in Cambridge to participate, so the pilot study was also restricted to those living within 50-60 miles of Cambridge.

In total there are 471 study members who were identified as living within the target area and participating in the cognitive assessments at both age 11 and age 50.

From this pool three groups of individuals, were identified for potential inclusion in the pilot study. The three groups were constructed by using age 11 GAT score to predict the summed score on the immediate and delayed word-list recall tests conducted at age 50 (see Section 2) using ordinary least squares (OLS) regression.

1) The main experimental group or '**Decline**' group showed a decline in memory at the age of 50 as compared to childhood cognitive scores. The group were selected on the basis that their summed score on the immediate and delayed word-list recall tests conducted at age 50 was more than one standard deviation lower than was predicted from their GAT score. In total there were 54 cases in the Cambridge area identified as belonging to this group.

   This group was then matched with two control groups:

2) **Control group 1: 'Consistent high scorers** – This group were matched to the experimental group on childhood cognitive ability level, but did not exhibit any signs of decline[1]. In total this group also consisted of 54 cases.

3) **Control group 2: 'Consistent low scorers'** – This group were matched to the experimental group on their age 50 cognitive ability (as measured by the summed score on the two word-list recall tasks), but had different cognitive ability levels in childhood (most likely having low cognitive ability throughout their lives)[2]. In total 55 individuals were allocated to this group.

[1] The 54 individuals identified as belonging to the decline group achieved GAT scores at age 11 that ranged between 14 and 75 (out of 80). In constructing control group 1 the aim was to replicate this distribution, but with cohort members whose summed score on the two word-list recall tasks was almost exactly as predicted. Initially all those whose combined score on the two word-list recall tasks was within 0.2 standard deviations of the score predicted from their childhood cognitive ability score were identified. Amongst this group there were a good set of matches for everyone in the decline group whose GAT score was between 26 and 75, but nobody who scored lower than 26. In order to find matches for these remaining cases it was necessary to include cases whose summed score on the two word-list recall tasks at age 50 was within 0.5 standard deviations from their predicted score.

[2] With this group the aim was to identify cohort members with similar cognitive ability at age 50 to the experimental group, but whose age 11 score was sufficiently low, that it was consistent with their age 50 level of achievement.

So in total 163 individuals were considered eligible for invitation to participate in the pilot.

The aim of the pilot study was to conduct 20 assessments with each group to result in an achieved sample size of 60.

There was a significant methodological problem with this, resulting from the fact that linear regression aims to produce a 'fit' based on minimising the squared distance (sum of squares) of all the observed values from the straight line which attempts to predict them. Thus, accuracy at the extremes has to be sacrificed in order to produce the best fit for the great majority of cases in the middle. One might reasonably assume that a score of zero on the GAT at age 11 would predict a combined score of zero on the two word-list recall tasks at age 50, and that a maximum score on the GAT (80) would predict a maximum score on the word-list recall tasks (20). However, the intercept on the y axis in the OLS regression model is 8.53 and the maximum predicted word-list recall score is 14.4 (out of 20) so even someone who scores 0 at age 11 will still be predicted to get 8.53 out of 20 at age 50, and a person scoring 80 at age 11 will be predicted to get 14.4/20 at age 50.

The combined word-list recall scores achieved by the experimental group at age 50 ranged between 3 and 10. Although it would have been possible to 'pair' each member of the discrepancy group with someone who scores the same at age 50 (i.e. one person scoring 3, one scoring 4 and three scoring 5 etc), these people will, like the discrepancy group, be deemed to have suffered a cognitive decline, because no matter how low their age 11 scores were, their predicted score will have been at least 8.53. In practice this meant that in order to construct control group 2 it was necessary to select individuals who had declined somewhat, but not as markedly as the discrepancy group.

It was possible to identify 55 cases whose combined score on the two word-list recall tasks was less than 10 and where achieved scores at age 50 were not more than 0.78 standard deviations below the scores that were predicted. As a result though this group has a rather flat distribution of achieved scores at age 50; all cases achieved a summed score of between 8 and 10 on the two word-list recall tasks.

3. Overview of the elements of the study

The cognitive testing session was comprised of three main elements:

1) Repetition of the cognitive assessments included in the NCDS Age 50 Survey: Word-list recall, animal naming, letter cancellation and delayed word-list recall.

2) 5 CANTAB (Cambridge Neuropsychological Test Automated Battery) tasks:
    a. Paired Associates Learning (PAL)
    b. Graded Naming Test (GNT)
    c. Affective Go/No-go(AGN)
    d. Cambridge Gambling Task (CGT)
    e. Rapid Visual Processing (RVP)

3) A short questionnaire covering health, mental activities, feedback on taking part in the research study and willingness to take part in functional Magnetic Resonance Imaging (fMRI) research studies.

Each of the assessments is described below.

3.1 Cognitive assessments included in the NCDS Age 50 Survey:

3.1.1 Word-list recall

A test of verbal learning and recall where participants are required to remember a list of 10 common words.

In the age 50 survey the computer-assisted personal interviewing (CAPI) program randomly selected one of four lists of words, which were presented to the respondent by the computer using a recorded voice. In cases where the computer voice was not audible the list was read aloud by the interviewer, who was asked to imitate the pace and clarity of the recorded voice, reading the words at approximately 2 second intervals.

In the pilot study participants were again randomly allocated to one of the four word-lists, but it was ensured that they were not allocated the list of words they had been asked to recall at age 50. In all cases the word-list was read by the computer (using the same recordings that were used at age 50).

3.1.2 Animal naming

A test of verbal fluency, which measures how quickly participants can think of words from a particular category, in this case naming as many different animals as possible within one minute. The researcher made a note of each named animal and recorded the total score. Repetitions, named animals (e.g. Bambi) and redundancies (e.g. white cow, brown cow) are excluded from the total score.

3.1.3 Letter cancellation

A test of attention, mental speed and visual scanning was used. The participant is given a page of random letters of the alphabet and asked to cross out as many “Ps” and “Ws” as possible within one minute. Two scores are calculated: speed and accuracy. The ‘speed’ score is measured by the total number of letters scanned, the ‘accuracy’ score is measured by the number of Ps and Ws which were scanned, but missed.

3.1.4 Delayed word list recall

A test of delayed memory, which asks the participant to recall as many words as they can from the original list presented to them during the first word-recall task. The word lists are not repeated and participants have again two minutes to recall as many as they can. The researcher made a note of each word correctly recalled and recorded the total.

In the age 50 survey, participants completed one delayed word list recall task. This task was completed after the animal naming and letter cancellation tasks, so approximately four to five minutes after first hearing the list of words. This time around participants were additionally asked to perform a second delayed word list recall task, which was completed after one of the CANTAB tasks, so approximately 15 minutes after first hearing the list of words.

3.2 CANTAB assessments

3.2.1 The Paired Associates Learning test (PAL)

The PAL is a visuospatial associative learning test which assesses visual memory and new learning. Boxes are displayed on the screen and are opened in a randomised order. One or more of them will contain a pattern. The patterns are then displayed in the middle of the screen, one at a time, and the subject must touch the box where the pattern was originally located. If the subject makes an error, the patterns are re-presented to remind the subject of their locations. The difficulty level increases through the test.

3.2.2 The Graded Naming Test (GNT)

The GNT assesses semantic and/or verbal memory. Thirty different line drawings are displayed on the screen, one at a time. The subject must identify the object depicted in each drawing. The task becomes progressively more difficult so that the objects displayed towards the end of the test are correctly named by only a very few of the subjects.

