

1970 British Cohort Study

Ethical Review and Consent

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Centre for Longitudinal Studies

Following lives from birth through the adult years
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The Centre for Longitudinal Studies (CLS) is an ESRC Resource Centre based at the Institution of Education. It provides support and facilities for those using the three internationally-renowned birth cohort studies: the National Child Development Study (1958), the 1970 British Cohort Study and the Millennium Cohort Study (2000). CLS conducts research using the birth cohort study data, with a special interest in family life and parenting, family economics, youth life course transitions and basic skills. The views expressed in this work are those of the author(s) (amend as necessary) and do not necessarily reflect the views of the Economic and Social Research Council. All errors and omissions remain those of the author(s).

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Introduction

This note reports on the approach adopted to ethical review and informed consent for the various stages of the 1970 British Cohort Study (BCS70) - a continuing, multi-disciplinary longitudinal study which takes as its subjects all the people born in one week in England, Scotland and Wales in one week in 1970.

Below, a brief summary of the background to the study is followed by an account of how the approach to ethical review and consent has changed over the course of the study to date. Examples of letters, leaflets and consent forms used for various BCS70 surveys are provided in an Annex

Background

BCS70 has its origins in the British Births Survey. Sponsored by the National Birthday Trust Fund, this was designed to examine the social and obstetric factors associated with stillbirth and death in early infancy among the children born in Great Britain in that one week. Information was gathered from almost 17,500 babies. BCS70 was the third in a series of four similar birth cohort studies, the others being based on a week's births in GB in 1946 and 1958, and on births in selected UK areas in 2000/01¹. Each has formed the basis of a continuing, national longitudinal study. The studies present, both individually and in combination, an unprecedented opportunity to investigate the forces and patterns that have shaped and continue to shape the lives of four generations of people in the GB and the UK².

Since the birth survey there have to date been nine other major data collection exercises in order to monitor their health, education, social and economic circumstances. These were carried out in 1975 (age 5 years), 1980 (age 10 years), 1986 (age 16 years), 1996 (age 26 years), 2000 (age 30 years), 2004 (age 34 years), 2008 (age 38 years), 2012 (age 42 years) and 2016 (age 46 years).

During the age 34 survey (2004), a special study was also undertaken of the children of a one in two sample of the cohort members this, including assessments of the behaviour and cognitive development of approximately 5,000 children. There have also been surveys of sub-samples of the cohort.

Anonymised data from the BCS70 is made available to the research community via the UK Data Service³.

¹ The *National Survey of Health and Development (NSHD)* and the *National Child Development Study (NCDS)*, based on births in GB during one week in 1946 and 1958 respectively; and the *Millennium Cohort Study (MCS)*, based on births in selected areas of the UK over one year beginning 2000.

² GB (Great Britain) comprises England, Wales and Scotland. UK (United Kingdom) comprises GB and Northern Ireland.

³ <http://www.ukdataservice.ac.uk/>

BCS70 and ethical review

Over the years, those responsible for the study have been concerned that appropriate procedures for ethical review and consent are followed but the approach has changed significantly. Currently in the UK, probably the most important route for ethical approval for studies like BCS70 is the National Health Service (NHS) Research Ethics Committee (REC) system. This remains a decentralised system. Local research ethics committees (LRECS), based in each Health Authority, were the first to be established; and smaller number of multicentre research ethics committees (MRECs) later removed the need for national studies (like NCDS) or those covering more than one Health Authority area to approach many/all LRECs.

NHS Research Ethics Committees (RECs) are appointed by the Strategic Health Authorities in England, their equivalents in Scotland and Wales and the Health and Social Care Business Services Organisation in Northern Ireland. RECs safeguard the rights, safety, dignity and well-being of people participating in research.

They review applications for research and give an opinion about the proposed participant involvement and whether the research is ethical. Each consists of between seven and 18 volunteer members. At least one-third of the members must be 'lay' whose main personal or professional interest is not in a research area. The remainder of the committee are expert members, who are specialists including doctors, other healthcare professionals and academics.

MREC ethical approval has been sought for BCS70 follow-ups from 2000 onwards, as indicated in the table below. The 1970, 1975, 1980, 1986 and 1996 follow-ups pre-dated the establishment of the MREC system. Available records suggest that there was only internal ethical review for these surveys⁴.

⁴ For more details see the NHS National Research Ethics Service website: <http://www.nres.npsa.nhs.uk/>

BCS70 Ethical approval 1970-2016

Survey	Age	Year	Approval	
BBS	Birth	1970	Internal review only*	n/a
CHES1	7	1975	Internal review only*	n/a
CHES2	11	1980	Internal review only*	n/a
Youthscan	16	1986	Internal review only*	n/a
BCS70	26	1996	Internal review only*	n/a
BCS70	30	2000	London MREC	98/2/120
BCS70	34	2004	Internal review only	n/a
BCS70	38	2008	Southampton & South West Hampshire	08/H0504/144
BCS70	42	2012	London- Central	11/LO/1560
BCS70	46	2016	South East Coast – Brighton and Sussex	15/LO/1446

* = Predates establishment of MRECs in 1997

BCS70 and consent

The approach to consent has also changed over the years. In 1970, when the birth survey was carried out, consent to participate in surveys was gained by respondents agreeing to be interviewed or respondents returning the completed questionnaire to the study team. Involvement in subsequent surveys adopted the same approach. Individuals could withdraw from the study at any time by simply expressing the wish to do so. Currently, MRECs are most often concerned to see explicit written consent to all or particular elements of a survey.

BCS70 sought informed parental consent for the 5-year (1975), 10-year (1980) and 16-year (1986) surveys - see below. Copies of the relevant letters are not available. There is no evidence that written consent was obtained.

For surveys at 26-years (1996), 30-years (2000), 34-years (2004), 38-years (2008), 42-years (2012) and 46-years (2016) the approach was similar. During fieldwork, study members were sent an advance letter advising them about the survey. The letter was accompanied by an information leaflet explaining what is involved. Study members had the opportunity to request further information, or to opt out of the survey at this point. They could also seek further information, or refuse further involvement, when the interviewer attempted to make an appointment to visit; when the interviewer visited and at any point during the administration of any elements of the surveys.

The table below illustrates the rates of consent and participation for the BCS70 surveys to date.

Year	Target	Achieved	Percent
1970	17,287	16,571	95.9
1975	16,381	13,071	79.8
1980	16,586	14,874	89.7
1986	16,750	11,621	69.4
1996	16,266	9,003	55.3
2000	16,068	11,261	70.1
2004	13,107	9,656	73.7
2008	11843	8,875	74.9
2012	12198	9717	79.7
2016	12192	8581	70.4

During the survey at 34-years (2004) a similar approach was also adopted for the inclusion in the survey of the natural or adopted children of a 1 in 2 sample the study members.

It was essential that interviewers gained parental consent before carrying out the child assessments. During the interview, parents were asked to give their verbal consent which was recorded. Written consent was not required. Only those children for whom verbal consent had been obtained and recorded were assessed.

Similarly, interviewers had to record parental consent before handing the child paper self-completion questionnaire to any 10-16 year old children in the household. The child was instructed to put the completed questionnaire in the envelope provided and seal it.

The cohort member or another responsible adult had to be present at the time of the child assessments, though not necessarily in the same room. In general, interviewers were briefed to avoid physical contact with children. A total of 2,846 cohort members took part in this element of the survey and data was collected about 5,207 children.

During the survey at 42 years, consent from cohort members, and their partners (if they were cohabiting), to link the data collected in the study over the years with information from

records which are routinely collected by government departments and agencies. These records are held by the National Health Service (NHS), Her Majesty's Revenue and Customs (HMRC), and the Department for Work and Pensions (DWP) respectively. The information contained in the health records focus on details of hospital visits, any long lasting health conditions, treatments received and medications prescribed. The economic records from DWP and HMRC include details of benefits being received, national insurance and tax payments, and a full employment history.

Cohort members and their partners had to consent separately and distinct consent forms were provided, one for the cohort member and one for the partner. They were asked to give three consents: one to allow CLS to access information relating to NHS records, one to allow access to DWP records, and one to allow access to HMRC records. All three consents were included on each consent form but the cohort member and partner could opt to consent to none, one, two, or all three types of data linkage. The consent form was carbon-backed and printed in duplicate. One copy was retained by the cohort member and/or partner, and the other copy taken by the interviewer and returned CLS.

An information leaflet explaining why CLS wanted to link to records and the records they would be looking at was provided by the interviewer when seeking consent. In circumstances where the partner was not available, the cohort member was asked to pass on the consent form and leaflet to their partner, along with a letter addressed to the partner with more detail about why the study wanted to link to their records. Copies of the consent forms and leaflet can be found in the Annex below.

