Understanding Individual Behaviour Exploratory Networks

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

Pilot Study

Guide to Dataset

February 2011

Matt Brown

Centre for Longitudinal Studies

Institute of Education, University of London

Table of Contents

1. Introduction

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

The pilot study was completed by an inter-disciplinary network of researchers as part of the ESRC's Understanding Individual Behaviour programme. The network's core aim was to to explore individual differences in mid-life cognitive capacity and how these relate to experiences and behaviour earlier in life.

The pilot study was conducted with a sub-sample of National Child Development Study members living in and around Cambridge in 2010, when study members were aged 52, and sought to investigate the potential for conducting neuro-psychological assessments with purposive sub-samples from the British Birth Cohort Studies.

The aim was to recruit individuals with particular cognitive ability trajectories between childhood and mid-adulthood. Childhood cognitive ability was measured using the age 11 General Ability Test (GAT). Adult cognitive ability was measured using cognitive assessments conducted at age 50 (Brown & Dodgeon, 2010).

Potential participants were invited to a research centre at the University of Cambridge to complete a 90 minute testing session involving a range of cognitive and neuro-psychological assessments and a self-completion questionnaire.

This data collected during the pilot study has now been deposited at the UK Data archive. This document accompanies the deposit and provides users with an overview of the data collected and the pilot study's methodology. A technical report is also available which provides further detail about the pilot study's methodology (Brown et. al., 2010).

A fuller discussion of the motivation for conducting the pilot study and some of 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 was 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 3) 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.

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.

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).

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.

3.1 Cognitive assessments included in the NCDS Age 50 Survey

Each of the assessments is described below. Variable names and variable labels are provided for reference.

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).

Variable name	Variable label
WRC1	Word recall 1 (immediate)

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.

Variable name	Variable label
CfAni_2	NUMBER OF ANIMALS MENTIONED

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.

Variable name	Variable label
LC_Speed	Letter cancellation speed
LC_Acc	Letter cancellation accuracy
LC_corr	Letter cancellation correct

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.

Variable name	Variable label
WRC2	Word recall 2 (first delayed)
WRC3	Word recall 3 (second delayed)

3.2 CANTAB assessments

A brief description of each assessment is provided below. Further information is available here: www.camcog.com.

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.

Variable name	Variable label
PALTERR	PAL total errors
PALTERAJ	PAL total errors adjusted
PALTERR6	PAL total errors 6 shapes
PALTERR8	PAL total errors 8 shapes
PALTR6AJ	PAL total errors 6 shapes adjusted
PALTR8AJ	PAL total errors 8 shapes adjusted
PALMERR	PAL Mean errors to success
PALMTRIL	PAL Mean trials to success
PALTTRIL	PAL Total trials
PALTRADJ	PAL Total trials (adjusted)
PALTTR6	PAL Total trials (6 shapes)
PALTT6AJ	PAL Total trials (6 shapes) adjusted
PALTTR8	PAL Total trials (8 shapes)
PALTT8AJ	PAL Total trials (8 shapes) adjusted
PALFTMS	PAL First trial memory score
PALSTGES	PAL Stages completed
PALSTGFT	PAL Stages completed on first trial

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.

Variable name	Variable label
GNTTCOR	GNT total correct
GNT_Z_SC	GNT Z score
GNTTERR	GNT total errors
GNTTATT	GNT total attempts
GNTPCORR	GNT_percent correct

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.

Variable name	Variable label
AGNMLAT	AGN Mean correct latency
AGNMLSH	AGN Mean correct latency shift
AGNMLNSH	AGN Mean correct latency non shift
AGNMLPOS	AGN Mean correct latency positive
AGNMLNEG	AGN Mean correct latency negative
AGNMLB4	AGN Mean correct latency block 4
AGNMLB6	AGN Mean correct latency block 6
AGNMLB8	AGN Mean correct latency block 8
AGNMLB10	AGN Mean correct latency block 10
AGNTC	AGN Total commissions
AGNTCSH	AGN Total commissions shift
AGNTCNSH	AGN Total commissions shift non shift
AGNTCPOS	AGN Total commissions positive
AGNTCNEG	AGN Total commissions negative
AGNTCB4	AGN Total commissions block 4
AGNTCB6	AGN Total commissions block 6
AGNTCB8	AGN Total commissions block 8
AGNTCB10	AGN Total commissions block 10
AGN_T_OM	AGN Total omissions
AGNTOSH	AGN Total omissions shift

AGNTONSH	AGN Total omissions non shift
AGNTOPOS	AGN Total omissions positive
AGNTONEG	AGN Total omissions negative
AGNTOB4	AGN Total omissions block 4
AGNTOB6	AGN Total omissions block 6
AGNTOB8	AGN Total omissions block 8
AGNTOB10	AGN Total omissions block 10

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.

The assessment involved involved trials where the bets ascended and trials where bets descended. The direction of change was switched mid-way through the assessment. Respondents were randomly allocated to two versions of the assessment – an 'ascending first' version or a 'descending first' version. The version used for each respondent is indicated in variable 'CGTBAT'.

Variable name	**Variable label**
CGTBAT	CGT Battery administered
CGTFAC11	CGT A-R factor score 1 for analysis 1
CGTFAC21	CGT A-R factor score 2 for analysis 1
CGT_QDM	CGT Quality of decision making
CGT_DT	CGT Deliberation time
CGTDTL10	CGT Deliberation time log10
CGT_RT	CGT Risk taking
CGTR_ADJ	CGT Risk adjustment
CGTDADV	CGT Delay aversion
CGT_OPB	CGT Overall proportion bet

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.

Variable name	Variable label
RVPTHITS	RVP total hits
RVPTMIS	RVP total misses
RVP_T_AL	RVP total false alarms
RVPTCORJ	RVP total correct rejections
RVPPRBH	RVP probability of hit
RVPPRBFA	RVP probability of false alarm
RVP_A	RVP A'
RVP_B	RVP B"
RVPMLAT	RVP mean latency

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[1].

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

[1] 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 Conducting the assessments

All assessments were conducted between March and June 2010.

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.

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). (The data collected from three individuals has been excluded from the deposited data as health conditions they suffered from were judged to have been likely to have had a detrimental impact on performance in the assessments). 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. References

Brown, M. & Dodgeon, B. (2010) NCDS Cognitive Assessments at age 50: Initial Results, Centre for Longitudinal Studies Working Paper 2010/1.

Brown, M., Dodgeon, B., Elliott, J. and Knight, H.M. (2010) Investigating the genetic, social and neuropsychological influences on individual differences in memory using a lifecourse approach – Pilot Study Technical Report, Centre for Longitudinal Studies.

Knight, H.M., Brown, M., Dodgeon, B., Maughan, B., Richards, M., Elliott, J., Sahakian, B.J., and Robbins, T.W. (2010). 'Investigating individual differences in memory and cognition in National Child Development Study (NCDS) cohort members using a life course approach – Pilot Study Results Report, Centre for Longitudinal Studies Working Paper 2010/10.

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

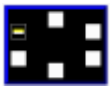
Not at all **Very much**

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

SELECT ALL THAT APPLY

1. Graded naming test (naming objects test)

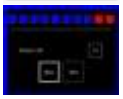
2. Paired Associates Learning (Patterns within boxes)



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

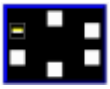
7. None

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

SELECT ALL THAT APPLY

1. Graded naming test (naming objects test)

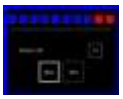
2. Paired Associates Learning (Patterns within boxes)



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,

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.