3.2.3 The Affective Go/No-go(AGN)Task

The AGN assesses affective decision making and information processing biases for positive and negative stimuli. The test consists of several blocks, each of which presents a series of words from two of three different affective categories: positive (for example, joyful) and negative (for example, hopeless). The subject is given a target category, and is asked to press the press pad when they see a word matching this category.

3.2.4 Cambridge Gambling Task (CGT)

The CGT assesses decision-making and risk-taking behaviour outside a learning context. On each trial, the subject is presented with a row of ten boxes across the top of the screen, some of which are red and some of which are blue. At the bottom of the screen are rectangles containing the words ‘Red’ and ‘Blue’. The subject must guess whether a yellow token is hidden in a red box or a blue box.

In the gambling stages, subjects start with a number of points, displayed on the screen, and can select a proportion of these points, displayed in either rising or falling order, in a second box on the screen, to gamble on their confidence in this judgement. A stake box on the screen displays the current amount of the bet. The subject must try to accumulate as many points as possible.

3.2.5 Rapid Visual Information Processing (RVP)

The RVP is an attention task which is also a sensitive measure of general information processing performance. A white box appears in the centre of the computer screen, inside which digits, from 2 to 9, appear in a pseudo-random order, at the rate of 100 digits per minute. Subjects are requested to detect target sequences of digits (for example, 2-4-6, 3-5-7, 4-6-8) and to register responses using the press pad.

3.3 Questionnaire

On completion of the assessments participants were presented with a short self-completion questionnaire which was completed on the computer. In most cases the questionnaire was completed independently, but the researcher was available to assist if necessary.

The questionnaire covered the following topics:

- Physical and mental health
- Alcohol consumption
- Health issues which may have affected performance in assessments (e.g. colour blindness, problems with moving fingers, hands etc.)
- Mental activities (e.g. crosswords, Sudoku)
- Feedback on experience of participating in research
- Attitudes towards participating in potential fMRI studies[3].

A copy of the questionnaire can be found in Appendix A.

[3] This final section of the questionnaire was not completed independently. The researcher explained what participating in an fMRI study would involve using a prepared script. The researcher was then able to answer any questions which participants might have before they went on to answer the questions.

4. Fieldwork procedures

4.1 Advance Materials

Advance letters were sent to selected participants inviting them to take part. Enclosed with this letter was an information sheet which explained exactly what taking part in the study would involve.

The letter and information sheet explained that taking part would involve completing a series of assessments which had been developed to measure various aspects of cognitive function and that the purpose of the study was to investigate differences between individuals in performance in these assessments. It was explained that the results of the assessments would be compared with the results of tests completed during childhood so that changes in cognition over the lifecourse could be investigated. The information sheet informed potential participants that individuals with a range of scores on the cognitive assessments conducted at age 50 had been invited to participate.

Potential participants were told that completing the assessments would take around 90 minutes, that they would need to travel to the Behavioural and Clinical Neuroscience Institute (BCNI) in Cambridge and that appointments could be arranged between 09:30 and 20:00 on Monday to Friday and between 10:00 and 17:00 on Saturdays and Sundays.

It was also emphasised that:

1) Participation in the study was entirely voluntary and would not have any impact on further involvement in the National Child Development Study.
2) Any part of the assessment session could be skipped if wished and that the session could be ended at any point without having to provide any form of explanation.
3) The researcher conducting the tests would be unable to provide study members with any feedback on their performance.
4) The results of the tests would never be stored with personal details (names, addresses etc).
5) Travel expenses would be paid, but no other payments would be made.

The invitation letter requested that participants who were interested in participating in the study contacted either the BCNI researcher or CLS to arrange an appointment. It was also explained that after a short period, those who had not telephoned to arrange an appointment would be contacted by the research team, by phone, to see if they were interested in taking part.

Copies of the invitation letter and information sheet can be found in Appendix B and Appendix C.

4.2 Serial numbers

Each case identified as eligible to be invited to participate in the pilot study was allocated an unique serial number (UIBID) which was distinct from the serial number which identifies individuals on the CLS database (CLS Serial) and distinct from the serial number which identifies individuals in the data files from previous sweeps of the National Child Development Study which have been deposited at the UK Data Archive (NCDSID). The file linking UIBID and NCDSID

was held at CLS and not shared with BCNI. All materials sent to the cohort member included UIBID.

4.3 Batches

NCDS cohort members have been involved in the study for over 50 years and as such are well used to participating in research projects. There is a high degree of loyalty amongst those who are still participating and consequently response rates to the follow-up sweeps are typically high (for example 85% of those invited to participate in the age 50 follow-up agreed to do so). However, cohort members are used to being visited (or telephoned) by interviewers; they are not used to being asked themselves to travel and they are not used to intensive batteries of neuro-psychological assessments. The research team therefore predicted that participation rates for this particular project would be lower than those typically achieved in the core follow-up sweeps, but quite how much lower was not known. It was also expected that participation rates might vary across the three groups.

As mentioned above, the aim was to achieve a final sample size of 60 assessments (20 assessments from each group). In order to gauge potential participation rates study members were invited to participate in the research in batches. The first batch of individuals to be invited was comprised of 90 individuals (30 individuals from each group – 15 men and 15 women). Where possible the cases invited from the two control groups were the cases that had been paired with an individual from the experimental group.

A further two batches of invitation letters were sent out later in the fieldwork period. Decisions on the size and composition of the two later batches, in terms of group status and sex, were made on the basis of the number of assessments completed from previous batches.

The composition of each batch in terms of group status and sex is shown in Table 4.1 below. The dates on which letters were mailed are also shown.

Table 4.1 – Batch composition and dates of mailings

Batch	**Date letters mailed**	**Experimental 'decline' group**			**Control group 1 - 'Consistent high scorers'**			**Control group 2 – 'Consistent low scorers'**			**Total**
		M	F	Total	M	F	Total	M	F	Total	
1	17/3/2010	15	15	30	15	15	30	15	15	30	**90**
2	14/5/2010	6	9[4]	15	2	1	3	7	8	15	**33**
3	03/6/2010	0	0	0	0	0	0	6	4	10	**10**
Total		**21**	**24**	**45**	**17**	**16**	**33**	**28**	**27**	**55**	**133**

[4] In total there were only 15 women in the 'Cambridge' area who were identified as obtaining a combined score on the two word-list recall tasks at age 50 which was more than 1 standard deviation below the score which was predicted from their age 11 General Ability Test score. All of these 15 women had been invited to participate in the study in the first batch of letters. In order to ensure that the final sample included sufficient numbers of women showing signs of decline it was necessary to include the 9 women in the target area who achieved a combined score on the two-word list recall tasks at age 50 which were between 0.85 and 1 standard deviations below their predicted scores.

4.4 Making appointments

Appointments were recorded by the research team on a calendar which was shared between CLS and BCNI on a secure portal which was password protected. Once appointments had been arranged a confirmation letter was sent to participants confirming the date and time of the appointment and providing directions to the research centre (including a number of maps). Confirmation letters were generally sent by post, but were sent by email in cases where the appointment was to take place very shortly after telephone contact.

Only 9 (out of 133) invited individuals contacted the research team in response to the initial letters, meaning it was necessary for the research team to attempt to contact the majority of potential respondents themselves.