Cohort members who had completed a productive personal interview were asked for consent to link their survey data to information from routine health and economic records. The consent rate to link health records was slightly higher than that for economic records (71.9% compared with 67.3% for DWP linkage and 65.2% for HMRC linkage). Consent was provided to the interviewer directly in most cases, with a small proportion of respondents completing the form at a later date and returning to the office by post. A small number of cohort members contacted the office to withdraw their consent after their interview.

Cohort members who had co-resident partners were also asked if their partners would give consent to health and economic data linkage. Overall 7,333 cohort members who completed a personal interview had co-resident partners (75.7% of productive personal interviews). Forty five per cent of partners were present at the time of the interview. Of these: 74.3% consented to health linkage; 71.2% to DWP linkage and 70.2% to HMRC linkage (33.2%, 31.9% and 31.4% respectively of all co-resident partners). As for the cohort members any subsequent withdrawals have been taken account of when calculating the figures.

The survey at age 46 had a biomedical focus. As well as collecting information using interviews and questionnaires, cohort members were ask to provide biomedical data, including:

- Height, weight and body fat measurements
- Waist and hip measurements
- A balance assessment
- Grip strength measurement
- Blood pressure measurement
- A blood sample, for immediate analysis, DNA extraction, and storage for future unspecified analysis
- Data from an accelerometer, to be worn after the visit

7673 participants took part in the biomeasures element of the survey (63% of the issued sample). Written consent was obtained for the blood sample collection and subsequent analysis and storage, and for the results of the blood analysis and blood pressure measurement to be sent to the cohort member's GP if they wished. 81% agreed to and subsequently provided a blood sample for immediate analysis, 78% agreed to and provided a blood sample for DNA extraction, and 79% agreed to and provided a blood sample for unspecified future analysis.

Letters, leaflets and consent forms

Examples of letters, leaflets and consent forms used for various BCS surveys are provided in the Annex below.

Further information

Further information is available from the CLS website (<http://www.cls.ucl.ac.uk/>) or by emailing: clsfeedback@ucl.ac.uk. This document will be updated as new BCS70 datasets are available.

ANNEX: Examples of letters, leaflets and consent forms

Examples of letters, leaflets and consent forms used for various BCS70 surveys are reproduced below as follows

BCS70 2004

Advance Letter

Ref:

October 1999

Dear

I am writing to tell you about an important event – the next stage of the 1970 British Cohort Study of which you are a valued member. This long running project has been gathering information over the years about everyone in Britain born in the same week as you - 5 to 11 April 1970.

The study is essential for planning services and developing policies to improve the lives of people in Britain as we move into the new millennium. This is why it is so important that you take part in this survey.

An interviewer from our partner organisation, the National Centre for Social Research, will be in touch with you shortly to arrange a convenient time to visit. If your address or telephone number has changed please let us know as soon as possible, by calling **Freephone 0500 600 616**.

As always, all the information you supply will be treated in strict confidence. It will not be released in any way that enables you to be identified - and will be used only to produce a picture of life in Britain today. We shall be sending you some of the results as soon as they are available.

If you have any questions or would like any further information please do not hesitate to contact us on **Freephone 0500 600 616**.

Many thanks for your continuing help.

Yours sincerely,



Professor John Bynner

Professor Neville Butler

“...No other study has such a treasure trove of knowledge about life in the 20th century...”

Advance Letter – Core sample

The next stage of the 1970 British Cohort Study, of which you are such a valued member, is about to begin and we are writing to ask for your help. As you will know, this long running project has been gathering information for 33 years about everyone in Britain born in the same week as you.

The current survey is being carried out by the National Centre for Social Research (NatCen), an independent research organisation, on behalf of the Centre for Longitudinal Studies at the Institute of Education. We would like to visit you, at your convenience, to see what has happened in your life since the last time we contacted you.

The study is essential for planning services and developing policies to improve the lives of people in Britain. The information collected so far has provided important insights into the way that individual lives are shaped by different factors, from health and family life to education and employment. You can therefore see how important your continuing participation in the study is.

An interviewer from NatCen will be in touch with you shortly to arrange a convenient time to visit. If you would prefer the interviewer to make their initial contact by telephone please call Freephone xxxx xxx xxx. If your address or telephone number has changed, or if you have any questions or would like further information, please contact us on the above freephone number.

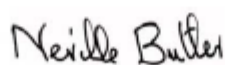
Your answers will be treated in strict confidence in accordance with the Data Protection Act. The information you provide will be used solely to produce a picture of life in Britain today, and will not be released in any way that enables you to be identified. We shall be pleased to send you some of the results when they are available.

We are very grateful for the help you have given us to date and hope very much that you will wish to help us again.

Yours sincerely,



Professor John Bynner



Professor Neville Butler

Advance letter – Parent and Child sample

The next stage of the 1970 British Cohort Study, of which you are such a valued member, is about to begin and we are writing to ask for your help. As you will know, this long running project has been gathering information for 33 years about everyone in Britain born in the same week as you. The current survey is being carried out by the National Centre for Social Research (NatCen), an independent research organisation, on behalf of the Centre for Longitudinal Studies at the Institute of Education.

We would like to visit you, at your convenience, to see what has happened in your life since the last time we contacted you. Also, for those of you who have children, we would like to gather some information about them. Our interviewer will gladly explain more about this.

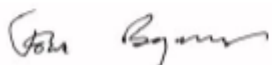
The study is essential for planning services and developing policies to improve the lives of people in Britain. The information collected so far has provided important insights into the way that individual lives are shaped by different factors, from health and family life to education and employment. You can therefore see how important your continuing participation in the study is.

An interviewer from NatCen will be in touch with you shortly to arrange a convenient time to visit. If you would prefer the interviewer to make their initial contact by telephone please call Freephone xxxx xxx xxx. If your address or telephone number has changed, or if you have any questions or would like further information, please contact us on the above freephone number.

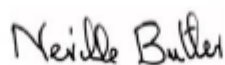
Your answers will be treated in strict confidence in accordance with the Data Protection Act. The information you provide will be used solely to produce a picture of life in Britain today, and will not be released in any way that enables you to be identified. We shall be pleased to send you some of the results when they are available.

We are very grateful for the help you have given us to date and hope very much that you will wish to help us again.

Yours sincerely,



Professor John Bynner



Professor Neville Butler

BCS70 2008

Advance Letter

Dear

1970 British Cohort Study

As a valued member of the 1970 British Cohort Study (BCS70) we are writing to ask for your help as the next stage of the study begins.

This latest stage of the study is being carried out by the National Centre for Social Research (NatCen), an independent research organisation, on behalf of the Centre for Longitudinal Studies (CLS) at the Institute of Education in London.

We have enclosed a leaflet which provides information about this year's study and explains exactly what taking part will involve. Also enclosed are three showcards that you will need to refer to during your interview, so please keep them safe. The survey this time round is being conducted via telephone and your interviewer will be in touch in the next couple of weeks to invite you to take part. If you would like to arrange a convenient time for your interviewer to call then please contact NatCen and leave a message on the following freephone number 0800 652 0601.

If you have any further queries about the study please call us at CLS on Freephone 0500 600 616. This number is staffed 09:00-17:00 Monday to Friday. Outside these hours an answer phone service operates. You can also email us at bc70@ioe.ac.uk.

We hope you enjoy taking part in the study this time around. Your continued support and involvement is vital to the success of the study and is greatly appreciated.

Thank you for your help.

Yours sincerely,



Jane Elliott
Study Director



Matt Brown
Survey Manager

Leaflet accompanying the Advance Letter

BCS70 Leaflet Revised BCS70 Leaflet 15/8/08 09:106 Page 1

Who is carrying out the study?

The study is run by the Centre of Longitudinal Studies (CLS), a research centre in the Institute of Education at the University of London.

It is being funded by the government's Economic and Social Research Council – an independent organisation that funds research and training.

Interviews will be conducted by the National Centre for Social Research (NatCen), an independent research organisation.

NatCen also conducted the interviews for the last two surveys in 2000 and 2004.

Who can I contact about the study?

If you would like any further information about the study please contact CLS in any of the following ways:

Freephone: **0500 600 616**
Email: **bcs70@ioe.ac.uk**
Write to: **1970 British Cohort Study,
FREEPOST, KE7770, London, WC1H 0BR**
(no stamp required if posted in the UK)

You can also find further information including summaries of the key findings to have emerged from the study on the BCS70 website: **www.bcs70.info**

To arrange an appointment or change an appointment you may have made with an interviewer please contact NatCen on Freephone: **0800 652 06 01**

1970 British Cohort Study

A study of everyone born in one week in 1970








1970 British Cohort Study

The next stage of the 1970 British Cohort Study is now underway.

As you know the study has been following the lives of over 17,000 people born in the same week as you.

The answers you have given to our questions in previous surveys have provided vital evidence about the changes and transitions which occur through people's lives.

The information collected continues to be a tremendously important resource for policy makers and service providers across a whole range of spheres including health, education and employment.

Over the years it has been your support and participation that has made the study such a success.

We hope you will take part in this year's survey and continue to be involved in the study for many years to come.

What will this year's study involve?

This year's survey will be conducted via telephone and will only take around twenty minutes.

Your interviewer will contact you by phone to invite you to take part. If you are willing the interviewer will be able to carry out the interview there and then. However, appointments can be arranged for the interviewer to call you back at any time which is convenient.

This year's survey will be focusing on your current situation and what you have been doing since we last spoke to you.

If you have helped with any of our recent surveys then the topics which will be covered will be familiar to you such as family life, employment, housing and health.

There will as usual be a few questions about your partner so please check that your partner is happy for you to answer them.

There will not be any assessments and we will not be asking to speak to any other members of your family.

Your participation is entirely voluntary and as in all previous surveys you are not obliged to answer any questions you do not wish to.

We will as usual be asking you for the contact details of a friend or relative who would be able to contact you in the future if we could not get in touch in any other way.

What will happen to the information you provide?

Your answers will be treated in strict confidence in accordance with the Data Protection Act, and used for research purposes only.

This means that:

- Names and addresses are never included with the results of our research studies.
- Neither households nor individuals are identified in any published report.

BCS70 2012

Advance letter (last sweep participants)

Advance letter (for people that took part at the last sweep)

[CMTitle] [CM first name] [CM surname]
[Address line 1]
[Address line 2]
[Address line 3]
[Address line 4]
[Postcode]

Personal ref: [cserial]
Survey ref: 224342
May 2012

1970 British Cohort Study – Age 42 Survey

Dear [CM first name],

I am writing to let you know that the next stage of the 1970 British Cohort Study is now underway. I hope you will wish to take part. **Your continued support and involvement is vital to the success of the study and is greatly appreciated.**

We have enclosed a leaflet which provides information about this year's survey and explains exactly what taking part will involve.

The Age 42 survey is being carried out by TNS-BMRB, an independent research organisation.

The interviewer named below will be in touch in the next couple of weeks to invite you to take part and, if you are willing, they will arrange a convenient time to visit you. You can also get in touch with them directly to arrange an appointment. Their phone number is at the bottom of this letter.

If you have any questions about the study please call TNS-BMRB on 0800 015 0302 or email bcs70@tns-bmr.co.uk. If this letter has reached you at a different address to the one printed above please let TNS-BMRB know your new address.

We hope you enjoy taking part in the study this time around.

Your interviewer will be _____

Contact number _____

Yours sincerely,

Dr. Alice Sullivan
BCS70 Director

Advance letter (refused at last sweep)

Advance letter (for people that refused at the last sweep)

[CM Title] [CM first name] [CM surname]
[Address line 1]
[Address line 2]
[Address line 3]
[Address line 4]
[Postcode]

Personal ref: [cserial]
Survey ref: 224342
May 2012

1970 British Cohort Study – Age 42 Survey

Dear [CM first name],

I am writing to let you know that the next stage of the 1970 British Cohort Study is now underway. I hope you will wish to take part.

The last stage of the study was conducted in 2008 and we understand that you chose not to take part at that time. Each study member has a unique story to tell so we would very much like to talk to you this year.

We have enclosed a leaflet which provides information about this year's survey and explains exactly what taking part will involve.

This latest stage of the study is being carried out by TNS-BMRB, an independent research organisation.

The interviewer named below will be in touch in the next couple of weeks to invite you to take part and, if you are willing, they will arrange a convenient time to visit you. You can also get in touch with them directly to arrange an appointment. Their phone number is at the bottom of this letter.

If you have any questions about the study please call TNS-BMRB on 0800 0150 302 or email bc70@tns-bmr.co.uk. If this letter has reached you at a different address to the one printed above please let TNS-BMRB know your new address.

We hope you enjoy taking part in the study this time around. Your continued support and involvement is vital to the success of the study and is greatly appreciated.

Your interviewer will be _____

Contact number _____

Yours sincerely,

Dr. Alice Sullivan
BCS70 Director

Advance letter (not contact at last sweep)

Advance letter (for people that could not be contacted at the last sweep)

[CM Title] [CM first name] [CM surname]
[Address line 1]
[Address line 2]
[Address line 3]
[Address line 4]
[Postcode]

Personal ref: [cserial]
Survey ref: 224342
May 2012

1970 British Cohort Study – Age 42 Survey

Dear [CM first name],

I am writing to let you know that the next stage of the 1970 British Cohort Study is now underway. I hope you will wish to take part.

The last stage of the study was conducted in 2008 but unfortunately we were unable to contact you at that time. Each study member has a unique story to tell so we would very much like to talk to you this year.

We have enclosed a leaflet which provides information about this year's survey and explains exactly what taking part will involve.

This latest stage of the study is being carried out by TNS-BMRB, an independent research organisation.

The interviewer named below will be in touch in the next couple of weeks to invite you to take part and, if you are willing, they will arrange a convenient time to visit you. You can also get in touch with them directly to arrange an appointment. Their phone number is at the bottom of this letter.

If you have any questions about the study please call TNS-BMRB on 0800 0150 302 or email bcs70@tns-bmrb.co.uk. If this letter has reached you at a different address to the one printed above please let TNS-BMRB know your new address.

We hope you enjoy taking part in the study this time around. Your continued support and involvement is vital to the success of the study and is greatly appreciated.

Your interviewer will be _____

Contact number _____

Yours sincerely,

Dr. Alice Sullivan
BCS70 Director

Leaflet accompanying the advance letter

1970 BRITISH COHORT STUDY

What will happen to the information I give you?

The information you provide will be treated in strict confidence in accordance with the Data Protection Act, and used for statistical research purposes only. This means that:

- Names and addresses are never included with the results of our research studies
- Neither households nor individuals are identified in any published report

When will we be coming back?

We hope you will continue to be part of the study for many years to come. It is currently planned that future surveys will take place every four years, so the next survey is likely to take place in 2016 when you will be 46.



1970 BRITISH COHORT STUDY

How can I find out more about the Age 42 Survey?

If you would like more information about the Age 42 survey please contact TNS-BMRB:

Freephone: 0800 015 0302
Email: bcs70@tns-bmr.co.uk

For further information about BCS70 in general you can contact the Centre for Longitudinal Studies on Freephone 0500 600 616, email bcs70@ioe.ac.uk or visit the study website: www.bcs70.info.

Who can I contact for further advice?

If you would like any advice on any of the issues included in the interview then the Citizen's Advice Bureau (www.adviceguide.org.uk) or Supportline (www.supportline.org.uk or 01708 765200) will be able to help.



1970 BRITISH COHORT STUDY



AGE 42 SURVEY



INFORMATION LEAFLET

TNS

1970 BRITISH COHORT STUDY

Why is the 1970 British Cohort Study (BCS70) important?

BCS70 has been following the lives of over 17,000 people, who were all born in the same week as you, since 1970.

Now that you are 42, and entering a new phase of life, the information that you have shared with us over the years allows us to understand where you are now and how you got there. There is no other study that focuses on your generation, and the factors that have influenced your journey through life.

BCS70 continues to help scientists and researchers understand changes in society and transitions which occur in people's lives. At this time of recession in particular, the information you provide can help policymakers and providers of services to plan for the future and improve the lives of people in Britain.

Findings from the study have had, and will continue to have, a significant impact on government policy and service provision across a whole range of spheres including health, education and employment.



What will the Age 42 Survey involve?

The Age 42 Survey has two parts: a short paper questionnaire and a face-to-face interview.

The paper questionnaire will be posted to you in advance of the interviewer's visit. It should take around 20 minutes to complete. We would be grateful if you could fill it out before your interview so the interviewer can collect it when they visit.

Some of the topics covered in the paper questionnaire are:

- Leisure activities
- Values and attitudes
- Religion

The main interview will last around an hour. Some of the topics that will be covered in the main interview are:

- Your family situation
- Your housing situation
- Your employment
- Your income
- Your health

If you live with a partner, there will be some questions about your partner too, so please check that he/she is happy for you to answer them.

As always your participation is entirely voluntary and you can miss any question you do not want to answer. For some questions, which might be more private, you will fill in the answers yourself on the interviewer's laptop.

What other information would we like to collect?