Telephone follow-up calls began to the first batch of invited participants (n=90) several weeks after the initial mailing. A number of individuals claimed not to have received the mailing and as such requested that invitation letters and information sheets were re-sent. Other individuals suggested that they did remember receiving the mailing, but had subsequently forgotten about it.

For the later batches, the strategy was changed so that invitation letters were followed up by a telephone call a few days after the mailings had been posted.

A 'logging' file was maintained by the research team which kept a record of the current status of each individual who had been invited to participate (e.g. assessments conducted, appointment arranged, refused to participate, not contacted etc.) so that the research team knew which individuals needed to be contacted. The logging file was also used to keep a record of the dates, times and outcomes of all telephone calls which were made.

Although telephone calls were initially made during office hours it was later found that calling during the evening was far more productive and led to a much higher rate of contact.

During the telephone calls potential participants were given an opportunity to ask questions about the study and what participating would involve.

In total 353 telephone calls were made by the research team.

Individuals who it was not possible to contact via the telephone were also emailed (if email addresses were held by CLS). In total, 8 emails were sent but no responses were received.

4.5 Conducting the assessments

All assessments were conducted between March and June 2010. Around four in ten assessments (42%) of the assessments were conducted at weekends.

Assessments were conducted in a 'testing room' at the BCNI by a BCNI researcher. The researcher had no knowledge of the 'group status' of the participants.

On arrival at the research centre participants were provided with another opportunity to ask the researchers any questions they had about what participating in the study would involve.

Once any questions had been answered participants were asked to sign a consent form on which they signed to declare that:

- They had read the invitation letter and invitation sheet.
- They had discussed any outstanding questions with the researcher and wished to participate in the study.
- They understood that participation was entirely voluntary and that they could stop the session at any time without giving any reason for doing so.
- They understood that the researcher will **not** be able to provide any feedback on performance in the assessments.
- They understood that all information provided will be treated in the strictest confidence and used for research purposes only.

Once the consent form had been signed the researcher began conducting the assessments. The order in which these assessments were conducted was as follows:

1. Affective Go / No-go (AGN)
2. Word-list recall
3. Animal naming
4. Letter cancellation
5. Delayed word-list recall (1)
6. Rapid Visual Processing (RVP)
7. Delayed word-list recall (2)
8. Paired Associates Learning (PAL)
9. Graded Naming Test (GNT)
10. Cambridge Gambling Task (CGT)
11. Questionnaire

The computerised tasks were conducted using a touch-screen PC. The scoring of the repeated cognitive assessments which had previously been conducted as part of the age 50 NCDS core survey was done using a modified version of the same paper booklet that had previously been used.

4.6 Thank you letters and payment of expenses

At the end of the session the researcher provided participants with a form to claim back travel expenses (with a freepost envelope which could be used to return the form to CLS). Once the expense claim had been processed, participants were sent a cheque alongside a letter which thanked them for participating in the study.

4.7 Insurance

The pilot study had budgeted for the purchasing of insurance to cover participants whilst they were being assessed (£33.50 per respondent). However, in practice it transpired that the insurance cover already held by the University of Cambridge provided adequate cover.

5. Response

In total, 133 individuals were invited to participate. Response is summarised below in Table 5.1. Response is broken down by group status and by sex.

Table 5.1: Summary of study outcomes by group status and sex.

	Overall		Experimental group		Control group 1		Control group 2		Men		Women	
	n	%	n	%	n	%	n	%	n	%	n	%
Assessments completed	**45**	**33.8**	**16**	**35.6**	**16**	**48.5**	**13**	**23.6**	**26**	**39.4**	**19**	**28.4**
Broken appointment	8	6.0	3	6.7	1	3.0	4	7.3	2	3.0	6	9.0
Refusals	57	42.9	21	46.7	9	27.3	27	49.1	26	39.4	31	46.3
No telephone contact	12	9.0	3	6.7	3	9.1	6	10.9	6	9.1	6	9.0
Contacted by phone but no appointment booked	11	8.3	2	4.4	4	12.1	5	9.1	6	9.1	5	7.5
Total issued	**133**		**45**		**33**		**55**		**66**		**67**	

Overall, assessments were conducted with 45 individuals (34% of those invited). Refusals accounted for the greatest proportion of non-response with 57 (43%) declining to take part when contacted by telephone. There were an additional 8 cases (6%) where appointments were arranged and then broken (where it was not possible to rearrange a further appointment) and 12 cases where it was not possible to make contact with the invited individual by phone (either because the telephone numbers that were held by CLS had become disconnected, the individual had moved and not informed CLS of their new telephone number, the telephone was never answered, or the telephone was only ever answered by another person such as a family member). These cases were all tried on repeated occasions at different times of the day and whenever it was possible messages were left on answer-phones and with family members asking them to make contact to discuss participating in the study.

Finally, there were a number of cases where contact was made by telephone and the individuals expressed interest in participating in the study, but could not be persuaded to arrange an appointment at that particular time. These cases typically asked to be called back at a later point to give them more time to think about whether and when they would be prepared to participate. Many of these cases were eventually assessed, but there were 11 cases who either repeatedly asked to be called back or it was not possible to re-contact them.

Table 5.1 clearly shows that participation rates varied across the three groups with members of control group 1 being more likely to agree to participate than members of the other two groups and members of control group 2 in particular. This variation can be attributed primarily to

differing levels of refusal rather than any other form of non-response; the control group 2 refusal rate was almost double the control group 1 refusal rate (49% compared with 27%).

Individuals that refused to participate were asked why and the overwhelming majority suggested that it was because they did not have time or it was too difficult for them to travel to Cambridge to participate. Other reasons for refusal included ill-health, lack of interest and a dislike of these kinds of tests although these reasons were cited by very small numbers.

There was no difference between the three groups in terms of the distance individuals lived from the research centre or levels of car ownership which suggests that even though a only a very small number of individuals stated that they were uninterested in this kind of research, or that they disliked these kinds of tests, it is possible that amongst the groups with lower levels of cognition these reasons were more common than explicitly mentioned.

The difficulties experienced in recruiting members of control group 2 and the experimental group meant that it was necessary to issue additional cases in order to ensure that the target number of assessments was achieved in each group (or at least approached).

Table 5.1 also shows that women were less likely to participate than men.

Table 5.2 below shows how response varied according to the distance that potential participants would need to travel to the research centre. There is a clear difference in participation rates between those asked to travel up to 20 miles and those asked to travel further. Just over half (51%) of those asked to travel up to 20 miles agreed to participate compared with around three in ten who were asked to travel either 21-40 miles (28%) or over 40 miles (32%).

Table 5.2: Survey outcomes by distance from research centre

	Overall		**0-20 miles**		**21-40 miles**		**Over 40 miles**	
	n	**%**	**n**	**%**	**n**	**%**	**n**	**%**
Assessments completed	**45**	**33.8**	**12**	**52.2**	**15**	**27.8**	**18**	**32.1**
Broken appointment	8	6.0	2	8.7	3	5.6	3	5.4
Refusals	57	42.9	7	30.4	26	48.1	24	42.9
No telephone contact	12	9.0	2	8.7	5	9.3	5	8.9
Contacted by phone but no appointment booked	11	8.3	0	0.0	5	9.3	6	10.7
Total issued	**133**		**23**		**54**		**56**	

6. Feedback from participants

Travelling to a research centre to complete an intensive battery of neuro-psychological assessments is very different from anything which cohort members have been asked to do previously. It was therefore important to provide participants with an opportunity to reflect on their experience of taking part in the study as their views could then be taken into account were a similar study to be planned in the future. If participants were to report that they had found completing such a lengthy battery of assessments to have been overly burdensome, then were a larger study to be planned for the future, this would need to be addressed or there could be a risk that participation could affect future participation in the core sweeps of the cohort study.

Feedback was gathered via a series of questions included in the self-completion questionnaire administered at the end of the assessment session.

6.1 Enjoyment of participating

Table 6.1 indicates below that participants were overwhelmingly positive about their experience of taking part in the study. Participants were asked to rate how much they enjoyed taking part in the study using a scale between 0 and 10. The mean response was just under 9 and the most common response was 10. One might have expected that enjoyment of the study would have varied across the three groups, with groups with lower levels of cognition being less likely to enjoy participating on the basis they would be more likely to have found the assessments difficult. However, Table 6.1 shows that this was not the case and members of control group 2 were actually marginally more positive than the other two groups; nine out of the 13 control group 2 cases who were assessed gave the maximum rating of their enjoyment.

It was hypothesised earlier that difficulties in recruiting individuals from the lower cognition groups was in part likely to stem from a dislike of these kinds of assessments. However, the positive feedback received from those that did participate suggests either that those who were recruited were a particular group of individuals who do enjoy these kinds of assessments or that the format of the assessments is such that even those who may have been concerned about being assessed actually found the experience to be enjoyable in the end.

Table 6.1: Participant feedback on how much enjoyed taking part in the study (0-10)

Group	Min	Max	Mean	N
Experimental	7	10	8.94	16
Control group 1	6	10	8.56	16
Control group 2	7	10	9.46	13
All	**6**	**10**	**8.96**	**45**

6.2 Advance Materials

Participants were also asked how well they thought the advance materials (the invitation letter and information sheet) explained what taking part in the research would involve (again on a scale between 0 and 10). Participants were again typically very positive with the mean rating

being 8.53 and with little variation between the three groups (see Table 6.2). There was however one participant who gave a low rating of 4 out of 10 and three participants who gave a rating of 5 out of 10. These four individuals were all from the two groups with lower levels of cognition which could perhaps indicate that improvements could have been made to the advance materials to ensure that they were understandable to all.

Table 6.2: Participant feedback on how well advance materials explained what taking part in the research would involve.

Group	Min	Max	Mean	N
Experimental	4	10	8.13	16
Control group 1	7	10	8.69	16
Control group 2	5	10	8.85	13
All	4	10	8.53	45

6.3 Whether cohort member would be prepared to take part in a similar study in the future

The high level of enjoyment which participants reported about their experience of taking part in the study was reflected in the fact that when asked whether they would participate in a similar research project in the future (if asked to do so) that the majority (82%) said they would be very likely to do so and the remainder said they would be fairly likely to do so. As Table 6.3 below shows over three quarters of all the groups reported that they would be very likely to participate in a similar study if asked to do so and amongst control group 2 over nine in ten (92% or 12 out of 13) reported that they would do so.

Table 6.3 : Participant feedback on whether they would take part in a similar study in the future (if asked to do so)

Group	Very likely	Fairly likely	Not very likely	Not at all likely	N
	%	%	%	%	
Experimental	75.0	25.0	-	-	16
Control group 1	81.2	18.8	-	-	16
Control group 2	92.3	7.7	-	-	13
All	82.2	17.8			45

6.4 Ease of travel to the research centre

Participants were asked to assess the journey that they had to make to reach the research centre in terms of whether it was easy or difficult. Table 6.4 shows that even amongst those who had needed to travel long distances only a small proportion expressed any negativity in terms of their journey.

Table 6.4: Participant feedback on ease / difficulty of journey to research centre

Distance from research centre	Very easy	Easy	Fairly easy	Fairly difficult	Difficult	Very difficult	N
	%	%	%	%	%	%	
0-20 miles	25.0	25.0	25.0	8.3	8.3	8.3	12
21-40 miles	46.7	20.0	20.0	13.3			15
Over 40 miles	33.3	38.9	16.7	11.1			18
All	35.6	28.9	20.0	11.1	2.2	2.2	45

6.5 CANTAB Assessments

Finally, participants were also asked which of the 5 CANTAB assessments they had enjoyed the most and which they had enjoyed the least. Responses are summarised below in Tables 6.5 and 6.6.

Table 6.5: Participant feedback on which CANTAB assessments enjoyed the most

	AGN	RVP	PAL	GNT	CGT	All equally	None	N
	%	%	%	%	%	%	%	
All	13.3	15.6	33.3	24.4	42.2	33.3	-	45
Experimental	6.2	18.8	25.0	18.8	31.2	37.5	-	16
Control group 1	25.0	25.0	50.0	43.8	62.5	12.5	-	16
Control group 2	7.7	-	23.1	7.7	30.8	53.8	-	13
Men	3.8	15.4	30.8	23.1	53.8	34.6	-	26
Women	26.3	15.8	36.8	26.3	26.3	31.6	-	19

Note: Participants were able to report that they enjoyed more than one task the most

Table 6.6: Participant feedback on which CANTAB assessments enjoyed the least

	AGN	RVP	PAL	GNT	CGT	All equally	None	N
	%	%	%	%	%	%	%	
All	6.7	37.8	28.9	6.7	2.2	15.6	15.6	45
Experimental	6.2	31.2	37.5	6.2	6.2	18.8	18.8	16
Control group 1	12.5	43.8	12.5	6.2	-	18.8	18.8	16
Control group 2	-	38.5	38.5	7.7	-	7.7	7.7	13
Men	-	42.3	23.1	7.7	3.8	15.4	15.4	26
Women	15.8	31.6	36.8	5.3	-	15.8	15.8	19

Note: Participants were able to report that they enjoyed more than one task the least

Overall, the assessment which was enjoyed the most was the Cambridge Gambling Task (CGT) which over four in ten (42%) reported they enjoyed. The CGT was particularly enjoyed by men and by members of control group 1. The second most popular assessment was the Paired Associates

Learning test (PAL) which was enjoyed most by a third (33%). This assessment (which is an assessment of memory) was enjoyed far more by those with higher levels of cognition (members of control group 1) than those with lower levels of cognition. Overall, a third (33%) reported that they enjoyed all the assessments equally, but members of control group 2 were particularly likely to report that this was the case (54%) and members of control group 1 were far less likely to choose this option.

The assessment which was disliked the most was the Rapid Visual Processing test (RVP) with just under four in ten reporting that they enjoyed this test the least (38%). Although the PAL test was enjoyed the most by a third of participants it was also enjoyed the least by a similar proportion (29%) and this was again particularly apparent amongst the two groups with lower levels of cognition as measured at age 50.

7. Results

In this section, we present a brief overview of the results of the assessments which were repeated assessments from the NCDS age 50 survey. A full discussion of the results of the CANTAB assessments is provided by Knight et al. (2010).

Table 7.1 presents the mean scores achieved by each of the three groups in each assessment which was completed both as part of the age 50 survey and again as part of the Understanding Individual Behaviour pilot. Variation in performance between the three groups is examined using one-way analysis of variance with a Tukey's Honestly Significant Differences (HSD) test for post-hoc comparisons. The scores at the two time-points are compared using a paired samples t-test[5].