We would like to collect some additional information about you (and your partner) from routine records held by the National Health Service (NHS), Her Majesty's Revenue and Customs (HMRC) and the Department of Work and Pensions (DWP). We can only do this with your permission. The interviewer will provide you with more information about this. You do not have to give us permission to do this, and we will not be able to access this information without your permission.


Who is carrying out the study?

The study is run by the Centre for Longitudinal Studies (CLS), a research centre in the Institute of Education at the University of London. It is being funded by the government's Economic and Social Research Council.

The Age 42 survey is being carried out by TNS-BMRB, an independent research company that specialises in conducting large-scale social surveys.

Consent form – Cohort Member data linkage

1970 BRITISH COHORT STUDY



COHORT MEMBER CONSENT FORM

+

Forename (print)

Surname (print)

+

Please complete this form to indicate whether or not you give us permission to pass your personal details to each organisation so that your records can be identified and sent to us to be linked with your responses to the study.

National Health Service (NHS) records

I give my permission for my name, address, sex and date of birth to be passed to the NHS for this purpose.

Please tick one of the boxes to indicate whether or not you give permission.

Yes
☐

No
☐

Department for Work and Pensions (DWP) records

I give my permission for my name, address, sex and date of birth to be passed to the DWP for this purpose.

Please tick one of the boxes to indicate whether or not you give permission.

Yes
☐

No
☐

Her Majesty's Revenue and Customs (HMRC)

I give my permission for my name, address, sex and date of birth to be passed to the HMRC for this purpose.

Please tick one of the boxes to indicate whether or not you give permission.

Yes
☐

No
☐

National Insurance Number

Please write your National Insurance Number below if you are willing for us to send this to the DWP and the HMRC. This will be used to help identify your records.

National Insurance Number:

Confirmation

I have read or been read the 'What other information would we like to collect?' leaflet and have had the opportunity to ask questions. I understand that the information released will be treated in strict confidence in accordance with the Data Protection Act and used for research purposes only. I understand that this consent will remain valid and ongoing unless revoked by me. I understand that I may withdraw my consent at any time by contacting the British Cohort Study team, without giving any reasons.

The study team can be contacted at 1970 British Cohort Study, FREEPOST, KE7770, LONDON, WC1H 0BR (no stamp required if posted in the UK), Freephone 0500 600 616 or bcs70@joe.ac.uk.

Signature

Date

FOR INTERVIEWER USE ONLY - ENTER COHORT MEMBER DETAILS

☐ Male


☐ Female

Serial number

Date of Birth

224342

Consent form – Partner data linkage

<div style="display: flex; justify-content: space-between; align-items: center;"><div>1970 BRITISH COHORT STUDY</div><div style="text-align: right;"></div></div> <div style="background-color: #444; color: white; padding: 5px; text-align: center;">COHORT MEMBER CONSENT FORM</div>	
+	<div>Forename (print) _____</div> <div>Surname (print) _____</div> <p>Please complete this form to indicate whether or not you give us permission to pass your personal details to each organisation so that your records can be identified and sent to us to be linked with your responses to the study.</p> <div style="background-color: #444; color: white; padding: 5px; text-align: center;">National Health Service (NHS) records</div> <p>I give my permission for my name, address, sex and date of birth to be passed to the NHS for this purpose.</p> <p>Please tick one of the boxes to indicate whether or not you give permission.</p> <div style="display: flex; justify-content: flex-end; align-items: center; gap: 20px;"><div>Yes <input type="checkbox"/></div><div>No <input type="checkbox"/></div></div> <div style="background-color: #444; color: white; padding: 5px; text-align: center;">Department for Work and Pensions (DWP) records</div> <p>I give my permission for my name, address, sex and date of birth to be passed to the DWP for this purpose.</p> <p>Please tick one of the boxes to indicate whether or not you give permission.</p> <div style="display: flex; justify-content: flex-end; align-items: center; gap: 20px;"><div>Yes <input type="checkbox"/></div><div>No <input type="checkbox"/></div></div> <div style="background-color: #444; color: white; padding: 5px; text-align: center;">Her Majesty's Revenue and Customs (HMRC)</div> <p>I give my permission for my name, address, sex and date of birth to be passed to the HMRC for this purpose.</p> <p>Please tick one of the boxes to indicate whether or not you give permission.</p> <div style="display: flex; justify-content: flex-end; align-items: center; gap: 20px;"><div>Yes <input type="checkbox"/></div><div>No <input type="checkbox"/></div></div> <div style="background-color: #444; color: white; padding: 5px; text-align: center;">National Insurance Number</div> <p>Please write your National Insurance Number below if you are willing for us to send this to the DWP and the HMRC. This will be used to help identify your records.</p> <p>National Insurance Number: <input type="text"/><input type="text"/><input type="text"/><input type="text"/><input type="text"/><input type="text"/><input type="text"/><input type="text"/><input type="text"/><input type="text"/></p> <div style="background-color: #444; color: white; padding: 5px; text-align: center;">Confirmation</div> <p>I have read or been read the 'What other information would we like to collect?' leaflet and have had the opportunity to ask questions. I understand that the information released will be treated in strict confidence in accordance with the Data Protection Act and used for research purposes only. I understand that this consent will remain valid and ongoing unless revoked by me. I understand that I may withdraw my consent at any time by contacting the British Cohort Study team, without giving any reasons.</p> <p>The study team can be contacted at 1970 British Cohort Study, FREEPOST, KE7770, LONDON, WC1H 0BR (no stamp required if posted in the UK), Freephone 0500 600 616 or bcs70@ice.ac.uk.</p> <div style="display: flex; justify-content: space-between; margin-top: 20px;"><div>Signature _____</div><div>Date _____</div></div> <div style="border: 1px solid black; padding: 10px; margin-top: 20px;"><div style="font-size: 0.8em; font-weight: bold; margin-bottom: 5px;">FOR INTERVIEWER USE ONLY - ENTER COHORT MEMBER DETAILS</div><div style="display: flex; align-items: center; margin-bottom: 10px;"><div style="border: 1px solid black; width: 30px; height: 30px; margin-right: 5px;"></div><div style="border: 1px solid black; width: 30px; height: 30px; margin-right: 5px;"></div><div style="border: 1px solid black; width: 30px; height: 30px; margin-right: 5px;"></div><div style="border: 1px solid black; width: 30px; height: 30px; margin-right: 5px;"></div><div style="border: 1px solid black; width: 30px; height: 30px; margin-right: 5px;"></div><div style="border: 1px solid black; width: 30px; height: 30px; margin-right: 5px;"></div><div style="border: 1px solid black; width: 30px; height: 30px; margin-right: 5px;"></div><div style="border: 1px solid black; width: 30px; height: 30px; margin-right: 5px;"></div><div style="border: 1px solid black; width: 30px; height: 30px; margin-right: 5px;"></div><div style="border: 1px solid black; width: 30px; height: 30px; margin-right: 5px;"></div><div style="margin-left: 10px;">Serial number</div></div><div style="display: flex; align-items: center; margin-bottom: 10px;"><div style="margin-right: 10px;"><input type="checkbox"/> Male <input type="checkbox"/> Female</div></div><div style="display: flex; align-items: center;"><div style="border: 1px solid black; width: 30px; height: 30px; margin-right: 5px;"></div><div style="border: 1px solid black; width: 30px; height: 30px; margin-right: 5px;"></div><div style="border: 1px solid black; width: 30px; height: 30px; margin-right: 5px;"></div><div style="border: 1px solid black; width: 30px; height: 30px; margin-right: 5px;"></div><div style="border: 1px solid black; width: 30px; height: 30px; margin-right: 5px;"></div><div style="border: 1px solid black; width: 30px; height: 30px; margin-right: 5px;"></div><div style="margin-left: 10px;">Date of Birth</div></div></div> <div style="margin-top: 20px; display: flex; justify-content: space-between;"><div style="border: 1px solid black; padding: 5px; width: 40%;"><div style="border: 1px solid black; width: 30px; height: 30px; margin-right: 5px;"></div><div style="border: 1px solid black; width: 30px; height: 30px; margin-right: 5px;"></div><div style="border: 1px solid black; width: 30px; height: 30px; margin-right: 5px;"></div><div style="border: 1px solid black; width: 30px; height: 30px; margin-right: 5px;"></div><div style="border: 1px solid black; width: 30px; height: 30px; margin-right: 5px;"></div><div style="border: 1px solid black; width: 30px; height: 30px; margin-right: 5px;"></div><div style="margin-left: 10px;">Date of Birth</div></div><div style="width: 55%; text-align: center; padding-top: 20px;"><div style="border: 1px solid black; width: 150px; height: 30px; margin: 0 auto; margin-bottom: 10px;"></div><div style="font-weight: bold; font-size: 1.2em;">224342</div><div style="border-top: 1px solid black; margin-top: 20px; width: 100%;"></div><div style="font-weight: bold; font-size: 1.2em;">224342</div></div></div>

+

Data linkage leaflet

1970 BRITISH COHORT STUDY

What am I being asked to give my permission for?