The clearest differences between the three groups were in performance in the word-list recall task. This is unsurprising as it was performance in this assessment at age 50 that was used to define the three groups in the first place (see Section 2). As would be expected therefore, there are significant differences in means scores achieved at the time of the age 50 survey between the decline group and the consistent high scorers (control group 1) and between the two control groups. The methodological problem relating to the construction of control group 2 (which is described in Section 2) leads also to a significant difference (p=0.025) between the mean scores achieved by the decline group and control group 2 which would not ideally have been the case. At the time of the re-test (approximately two years later) the only significant difference between groups was between the decline group and the consistent high scorer group.

The' decline' group and the consistently low scoring group (control group 2) both performed significantly better in the re-test than in the original assessment at age 50. On average, the consistently low scoring group could recall two more words at the time of the re-test than they had done previously which represents a substantial improvement.

For several 'decline' or 'consistent low scorer cases' the improved performance was of such a magnitude that if the pilot study scores had been used to select cases they would have not have been defined as belonging to these groups. There are two likely explanations for this improvement. Firstly, the pilot study assessments were conducted in a lab-setting and the age

[5] Analyses are based on 42 cases. Three cases are excluded because of health reasons which would likely have impacted upon performance.

50 assessments were conducted in respondents' homes. The lab-setting provides an environment which is optimum for conducting these kinds of assessments as distractions are kept to an absolute minimum. Secondly, it is probable that some proportion of the improvement can be explained by practice effects. The English Longitudinal Study of Ageing included the same word-list recall tasks in its first two waves which were conducted two years apart (the same interval as between the age 50 survey and the pilot study) and it was found that a significant proportion (40%) performed better in the second set of assessments than the first (Huppert et al, 2006) and previous studies have also demonstrated practice effects on these kinds of assessments lasting around two years (Rabbitt et al., 2001).

The only other significant difference between the three groups was found on the animal naming task where at the time of the re-test the consistently high scorers (control group 1) could recall a significantly greater number of animals ($p=0.008$) than the consistently low scorers (control group 2). There were no significant differences between the animal naming scores or the letter cancellation scores achieved at the two time points.

Table 7.1 Group means for GAT, word recall test, PAL and RVIP CANTAB outcome measures.

		Group Means			Analysis of Variance		Tukey's HSD Post Hoc Comparisons			Paired-sample t-test (Sig)		
		Mean Decline	Mean control 1	Mean control 2	F	Sig.	DEC vs CTL1	DEC vs CTL2	CTL1 vs CTL2	Decline	Control 1	Control 2
Immediate + Delayed wordlist Recall	Age 50	8.13	12.29	9.42	45.532	0.000**	0.000**	0.025*	0.000**	0.024*	0.433	0.019*
	UIB Retest	9.44	12.79	11.42	6.264	0.004**	0.003**	0.129	0.385			
Animal Naming	Age 50	23.06	22.64	20.25	0.783	0.464	0.981	0.466	0.592	0.889	0.277	0.805
	UIB Retest	23.25	25.43	19.92	5.116	0.011*	0.374	0.129	0.008**			
Letter Cancellation Speed (Total letters scanned in 60 seconds)	Age 50	304.50	332.50	331.92	0.577	0.566	0.618	0.654	1.000	0.807	0.225	0.199
	UIB Retest	308.94	306.86	310.08	0.008	0.993	0.996	0.999	0.992			
Letter Cancellation Accuracy (Number of target letters missed)	Age 50	3.38	3.86	6.25	2.379	0.106	0.929	0.106	0.223	0.492	0.543	0.089
	UIB Retest	4.56	3.21	4.17	0.347	0.709	0.694	0.971	0.853			
N		16	14	12								

Analysis is based on 42 cases rather than 45. 3 cases were excluded from analysis because of health reasons which would likely have impacted upon performance.

** = p<0.01, **=p<0.05

8. Lessons learned

The pilot study sought to assess the feasibility of inviting purposively selected sub-samples of cohort members from a British Birth Cohort Study to participate in an intensive battery of neuro-psychological assessments. The study was small in scale and conducted in one fairly tightly defined geographical area, but consideration may at some stage be given to conducting a larger scale study of a similar nature so this final section of the report summarises some of the key lessons which were learned from the experience of conducting the pilot study.

8.1 Low response rate

As discussed in Section 5 the response rate was low, with only a third of those invited to participate agreeing to do so. If a larger study were to be planned which sought to ensure that findings were representative of whichever group was being studied in the population, then steps would need to be taken to increase response rates significantly.

The most common reason for refusal by far was the distance that potential participants were being asked to travel (and the time that this would take). Potential participants were asked to travel up to approximately a round-trip of 130 miles. Section 4 highlighted the fact that levels of participation amongst those asked to travel over 20 miles were considerably lower than those asked to travel shorter distances.

It seems therefore important that any future study should seek to reduce the distance which potential participants are asked to travel. The equipment used to conduct these kinds of assessments is portable and so travel burden could be eliminated entirely by conducting the assessments in respondents' homes. This would likely be more expensive in terms of fieldwork costs, but would likely pay dividends in terms of boosting response rates. However, a disadvantage of this approach would be that the home setting does not always provide the optimum conditions for conducting these kinds of assessments (e.g. the telephone can ring, visitors can arrive, the television can be on etc.). Gains in participation rates may therefore be offset somewhat by a reduction in the quality of data collected.

An alternative approach would therefore be to increase the number of research centres within a particular area so that, for example, potential respondents were not asked to travel more than 20 miles. However, it must be remembered that in the pilot study, even amongst those asked to travel less than 20 miles the response rate was still only just over 50%. It is difficult to imagine that it would be practical to set up sufficient research centres to ensure that the maximum distance participants were asked to travel was considerably less than this (other than in large urban areas).

Section 5 also highlighted that response rates were lowest amongst the groups with lower levels of cognition. It was hypothesised that this may have been related to a dislike or lack of interest in these kinds of assessments amongst this group. In a future study, it would be necessary to take steps to engage this group. One strategy which could potentially boost participation amongst this group (and other groups also) might be to consider the use of incentives. Incentives have not typically been used on the cohort studies, primarily because participation rates have sufficiently high that they have not been considered necessary.

Participation in a study such as this though, particularly for those asked to travel longer distances, is particularly burdensome. It may be that the use of incentives would increase the inclination of participants to take part.

8.2 Recruitment strategy

The advance materials sent to potential respondents asked them to telephone or email to make an appointment and then advised that if no response was received they would be telephoned by a member of the research team to see if they wanted to participate. The number of invited individuals who telephoned to make an appointment themselves was very small meaning that the research team had to attempt telephone contact with the majority of potential participants. Even for a small pilot study this was resource-intensive as in many cases multiple telephone calls were required to make contact. A larger study would benefit from a dedicated individual or team being allocated to recruitment. This was beyond the scope of the pilot study, but with more resources it might be possible to take a more systematic approach to making phone calls so, for example, rigorously ensuring that individuals are telephoned at different times of day. This approach might have moderately increased participation and reduced the number of individuals who were not contacted (either at any stage during fieldwork or after requesting to be called back at a later date)

Telephone contact was not attempted with those invited as part of the first batch of letters for several weeks in order to assess the proportion of cases that would make contact to arrange appointments themselves. This was found to be problematic as many individuals claimed either not to have received the original mailing or to have forgotten about it and therefore requested that mailings be resent causing delay. As the proportion of invited cases calling to make appointments themselves was so minimal, then in future it would be advisable to ensure that all invitation letters are swiftly followed up by a phone call from the research team.