National Health Service (NHS) records

The NHS maintains information on all patients accessing health services through routine medical and other health-related records. These records are held within statistical health databases which record information about:

- Admissions or attendances at hospital (including dates of admission, discharge or attendance, diagnoses received, treatments given, surgical procedures)
- Visits to your family doctor or other health professional e.g. midwife
- Records of specific conditions such as cancer or diabetes
- Prescriptions given

Adding your NHS records will allow researchers to examine both the lifestyle factors associated with the onset of particular illnesses and the ways in which illnesses have an impact on other aspects of people's lives.

Department for Work and Pensions (DWP) records

The DWP keeps records of everybody's benefit claims and any periods people spend on employment programs. Adding your DWP records will help us get a better picture of those who are claiming benefits and how they can best be helped.

Her Majesty's Revenue and Customs (HMRC) records

HMRC keep records of everybody's employment, earnings, tax credits and occupational pensions (since 1998) and National Insurance Contributions since the early 1970s. These records will tell us a great deal about your economic situation – at present, in the past and in the future. This will allow researchers to examine how economic circumstances impact upon other aspects of life in greater detail.

Why are you asking for my partner's records?

The circumstances of those around you have a big effect on you. If, for example, your partner were to become seriously ill, or were to experience a prolonged period of unemployment this could clearly have a hugely significant impact on your life. We are only able to collect a very limited amount of information about your partner when we interview you, so adding their records will give us a much better understanding of your family circumstances.

What will happen if I give permission?

- 1) BCS70 will give your name, address and date of birth to the NHS, DWP and HMRC. Your national insurance number will be provided to the DWP and HMRC (if you provide it).
- 2) The DWP, HMRC and NHS will use these details to identify the correct records it holds about you.
- 3) The DWP, HMRC and NHS will send your records to BCS70.
- 4) The DWP, HMRC and NHS will not retain the information sent to them.
- 5) BCS70 will add the DWP, HMRC and NHS records to your study responses
- 6) Your personal information (e.g. name and address) will be removed before any research is done.

If your partner gives permission the same process will occur and their records will be added to your study responses.

What if I don't want to give my permission?

If you don't want to do this you can still take part in the rest of the survey.

COHORT STUDY

What will the information be used for and who will use it?

- Like your study responses, the additional information would be used by professional academic and social policy researchers for non-commercial research and statistics.
- Any sensitive information would only be made available to them under restricted access arrangements which make sure that the information is used responsibly and safely.
- Names and addresses are never included in the results and no individual can be identified from the research.
- The data will not be used to work out whether any individual is claiming benefits they should not be or is not paying the right amount of tax. Giving permission will not affect any current or future claims for benefits.
- Additional details about how this information will be used can be found on the study website: www.bcs70.info

What if I change my mind?

You can withdraw permission at any time for your NHS, DWP or HMRC records to be added to your study answers. If you do this, you can still continue to participate in the study.

Who do I contact?

If you want any further information or want to withdraw your permission please contact us by writing to:

1970 British Cohort Study
FREEPOST KE7770
LONDON
WC1H 0BR

(no stamp required if posted in the UK)

The study team can also be contacted on
Freephone: 0500 600 616
Email: bc70@ioe.ac.uk

COHORT STUDY

AGE 42 SURVEY

WHAT OTHER INFORMATION WOULD WE LIKE TO COLLECT?



Information routinely collected by government departments can help us understand much more about your experiences and how to support individuals and families if linked to the answers you have given us. We will ask you (and your partner) for permission to link your data in this way.

Data linkage letter - Partner

Ref:224342/DLPART

Dear _____

Your partner is a member of the 1970 British Cohort Study (BCS70), which is following the lives of over 17,000 people who were born in the same week in 1970. The study seeks to understand how different aspects of people's lives such as health, wealth, education, family circumstances and employment are inter-linked and how experiences during one stage of life can affect achievements in later life.

Findings from the study have had a significant impact on government policy and service provision across a whole range of areas including health, education and employment.

As part of the Age 42 survey we asked your partner if they would allow us to collect some additional information from routine records held by the National Health Service (NHS), the Department for Work and Pensions (DWP) and Her Majesty's Revenue and Customs (HMRC). This would give us a much more detailed picture of their health and economic circumstances.

We would also like to collect information from these records about you. Your experiences have a huge impact on your partner. If, for example, you were to become seriously ill, or were to experience a long period of unemployment this could clearly have a very significant effect on their life. When we interviewed your partner we did ask a very limited number of questions about you. However, the information held in these records would give us a much better understanding of your circumstances and how these could affect your partner.

We can only do this with your permission. You do not have to give this permission and we will not be able to access your records without your permission.

We have enclosed a leaflet which explains more about the information we would like to collect and what will happen if you do decide to give BCS70 permission. Further information is also available on the study website: www.bcs70.info. We have also enclosed a consent form.

We would be extremely grateful if you could read the leaflet, complete the consent form and return it to us in the enclosed Freepost envelope. Even if you do not wish to give us this permission, we would still be very grateful if you would return the completed form.

If you would like any further information before you make up your mind you can contact us in any of the following ways:

- Write to 1970 British Cohort Study, FREEPOST, KE7770, LONDON, WC1H 0BR (no stamp required if posted in the UK)
- Freephone: **0500 600 616**
- Email: **bc70@ioe.ac.uk**.

Best wishes

Dr. Alice Sullivan, BCS70 Study Director

BCS70 2016

Advance letter (last sweep participants)



<CM_Title> <CM_FirstName> <CM_Surname>
<AddressLine1>
<AddressLine2>
<AddressLine3>
<Town>
<County>
<Postcode>

Our ref: <AgencySerial> <CheckLetter>
<Month> <Year>

Dear <CM_FirstName>,

2016-18 SURVEY

I am writing to invite you to help us again with the next stage of the 1970 British Cohort Study. As you know, the study has been following everyone in Britain born in the same week as you, from childhood right through to the present day. As you will remember, we last interviewed you back in 2012.

Your continued support and involvement is vital to the success of the study and is greatly appreciated. Thanks to your continued participation we now hold a unique set of data that is used by academics, charities and policymakers around the world to examine how experiences and circumstances at one point in time impact upon later life.

The 2016-18 survey is being conducted by NatCen Social Research, Britain's largest independent social research agency. <NurseIntText> **The enclosed booklet tells you about what we would like you to do.**

WHAT HAPPENS NEXT?

<NurseInt> interviewer from NatCen Social Research will contact you over the next few weeks to ask if you would be willing to take part, and answer any questions you may have. If you would like to take part, they will then arrange a convenient time to visit you.

<Nurse_name_text>

ANY QUESTIONS?

If you have any questions or would prefer not to take part, please contact the NatCen research team by email at bcs70@natcen.ac.uk or on Freephone **0800 526 397** between 9:00am and 5:00pm (Monday to Friday). More information is also available on the study website: www.bcs70.info.

We hope you enjoy taking part.

Yours sincerely,

Alice Sullivan

Professor Alice Sullivan,
BCS70 Director

BCS70_MSR_ADV LETTER S_V1

NatCen
Social Research that works for society

Advance letter (refused last sweep)



<CM_Title> <CM_FirstName> <CM_Surname>
<AddressLine1>
<AddressLine2>
<AddressLine3>
<Town>
<County>
<Postcode>

Our ref: <AgencySerial> <CheckLetter>
<Month> <Year>

Dear <CM_FirstName>,

2016-18 SURVEY

I am writing to invite you to help us with the next stage of the 1970 British Cohort Study. As you know, the study has been following everyone in Britain born in the same week as you, from childhood right through to the present day. The previous stage of the study was conducted in 2012, and we understand that you were unable to take part at that time. As each study member has a unique story to tell, we are especially keen to speak with you this time around to find out how you are getting on. You can take part in the survey on a day and time that suits you – we are very flexible.

Your support and involvement is vital to the success of the study and is greatly appreciated. Thanks to your participation we now hold a unique set of data that is used by academics, charities and policymakers around the world to examine how experiences and circumstances at one point in time impact upon later life.

The 2016-18 survey is being conducted by NatCen Social Research, Britain's largest independent social research agency. <NurseIntText> **The enclosed booklet tells you about what we would like you to do.**

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<Nurse_name_text>

ANY QUESTIONS?

If you have any questions or would prefer not to take part, please contact the NatCen research team by email at bc570@natcen.ac.uk or on Freephone **0800 526 397** between 9:00am and 5:00pm (Monday to Friday). More information is also available on the study website: www.bcs70.info.

We hope you enjoy taking part.

Yours sincerely,

Alice Sullivan

Professor Alice Sullivan,
BCS70 Director

BCS70_MSR_ADV LETTER R_V1

NatCen
Social Research that works for society

Advance letter (non-contact at last sweep)



<CM_Title> <CM_FirstName> <CM_Surname>
<AddressLine1>
<AddressLine2>
<AddressLine3>
<Town>
<County>
<Postcode>

Our ref: <AgencySerial> <CheckLetter>
<Month> <Year>

Dear <CM_FirstName>,

2016-18 SURVEY

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<Nurse_name_text>

ANY QUESTIONS?

If you have any questions or would prefer not to take part, please contact the NatCen research team by email at bcs70@natcen.ac.uk or on Freephone **0800 526 397** between 9:00am and 5:00pm (Monday to Friday). More information is also available on the study website: www.bcs70.info.

We hope you enjoy taking part.

Yours sincerely,

Alice Sullivan

Professor Alice Sullivan,
BCS70 Director

Interviewer leaflet accompanying the advance letter

1970 BRITISH COHORT STUDY: 2016-18 SURVEY

Your guide to taking part

WELCOME TO THE 2016-18 SURVEY!

This booklet provides you with information about the survey and what it will involve.

WHY IS BCS70 SO IMPORTANT?

BCS70 is one of Britain's four birth cohort studies. These studies each follow a group of people born in the same year. The studies have really improved our knowledge of how people's early lives shape what happens when they grow up. They have also shown how lives change from one generation to the next. A recent article in the journal "Nature" called these studies the "envy of the world". It said they have advanced our understanding of topics like the impact of pre-birth experiences on health in later life, the introduction of free nursery places for 3- to 4-year-olds and the drive to promote adult literacy and numeracy.

Every year the information that you so generously provide is used by researchers and scientists to examine a huge variety of important questions. Here are just a few examples of findings from recent research projects conducted using BCS70 data:

BEING YOUNG AND MENTALLY HEALTHY

Having good mental health as a child increases the chances of being a healthy weight in later life. BCS70 shows that there's a link between emotional problems and weight-gain between ages 10 to 30, and that general behavioural problems at age 5 are related to an increased risk of being overweight at age 30.

BCS70

1970 British
Cohort Study

BCS70_MSR_INT_ADV_BOOKLET_V1

CLIMBING THE HOUSING LADDER IS GETTING HARDER FOR THOSE WHOSE PARENTS ARE NOT OWNERS

The chance of becoming a homeowner is influenced by whether your parents owned their own home. Using data from BCS70, researchers have shown that this link is much stronger for people born in 1970 than those born a generation earlier.

HEALTHY IN BODY AND MIND

BCS70 shows that those of you who often participated in a range of sports and activities when you were younger were happier than those who engaged in less energetic activities like darts and snooker.

ACADEMIC SUCCESS DOESN'T GUARANTEE TOP EARNINGS FOR FORTYSOMETHINGS

Doing well at school can open the door to better jobs, but it isn't always enough to secure a top income. Researchers have used BCS70 data to show that people who grew up with advantages, like a wealthier family or a private school education, were the most likely to be in the top 15% of earners by their early forties.

OLD HABITS DIE HARD

It appears we form habits at a young age. A recent study using BCS70 showed that those who watched a lot of TV when they were ten were the most likely to binge on television at age 42. Watching more TV at this age is linked with poor health outcomes such as obesity.

**BCS70 HAS IMPROVED OUR
KNOWLEDGE OF HOW PEOPLE'S
EARLY LIVES SHAPE WHAT
HAPPENS WHEN THEY GROW UP**

WHAT DOES THE 2016-18 SURVEY INVOLVE?

You will be contacted by an interviewer who will invite you to take part. Your participation is, of course, entirely voluntary.

The interviewer will arrange a convenient time to call at your home to conduct the interview.

PAPER QUESTIONNAIRE

Once you have arranged an appointment the interviewer will post you a paper questionnaire. If possible, we would like you to complete it before your interview. The paper questionnaire will include questions about well-being, physical activity and leisure activities, and will take about 20 minutes to complete. The interviewer will collect the questionnaire when they come to your house to conduct your interview.

**YOU CAN MAKE
A UNIQUE
CONTRIBUTION
TO IMPORTANT
RESEARCH**

THE INTERVIEW

The interview will take around 50 minutes and will collect information about lots of different topics, including your family situation, your employment and income, and your health.

As always, you can skip any question you do not wish to answer. For some questions, which might be more private, you will fill in the answers by yourself on the interviewer's laptop.

NURSE VISIT

We would like to follow up your interview with a visit from a nurse. If you agree, a nurse will visit you and ask to take a variety of measurements which will allow researchers to examine the causes and consequences of good and poor health in much more detail.

The health measurements include blood pressure, height and weight measurements and the collection of a blood sample (which will only be done with your written consent).

The interviewer will provide you with a leaflet which tells you more about the nurse visit and will ask whether you are happy to be contacted by a nurse.



WHO TO CONTACT IF YOU NEED MORE INFORMATION

We hope this booklet answers any questions you may have, but if you need any further information please do not hesitate to contact us using the details below.

For information about the 2016-18 Survey, you can contact NatCen on:

- Freephone 0800 526 397
- bcs70@natcen.ac.uk

Your interviewer will also be able to answer any further questions you might have when they contact you to make your appointment for the 2016-18 Survey.

For information about the 1970 British Cohort Study, you can:

- visit www.BCS70.info
- email CLS at bcs70@ucl.ac.uk
- call CLS Freephone on 0800 035 5761
- or write to CLS at FREEPOST RTCK-HBGC-CJSK, 1970 British Cohort Study, Institute of Education, 20 Bedford Way, London, WC1H 0AL.



MORE INFORMATION

WHO IS CARRYING OUT THE SURVEY?

The study is run by the Centre for Longitudinal Studies (CLS), a research centre in the Institute of Education, which is part of University College London. It is funded by the Economic and Social Research Council, the Medical Research Council and the British Heart Foundation. The 2016-18 Survey is being conducted by NatCen Social Research, an independent research institute.

ETHICAL APPROVAL

The 2016-18 Survey has been approved by an independent group of people called a Research Ethics Committee, to protect your safety, rights, wellbeing and dignity.

CONFIDENTIALITY AND DATA SECURITY

The information you provide will be treated in strict confidence in accordance with the Data Protection Act, and used for research purposes only. This means that the data we collect from you is always kept separately from information which could identify you (such as your name and address). When reports based on the data are published, care is taken to ensure that no information which could identify an individual is included.



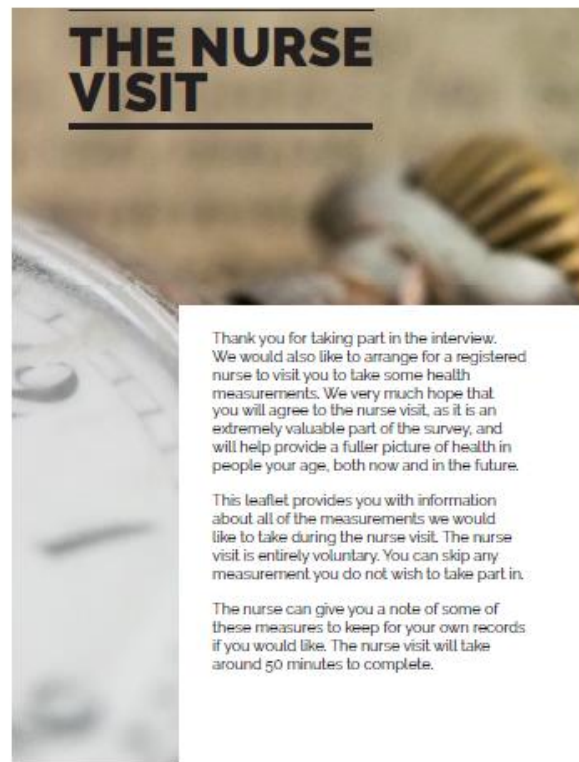
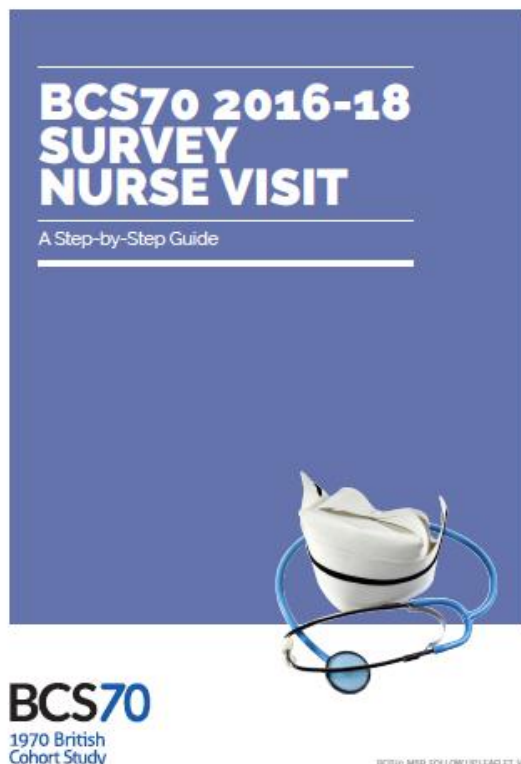
THANK YOU AGAIN FOR CONTINUING TO CONTRIBUTE TO THIS IMPORTANT STUDY