In a future study, it would also be advisable to consider the use of telephone reminders a couple of days in advance of appointments. Once appointments had been arranged confirmation letters were sent containing the details of the appointment, but there were a significant number of occasions throughout fieldwork when appointments were broken. This was particularly frustrating at weekends when the researcher had made a special journey to the research centre. Telephone contact was attempted with all those who did not arrive for their appointments and in many cases it was possible to re-arrange them as respondents had simply forgotten. The use of reminders would hopefully reduce this problem.

8.3 Payment of travel expenses

As mentioned previously, participants were given a travel expenses claim form at the end of the testing session which needed to be sent to CLS for processing. The information sheet explained to participants that processing expenses would take several weeks. It is quite possible that this may have been off-putting to some potential participants, particularly those on lower incomes. On being telephoned by the research team one participant explained that whilst they were very interested in part they felt unable to do so because they were unable to afford to pay the £40 return train fare to Cambridge upfront. It may have been the case that other potential participants felt similarly, but did not wish to admit this. In this particular instance, it was

possible to arrange for travel expenses to be paid upfront and the individual concerned was therefore able to participate. In a future study, it might be that explicitly mentioning the possibility of travel expenses being paid in advance would increase the proportion willing to participate. However, this approach would of course run the risk of people claiming travel expenses and then not actually participating.

8.4 Preference for weekend testing

Just over four in ten assessments were conducted at weekends. The majority of participants (76%) worked full-time and amongst this group half (50%) of the assessments were conducted at weekends (compared with 18% of assessments conducted with those not working part-time). This emphasises the need to provide flexibility to participants as if the time slots made available for testing had been restricted, it is likely that recruitment would have been less successful.

8.5 Respondent concerns

A number of participants expressed concerns about their cognitive ability or worries about future decline in cognitive ability to the researcher. Some of these concerns were related to performance in the assessments. All assessments in the pilot study were conducted by the same researcher who typically dealt with these concerns by reassuring participants that the assessments employed are not diagnostic tools and a perception that they have performed poorly should not in itself be a cause for concern. Any future study would need to ensure that those conducting the assessments were able to deal with these kinds of issues. Increasing the scale of the study would require an increase in the number of assessors meaning that those conducting the assessments might become less specialist and if home visits were to be conducted it could be feasible for the assessments to be conducted by the kinds of research agency interviewers who typically conduct the interviews on the cohort studies. If this were to be the case, it would need to be ensured that they were well trained in how to deal with these kinds of concerns.

8.6 Positive feedback

Despite the difficulties experienced in terms of recruitment, feedback from those who did take part was on the whole extremely positive. In general, participants reported that they enjoyed the study very much, that they thought the advance materials prepared them well and that they would take part in a similar research study if asked to in the future. This feedback could hopefully be used to encourage other study members to participate in any future study.

9. References

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Rabbitt, P., Diggle, P., Smith, D., Holland, F. and McInnes, L. (2001), 'Identifying and separating the effects of practice and of cognitive ageing during a large longitudinal study of elderly community residents', Neuropsychologia, 39(5), pp. 32–543.

Appendix A – Questionnaire

National Child Development Study – Understanding Individual Differences in Learning and Memory - Questionnaire

Instructions given verbally by researcher to participants

"The final part of the session involves you completing a short self-completion computerized questionnaire similar to surveys you have completed in the past. You may read and answer the questions by yourself without me in the room or alternatively, if you wish, I can assist you. Most of the questions are about your health but we also ask you to provide some feedback about your experience of coming here today to participate in this research. The final questions are about imaging studies and I will provide you with some further details on this.

Each question will appear on the screen one at a time. There will be clear instructions on how to answer each question. When you have read the question, please indicate your response either by touching the screen or by clicking the mouse over the answer options, then press the 'next' button. (INTERVIEWER DEMONSTRATE).

On some questions you will be only be able to give one answer, other questions will allow you to give several answers. Once you have answered a question you will not be able to go back and change your answers. Occasionally you might be asked to answer a question in your own words. If you do not wish to answer a question please press 'no response' option, and if wish to stop the questionnaire at any time please press the 'exit' option.

If you have any questions please ask me. Would you be willing to have a go?"

(The first screen that participants will see will be an example page so that the researcher can demonstrate how the questions should be answered, i.e. touch screen or using the mouse to click buttons. The second screen presented to the participants will have fields in which the research provides details such as the participants name, study ID, date of birth and whether the participants will: self-complete the questionnaire independently; do the self-completion questionnaire with the researcher assistance; or has refused to do self-complete questionnaire. The third screen will present the first question in the questionnaire.)

We would first like to ask you a number of questions about your general health.

Q1 In general, would you say your health over the last 12 months has been….

SELECT ONE ANSWER ONLY

1. Excellent
2. Very good
3. Good
4. Fair
5. Poor

IF Q1 = 5 ASK Q2

Q2 Do you rate your health as poor owing to:

SELECT ALL THAT APPLY

1. A long standing illness/condition
2. A recent acute illness
3. A recent accident
4. Recovering from an operation
5. Recent stress, e.g. divorce, bereavement or unemployment
6. Other

Q3 Compared to one year ago, how would you rate your health in general now?

SELECT ONE ANSWER ONLY

1. Much better than one year ago
2. Somewhat better than one year ago
3. About the same as one year ago
4. Somewhat worse than one year ago
5. Much worse than one year ago

We would now like to ask you a few questions about specific health problems.

Q4. Do you currently, or have you ever suffered from any of the following health conditions?

SELECT ALL THAT APPLY

1. Parkinson's disease
2. Multiple sclerosis
3. Alzheimer's disease
4. Diabetes
5. Stroke
6. Heart disease
7. Head trauma
8. Another condition affecting the nervous system, e.g. epilepsy
9. No – none of the above.

IF Q4 = 8 ASK Q5

Q5. Would you mind telling us what condition you have?

(open question)

Q6. Do you ever worry about developing any of the following conditions?

SELECT ALL THAT APPLY

1. Parkinson's disease
2. Multiple sclerosis
3. Alzheimer's disease
4. Diabetes
5. Stroke
6. Heart disease
7. Other
8. No – none of the above

IF Q6 = 1-7 ASK Q7

Q7. Is this because.....

SELECT ALL THAT APPLY

1. There is a history of this (these) condition(s) in your family?
2. You have provided support for a family member or friend who has/had this/these condition(s)?
3. Other

Q8. Have you consulted your GP or a psychiatrist about feeling depressed or anxious in the past 12 months?

SELECT ONE ANSWER ONLY

1. Yes
2. No

Q9. Have you been prescribed any antidepressant medication in the last 12 months

SELECT ONE ANSWER ONLY

1. Yes
2. No

IF Q9 = 1 ASK Q10

Q10. Are you still taking the medication?

SELECT ONE ANSWER ONLY

1. Yes
2. No

Q11. How often do you have an alcoholic drink of any kind? Would you say you have a drink.....

SELECT ONE ANSWER ONLY

1. On most days
2. 2 to 3 days a week
3. Once a week
4. 2 to 3 times a month
5. Once a month
6. Less often or only on special occasions
7. Never nowadays
8. Never had an alcoholic drink

IF Q11 = 1-6 ASK Q12

Q12. How often do you have six or more drinks on one occasion?

SELECT ONE ANSWER ONLY

1. Never
2. Less than monthly
3. Monthly
4. Two to three times per week
5. Four or more times a week

We would also like to ask you about any health issues which could have potentially interfered with you performing our computerised cognitive tasks.

Q13. Are you colour blind?

SELECT ONE ANSWER ONLY

1. Yes
2. No

Q14. Do you currently have any problems with your hearing? E.g. do you have a hearing aid?

SELECT ONE ANSWER ONLY

1. Yes
2. No

Q15. Do you currently have any problems with moving your fingers or hands which may prevent you from pressing buttons on computer quickly, e.g. rheumatism?

SELECT ONE ANSWER ONLY

1. Yes
2. No

Now we'd like to get a few details about your current mental activity routines

Q16. Do you currently do any of the following mental activities?

SELECT ALL THAT APPLY

1. Crossword puzzles and other puzzles such as Sudoku.
2. Brain training exercises or games like 'Brain age' by Nintendo
3. Read or write classic, scientific or educational literature
4. Do mathematical related activities
5. Do educational courses (e.g. IT, Open University or foreign language courses)
6. Other mental activities, e.g. chess
7. No – none of the above,

IF Q16 = 1-6 ASK Q17 AND Q18

Q17. You said that you do one of the following mental activities:

Which one do you do most often:

1. Crossword puzzles and other puzzles such as Sudoku.
2. Brain training exercises or games like 'Brain age' by Nintendo
3. Read or write classic, scientific or educational literature
4. Do mathematical related activities
5. Do educational courses (e.g. IT, Open University or foreign language courses)
6. Other mental activities, e.g. chess

Q18. How often do you do this activity?

SELECT ONE ANSWER ONLY

1. Every day
2. 4-5 days a week
3. 2-3 days a week
4. Once a week
5. Once a month
6. Two or three times a month
7. Less often

We realise that this taking part in this research has been a little different from anything we have asked you to do previously. This research has involved a very small number of study members but we may consider running this kind of research again with a larger number of study members so we would be very interested to hear how you have felt about being involved.

Q19. Do you feel that the letter and information sheet we sent you explained adequately what taking part in this research would involve?

PLEASE SLIDE THE POINTER TO INDICATE YOUR OPINION

Not at all **Very much**

Q20. Do you feel that travelling here today was.....

SELECT ONE ANSWER ONLY

1. Very easy
2. Easy
3. Fairly easy
4. Fairly difficult
5. Difficult
6. Very difficult

Q21. How much have you enjoyed being involved in this research project?

PLEASE SLIDE THE POINTER TO INDICATE YOUR OPINION

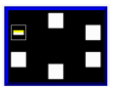
Not at all **Very much**

Q22. Which of the cognitive tasks did you enjoy undertaking the most?

SELECT ALL THAT APPLY

1. Graded naming test (naming objects test)

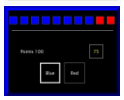
2. Paired Associates Learning (Patterns within boxes)



3. Rapid Visual Information Processing task (Number sequence task)

4. Affective Go/No go task (Word task)

5. Cambridge Gambling Task (gambling points task)



6. All equally

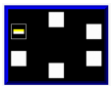
7. None

Q23. Which of the cognitive tasks did you least enjoy?

SELECT ALL THAT APPLY

1. Graded naming test (naming objects test)

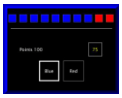
2. Paired Associates Learning (Patterns within boxes)



3. Rapid Visual Information Processing task (Number sequence task)

4. Affective Go/No go task (Word task)

5. Cambridge Gambling Task (gambling points task)



Q24. If you were asked to participate in a similar research project again in the future how likely would you be to do so?

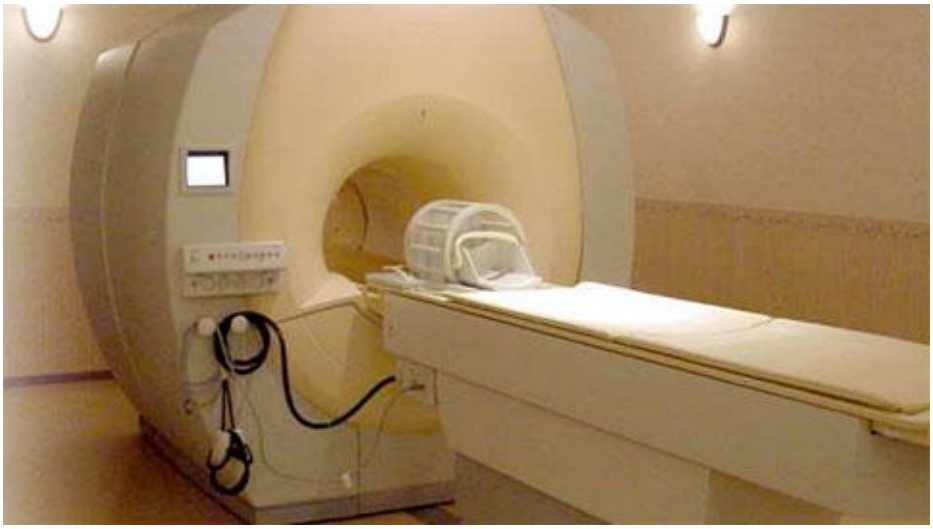
SELECT ONE ANSWER ONLY

1. Very likely
2. Fairly likely
3. Not very likely
4. Not at all likely

Researcher returns to testing room.

At some point in the future CLS might consider asking members of the National Child Development Study to participate in an fMRI research study. We would like to ask you a few questions about whether you might be prepared to participate in this kind of study.

Here is a picture of an fMRI scanner.



Description given verbally by researcher to participants

fMRI is a commonly used imaging technique which enables researchers to study the brain and how it is working while people are performing certain tasks. The person being scanned lies on a couch in a powerful tubular magnet for at least half an hour while the brain is scanned. Most people find the scan easy to tolerate although some people can find it noisy and slightly claustrophobic at the beginning.

Q25. Have you ever been scanned in an MRI scanner and if so was it for clinical diagnosis and/or as part of a research?

SELECT ONE ANSWER ONLY

1. No
2. Yes, for clinical diagnosis
3. Yes, as part of a research study
4. Yes, both for clinical diagnosis and as part of a research study
5. Don't know

Like faces, brains come in all shapes and sizes, so that there are many normal variations of what the scan shows. It is possible, though, that a scan could reveal something that suggests that there could be a more serious problem. This is estimated to happen in about one in forty scans.

However, for the great majority of people who are scanned in research studies no significant problems will be observed.

People may differ in their views about feedback from research fMRI studies. Some people would like to know if their scan result reveals anything that might suggest they might have a serious problem, regardless of whether this may turn out to be treatable or not. Others would prefer only to know if the scan revealed clear evidence of a serious problem that is likely to be treatable. Some do not want any feedback whatever the scan may reveal. They prefer, should they develop a serious condition, to wait until they have symptoms and then to seek a diagnosis and treatment from a doctor at that time.

Q26. If you were asked by CLS to participate in an fMRI research study do you think you would be prepared to do so?