We hope you find the experience enjoyable and interesting

NatCen

Social Research that works for society

Nurse leaflet



MEASUREMENTS

HEIGHT, WEIGHT, BODY FAT, WAIST & HIP MEASUREMENTS

All of these measurements are important in assessing health. Lately there has been much discussion about the relationship between weight, body fat and health. In addition, waist and hip measurements are useful for assessing distribution of weight over the body. A stadiometer will be used to measure your height, a set of scales to measure your weight and body fat, and a tape measure to measure your waist and hip circumference.

BLOOD PRESSURE AND HEART RATE

High blood pressure (also known as hypertension) is one of the biggest risk factors for health conditions such as heart disease and stroke. Collecting data on blood pressure, especially alongside the other types of information collected in BCS70, is therefore extremely valuable in helping us to get a better understanding of health in the population.

It is particularly useful to measure it in BCS70 as we can look at whether there are aspects of people's childhoods that are linked to having high blood pressure later in life.

Blood pressure is measured using an inflatable cuff that goes around the upper arm. The nurse can tell you your blood pressure, along with an indication of its meaning, if you would like. Whilst a diagnosis cannot be made on measurements taken on a single occasion, we can send your blood pressure results to your GP (if you give us permission to do so), as they are best placed to interpret the results in the light of your medical history.



GRIP STRENGTH

We would like to measure your upper body strength by seeing how strong a grip you have. Grip strength is an indicator of people's general health and it has also been shown to be linked to people's future health. Those who have stronger grip strength in their 40s and 50s are more likely to be physically healthier in their 60s. Some studies have shown that grip strength is linked to what people eat. Measuring grip strength in BCS70 will allow us to compare it with data collected when you were younger to see whether early life factors can predict having a strong grip in adulthood.

In order to measure your grip strength we will ask you to grip and squeeze a handle on a small device for a few seconds.

BALANCE

Measuring your ability to balance involves asking you to perform a few simple movements. This measurement can be an indicator of overall health and some studies show there is a link between balance and future health. The nurse will explain exactly what we would like you to do when they visit.

YOUR HEALTH MEASUREMENTS WILL HELP PROVIDE A FULLER PICTURE OF PEOPLE YOUR AGE

BLOOD SAMPLE COLLECTION

The nurse will ask you if you are willing to provide us with a blood sample. This is an important part of the survey, as blood samples will tell us a lot about the health of your generation. We would also like to extract and analyse DNA from your blood sample, to help us to understand how our genes can affect our health and other aspects of our lives.

With your written permission, the nurse will take a blood sample from a vein in your arm.

WHAT WILL MY BLOOD BE TESTED FOR?

Part of the sample will be sent to a medical laboratory to be tested for the following:

- **Total and High Density Lipoprotein (HDL) Cholesterol.** Cholesterol is a type of fat present in the blood, related to diet. Too much cholesterol in the blood increases the risk of heart disease. However, cholesterol is made up of two parts or types; HDL is the 'healthy' type, which helps to keep 'bad' cholesterol levels lower.
- **Glycated haemoglobin.** This is an indicator of long term blood sugar levels and is associated with the risk of developing diabetes.

We would also like to store some of your blood sample for future analysis. This part of your sample will be sent to a specialist storage facility at the University of Bristol.

WHY DO YOU WANT A DNA SAMPLE?

We will ask for your written permission to extract, analyse and store DNA from your blood sample for research purposes. Research shows that an increasing number of illnesses have a genetic component. For example, research using DNA from the blood samples given by participants in the 1958 birth cohort study has led to important breakthroughs in our understanding of the role of genetics in common medical conditions such as diabetes, rheumatoid arthritis and coronary heart disease. Combining information about your genes with all of the other information we have collected about your health and your lifestyle will help researchers to identify which genes are linked to certain conditions. This will help with understanding who is most at risk, which may in turn lead to improved diagnosis, treatment and disease prevention.

CAN YOU LET ME KNOW THE RESULTS?

If you would like, we can send you your total and HDL cholesterol, and glycated haemoglobin results. If you wish, we can also send these results to your GP. We will need your permission to do this. If we send you (or your GP) your results, we can let you (or your GP) know whether or not they are in the normal range.

It will not be possible to routinely feedback any results from genetic testing.

HOW WILL MY BLOOD SAMPLE AND DNA BE STORED?

The blood sample and DNA will be stored securely and anonymously. Your name and address will not be attached to the blood sample when it is sent to the lab, nor will it be stored with your samples. Researchers using your samples will not have access to your name and address.

WHAT WILL THE STORED SAMPLES BE USED FOR?

The samples will be used for research purposes only. They cannot be accessed by lawyers or insurance companies and will not be used for cloning. Any future analysis will be done at the specialist storage facility or at another laboratory, which may be outside the UK. This could include research by the commercial sector. We will not sell or make any profit from the samples you donate and they will only be used in research which meets ethical guidelines.

Researchers who want to use your blood sample or DNA will have to apply for permission to an independent committee which oversees access to the samples and resulting data. Permission to use the samples and resulting data is only given to bona fide researchers who can explain the potential impact of the research and its wider value for society.

The anonymised samples will be treated in strict confidence in accordance with the Data Protection Act.

WHAT IF I CHANGE MY MIND AFTER I HAVE GIVEN A SAMPLE?

You can withdraw your consent for the use of your samples at any time, without giving any reasons, by writing to the Centre for Longitudinal Studies (see details at the end of this booklet). They will inform the laboratory and the stocks of your samples will be destroyed.



WHAT ABOUT HYGIENE STANDARDS?

The survey nurses maintain the highest hygiene standards to reduce any risk of infection. We use a new sterile needle and tubes for every person.

IS ANY SPECIAL EQUIPMENT NEEDED?

Before a needle is inserted into your vein, the survey nurse will apply a tourniquet (a band put round your arm to control your blood flow). This keeps more blood in the vein, making it easier for the nurse to see and access the vein.

WHAT IF I FEEL FAINT?

You might feel faint during or immediately after giving a blood sample, although most people don't. If you begin to feel faint at all, tell the nurse as soon as possible, if you can. The nurse will be watching you for any signs of fainting, and if necessary will stop taking the blood sample.

If you experience any of the following after giving a blood sample, you should seek further help, for instance from your GP or dialling the NHS 111 service (for England and Scotland) or NHS Direct Wales on 0845 4647:

- severe pain
- numbness or persistent 'pins and needles' in the arm, hand or fingers
- swelling which is large or increasing in size
- painful redness/inflammation.

MEASURING YOUR PHYSICAL ACTIVITY

WHAT IS ACTIVITY MONITORING?

We would like you to wear an activity monitor, a small device that records body movements during normal daily activities such as standing up, walking or running. It also captures inactive periods such as time spent sitting or sleeping.

Studies have shown that the time people spend doing physical activity, versus being inactive, can affect their physical and mental health. However, these studies usually rely on asking people to remember the amount of time they have spent doing different activities, which can give inaccurate results.

The information recorded by the activity monitors will let researchers look at the link between physical activity and health in much more detail.

HOW SHOULD I WEAR THE ACTIVITY MONITOR?

The nurse will instruct you on how to wear the monitor and will attach it to the front of your thigh (or you can do this yourself) using a special dressing. Please do not change the positioning of the monitor once it is fixed in place as this will affect the quality of the data.



WHAT IF I AM SICK OR CANNOT DO MUCH PHYSICAL ACTIVITY FOR ANY REASON DURING THE DAYS I AM WEARING THE DEVICE?

Please wear the monitor as normal. We are interested in your physical activity patterns no matter how inactive or active you are.

WHAT IF I DON'T WEAR THE MONITOR FOR THE FULL 7 DAYS?