SELECT ONE ANSWER ONLY

1. I would not be prepared to take part in an fMRI research study
2. I would be prepared to take part in an fMRI study regardless of whether feedback was to be provided.
3. I would **only** be prepared to take part in an fMRI study which provided feedback on **all potential problems** that were observed.
4. I would **only** be prepared to take part in an fMRI study which **only** provided feedback on potential problems that were considered to be **serious and treatable**.
5. I would **only** be prepared to take part in an fMRI study which provided **no** feedback.

Q27. Please give reasons for your answer (open ended question).

Appendix B – Advance Letter

(DATE)

Dear (NAME)

National Child Development Study –

Understanding individual differences in learning and memory

Firstly, thank you for being part of the National Child Development Study for many years and for taking part in our 'Age 50' survey which took place in 2008/9. We are writing to 100 study members in and around the Cambridgeshire region to invite you to take part in a research project that we are carrying out with colleagues from the University of Cambridge.

You might recall that your last interview in 2008/9 contained a number of memory and concentration tasks. We would like you to ask you to come to a research centre at The Behavioural and Clinical Neuroscience Institute at the University of Cambridge to complete a further series of tasks which assess additional aspects of learning and memory or 'cognitive function'. The results will then allow us to investigate differences between individuals and in particular, by comparing the results with tests that you completed during childhood we will be able to examine how 'cognitive function' can change over time between childhood and later adult life.

Completing the tasks would take between an hour and an hour and a half. We would pay any travel expenses incurred by travelling to Cambridge.

An information sheet is enclosed which provides you with more information about exactly what taking part would involve. I would ask you to read this carefully.

We realise this is a little different from anything we have asked you to do before but we hope you will find it an interesting and enjoyable experience. If you would like to participate you can either call Helen Knight, the researcher from the University of Cambridge who will conduct the assessments on (01223) 333535 or Matt Brown at the Centre for Longitudinal Studies on (020) 7911 5325 to arrange a convenient time for you to visit the research centre. If we do not hear from you we may attempt to telephone you to see if you wish to take part but participation is, of course, entirely voluntary.

If you have any questions or if your address or telephone number has changed please contact us on the above number.

Many thanks for your continuing help.

Yours sincerely,

Jane Elliott

Professor Jane Elliott - Research Director (NCDS)

Appendix C – Information Sheet

INFORMATION SHEET

National Child Development Study –

Understanding individual differences in learning and memory

What is the purpose of this study?

The purpose of this study is to investigate differences between individuals in terms of learning and memory or 'cognitive function'. A number of computerised psychological tasks have been developed to measure aspects of information processing, attention, learning and memory. We would like you to complete these tasks so that we can compare the results with tests that you completed during childhood so that we can see how 'cognitive function' can change between childhood and later adult life.

What exactly will participation in the research involve?

In order to complete the assessments you will need to visit a research centre at The Behavioural and Clinical Neuroscience Institute, University of Cambridge and the session will take around an hour.

A researcher will take you through a series of assessments. This will include repeating the memory tests you performed in the Age 50 survey as well as performing new tasks which are run on a computer and are like computer games. We will also ask you to complete a short questionnaire about your current health.

When you visit the research centre for your appointment you will be asked to sign a consent form to indicate that you understand what taking part in the study will involve and that you are happy to take part.

Why have I been selected to take part?

At present we are inviting a small number of study members from in and around the Cambridgeshire region to participate. We have selected individuals with a full range of scores on the memory tasks that were included in the Age 50 survey. If this project is successful then we plan to invite a much larger number of study members from other parts of Great Britain to participate.

Do I have to take part?

Participation in this study is entirely voluntary and you do not have to participate in any part that you do not want to. You may end the session at any point without giving any reason or explanation for doing so. The choice of whether or not to participate in this study has no impact on your continued involvement with the National Child Development Study.

What will happen to the results of the research study?

The researcher will not be able to provide you with any feedback on your performance in the assessments. The results of all the assessments, along with all other information collected from you in the course of this research, will be kept strictly confidential and used for research purposes only. The results of the assessments will never be linked with your name or address.

What will happen next?

If you would like to participate you can either call Helen Knight, the researcher from the University of Cambridge who will conduct the assessments on (01223) 333535 or Matt Brown at the Centre for Longitudinal Studies on (020) 7911 5325 to arrange a convenient time for you to visit the research centre. If we do not hear from you within a couple of weeks we may attempt to telephone you to see if you wish to take part.

Once an appointment has been arranged we will send you a letter to confirm the date and time of your appointment as well as a map showing how to get to the research centre.

If you have any questions or if your address or telephone number has changed please contact us on either of the above numbers.

Where and when will the session take place?

The sessions will take place at The Behavioural and Clinical Neuroscience Institute, University of Cambridge.

Behavioural and Clinical Neuroscience Institute (BCNI)
Dept. Experimental Psychology
University of Cambridge
Downing St.
Cambridge
CB2 3EB

Appointments can be arranged at the following times:

Monday – Friday: 9.30 a.m. to 8:00 p.m.

Saturday – Sunday: 10:00 a.m. to 5:00 p.m.

Will you pay my travel expenses, (eg car mileage)?

Yes, you will be able to claim back your travel expenses. Please complete a participant expense claim form which we will provide when you visit the research centre. Please attach all original travel receipts for the round trip made for your appointment and return the form in the FREEPOST envelope provided by the researcher. You can choose whether to have your expenses paid via cheque or directly into your bank account and should receive your expenses within a month of submitting your form.

If you travel by car, motorcycle or bike you will need to let us know the number of miles covered. Our mileage rate is 40p per mile for cars, 25p per mile for motorcyclists and 20p per mile for cyclists. Please remember to keep your travel or car park ticket.

Please note that if you are using public transport we can only pay expenses for standard class travel.

I don't have any transport - will you pay for a taxi?

We are able to pay for a taxi for people who are disabled. If you are not disabled, then we will only be able to reimburse you a maximum of £10.00 towards the cost of taxis (which will be sufficient to cover the cost of travel to and from Cambridge Railway Station).

Where can I park?

If you are registered disabled, we can arrange for a parking space to be made available on the Downing site near to the BCNI. However, such bookings have to be made in advance so please make sure that the researcher who will be conducting the assessments (Helen Knight) knows you will need a parking space.

If you are not registered disabled you will need to use a local car park. A map showing the location of local car parks will be sent to you with your confirmation letter once your appointment has been arranged. Please keep your car parking ticket and complete a participant expense claim form which we will provide when you visit the research centre. Please attach the car parking ticket to the form and return in the FREEPOST envelope provided by the researcher. You can choose whether to have your expenses paid via cheque or directly into your bank account and should receive your expenses within a month of submitting your form.

Can my husband/wife/partner/other relative/friend come with me, and will you pay their travel expenses?

You can certainly have someone accompany you on the visit. However, we are only able to pay travel expenses for your companion if you are disabled and need their help to travel.

I will need to have a baby-sitter/carer to look after my children/elderly relative - will you pay for this?

Unfortunately, we do not have any funds to pay for this. We do not have crèche facilities at the assessment centre and, due to the nature of the tests, we are unable to accommodate children at the centre. However, we can offer you a different appointment time to suit you, for example evenings or at weekends.

I'm self employed/ paid by the hour - will you reimburse me for the time I lose?

Sorry, we can't to do this. However, we can offer you a different appointment time to suit you, for example evenings or a Saturday.

Will you pay me to take part?

Sorry, we can't pay you to participate, but we will be happy to reimburse you for any travel expenses.