If you have to take the monitor off before the end of your 7 days, please use the sleep diary to record the date and time you did so, and why you took it off. The dressing used to attach the monitor is regularly used in hospitals and is unlikely to cause any skin irritation. In the unlikely event that the dressing does cause any skin irritation please remove it. Please do not reattach the monitor to your thigh.

WHAT DO I DO AFTER I HAVE WORN THE MONITOR FOR 7 DAYS?

Once your 7 days are over, you will receive a text message and email to remind you that the monitor can be taken off and returned. Please post back the activity monitor, along with the sleep diary, in the pre-paid envelope provided by the nurse as soon as you can.

If you lose the return envelope and need another one please contact NatCen on 0800 526 397.

WILL I GET ANY FEEDBACK ABOUT MY ACTIVITY LEVELS?

Yes, we can send you a summary report of your physical activity during the week you have worn the activity monitor.

HOW LONG DO I NEED TO WEAR IT FOR?

We would like you to leave it on for 7 full days starting from the day after your interview. If you take the monitor off at any time during this period, the data collected during that time will not reflect your true activity levels. The monitor can be worn comfortably at night.

Your nurse will write down for you when the monitor should be taken off.

SHOULD I TAKE IT OFF WHEN I'M IN THE SHOWER?

No. It is waterproof. You can even wear it in the bath or while swimming. We would like you to wear it when you are doing all activities, including water sports, and it is safe for you to do this.

CAN THE MONITOR TRACK MY WHEREABOUTS?

No, the monitor has no GPS technology or camera, and cannot track your whereabouts.

IS THERE ANYTHING ELSE I NEED TO DO?

We would also like you to complete a sleep diary for the period that you are wearing the activity monitor. This will help us interpret the information collected by the activity monitor. It will also act as a reminder of when you can remove the monitor.

WHAT IF I AM GOING THROUGH A METAL DETECTOR OR SCANNER?

The monitor should not set off a metal detector or scanner. However, if you will be passing through an airport security checkpoint in the next 7 days, we suggest that you remove the monitor beforehand. If you will be passing through a metal detector or scanner somewhere else, for example, at your place of work there should be no need to remove the device, unless you feel that it could be a problem if the device was identified.

FINDING OUT WHAT YOU EAT AND DRINK

We would like to collect information about your eating habits. The links between diet and health are well-established, and information about what we eat and drink is an important part of helping us to understand health and illness. This information will be collected using an online dietary questionnaire, on two of the seven days after the nurse visit. Completing the questionnaire will take 10-20 minutes on each of the two days.

YOU CAN MAKE A UNIQUE CONTRIBUTION TO HEALTH RESEARCH



MORE INFORMATION

ETHICAL APPROVAL

The 2016-18 Survey has been approved by an independent group of people called a Research Ethics Committee, to protect your safety, rights, wellbeing and dignity.

INSURANCE COVER

If you agree to your blood pressure or blood sample results being sent to your GP, then she/he may use them in medical reports about you. For example, if you apply for a new life assurance policy, or for a new job. When people apply for new policies, insurance companies may ask if they can obtain a medical report from the GP.

An insurance company cannot ask your GP for a medical report about you without your permission.

Having given your permission, you then have the right to see the report before your GP sends it to the insurance company, and you can ask for the report to be amended if you consider it to be incorrect or misleading.

CONFIDENTIALITY AND DATA SECURITY

The information you provide will be treated in strict confidence in accordance with the Data Protection Act, and used for research purposes only. This means that the data we collect from you is always kept separately from information which could identify you (such as your name and address). When reports based on the data are published, care is taken to ensure that no information which could identify an individual is included.

PREPARING FOR THE NURSE VISIT

There are a few things we would like you to do to prepare for the nurse visit:

- For 30 minutes before the nurse interviewer arrives, please do not eat, smoke or drink alcohol and avoid vigorous exercise, as this could affect your blood pressure readings.
- Please wear light, non-restrictive clothing and avoid anything which is tight (e.g. lycra, tight jeans) or has a thick belt, otherwise your waist and hip measurements will not be accurate. If possible, please do not wear very long garments which may prevent the nurse interviewer from seeing your feet during some of the measurements.
- To take the height, weight and body fat measurements, you will need to remove your shoes and socks or tights, to be barefooted.



WHO TO CONTACT IF YOU NEED MORE INFORMATION

We hope this booklet answers any questions you may have, but if you need any further information please do not hesitate to contact us using the details below.

For information about the 2016-18 nurse visit, you can contact NatCen on:

- Freephone 0800 526 397
- bcs70@natcen.ac.uk

Your nurse will also be able to answer any further questions you might have when they contact you to make your appointment for the 2016-18 Survey.

For information about the 1970 British Cohort Study, you can:

- visit www.BCS70.info
- email CLS at bcs70@ucl.ac.uk
- call CLS Freephone on 0800 035 5761
- or write to CLS at FREEPOST RTCK-HBGC-CJSK, 1970 British Cohort Study, Institute of Education, 20 Bedford Way, London, WC1H 0AL.



THANK YOU AGAIN FOR CONTINUING TO CONTRIBUTE TO THIS IMPORTANT STUDY

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NatCen

Social Research that works for society

Consent forms



BLOOD PRESSURE TO GP CONSENT

1.
I consent to NatCen Social Research/the Centre for Longitudinal Studies informing my General Practitioner (GP) of my blood pressure results.

I am aware that the results of my blood pressure measurement may be used by my GP to help monitor my health and that my GP may wish to include the results in any future report about me.

BP (A)

Please initial the box
if you consent

Initials

Print name (respondent):

Signed (respondent):

Date:

Print name (nurse):

Signed (nurse):

Date:

BLOOD SAMPLE CONSENT

1.
I consent to a qualified NatCen Social Research nurse taking a sample of my blood on behalf of the Centre for Longitudinal Studies for the analysis of cholesterol and glycated haemoglobin
2.
I consent to NatCen Social Research/the Centre for Longitudinal Studies informing my General Practitioner (GP) of the above blood sample analysis results.
3.
I consent to any remaining blood being stored for future analysis.

BS (A)
Please initial the box
if you consent

Initials

Initials

Initials

CONFIRMATION

- I have read and understood the information provided in the "Nurse Visit a Step-by-Step Guide" about giving a blood sample for the 1970 British Cohort Study: 2016-18 Survey.
- I have discussed any outstanding questions with the nurse.
- I wish to provide a blood sample.
- I understand that I can decline to provide the blood sample at any point.
- I understand that this consent remains valid unless revoked by me in writing and that I may withdraw my consent at any time by contacting the 1970 British Cohort Study in writing at FREEPOST RTCX-HBGC-CJSK, 1970 British Cohort Study, Institute of Education, 20 Bedford Way, London WC1H 0AL.

Print name (respondent):

Signed (respondent):

Date:

Print name (nurse):

Signed (nurse):

Date:

DNA EXTRACTION AND STORAGE CONSENT

1.
*I consent to giving a sample of my blood for DNA extraction,
analysis and storage for research purposes.*

Please initial the box
if you consent

Initials

CONFIRMATION

- I have read and understood the information provided in the "Nurse Visit a Step-by-Step Guide" about the extraction and storage of DNA from my blood sample for the 1970 British Cohort Study: 2016-18 Survey.
- I have discussed any outstanding questions with the nurse.
- I am happy for a sample of DNA to be extracted from my blood sample and stored for future analysis.
- I understand that I can decline to provide the DNA sample at any point.
- I understand that this consent remains valid unless revoked by me in writing and that I may withdraw my consent at any time by contacting the 1970 British Cohort Study in writing at FREEPOST RTCX-HBGC-CJSK, 1970 British Cohort Study, Institute of Education, 20 Bedford Way, London WC1H 0AL.

Print name (respondent):

Signed (respondent):

Date:

Print name (nurse):

Signed (nurse):

Date:

ACTIVITY MONITORING TASK CONSENT

Please initial the box
if you consent

1.
*I consent to wear an activity monitor to measure the amount
and types of physical activity I do over a 7 day period.*

Initials

CONFIRMATION

I have read and understood the information provided in
the "Nurse Visit a Step-by-Step Guide" about wearing an
activity monitor for the 1970 British Cohort Study: 2016-18
Survey, and have discussed any outstanding questions
with the nurse.

Print name (respondent):

Signed (respondent):

Date:

Print name (nurse):

Signed (nurse):

Date:

Centre for Longitudinal Studies
UCL Institute of Education
20 Bedford Way
London WC1H 0AL
Tel: 020 7612 6860
Fax: 020 7612 6880
Email: clsfeedback@ucl.ac.uk
Web: www.cls.ucl.ac.uk