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1970 British Cohort Study

Ethical review and consent

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November 2012



Centre for Longitudinal Studies
Following lives from birth and through the adult years
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Introduction

1. 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.

2. 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

3. 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.

4. Following the initial birth survey in 1958, there have to date been eight attempts to trace members of the birth cohort in order to monitor their health and their physical, educational, social and economic development. These were carried out by the National Children's Bureau at 7-years (1965), 9-years (1969), 16-years (1974), and 23-years (1981); by the Social Statistics Research Unit, City University, at 33-years (1991); and by the Centre for Longitudinal Studies, Institute of Education, University of London at 42-years (2000), 46-years (2004) and 50-years (2008)³.

5. Anonymised data from the surveys is made available to the research community via the Economic and Social Data Service⁴.

6. During the age 30 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.

¹ The *National Survey of Health and Development (NSHD)* and the *1970 British Cohort Study (BCS70)*, based on births in GB during one week in 1946 and 1970 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 The birth cohort was augmented by including immigrants born in the relevant week in the target sample for the first three follow-ups (NCDS 1-3).

⁴ <http://www.esds.ac.uk/>

BCS70 and ethical review

7. 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 (MRESs) later removed the need for national studies (like NCDS) or those covering more than one Health Authority area to approach many/all LRECs.

8. 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.

9. MREC ethical approval has been sought for BCS70 follow-ups from 2000 on, 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 surveys⁵.

BCS70 Ethical approval 1970-2008

Survey	Age	Year	Approval	
BBS	Birth	1970	Internal review only*	na
CHES1	7	1975	Internal review only*	na
CHES2	11	1980	Internal review only*	na
Youthscan	16	1986	Internal review only*	na
BCS70	26	1996	Internal review only*	na
BCS70	30	2000	London MREC	
BCS70	34	2004	Internal review only	na
BCS70	38	2008	Southampton & South West Hampshire	08/H0506/144

* = Predates establishment of MRECs in 1997

⁵ For more details see the NHS National Research Ethics Service website: <http://www.nres.npsa.nhs.uk/>

BCS70 and consent

10. 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.

11. 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.

12. For surveys at 26-years (1996), 30-years (2000), 34-years (2004) and 38 years (2008) 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.

13. 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	16266	9,003	55.3
2000	16068	11,261	70.1
2004	13,107	9,656	73.7
2008	11843	8,875	74.9

14. 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.

15. 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.

16. 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.

17. 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.

18. A total of 2,846 cohort members took part in this element of the survey and data was collected about 5,207 children.

<http://www.cls.ioe.ac.uk/shared/get-file.ashx?id=410&itemtype=document>
<http://www.cls.ioe.ac.uk/shared/get-file.ashx?id=417&itemtype=document>

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

Further information

25. Further information is available from the CLS website (<http://www.cls.ioe.ac.uk/>) or by emailing: clsfeedback@ioe.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 NCDS surveys are reproduced below.

BCS70 2000 – 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...”

BCS70 2004 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.

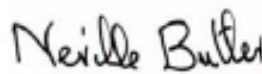
Your answers will be treated in strict confidence in accordance with the Data Protection Act. The information you provide will be used solely to produce a picture of life in Britain today, and will not be released in any way that enables you to be identified. We shall be pleased to send you some of the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

BCS70 2004 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.

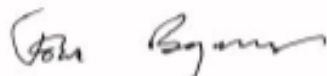
The study is essential for planning services and developing policies to improve the lives of people in Britain. The information collected so far has provided important insights into the way that individual lives are shaped by different factors, from health and family life to education and employment.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

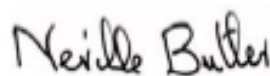
Your answers will be treated in strict confidence in accordance with the Data Protection Act. The information you provide will be used solely to produce a picture of life in Britain today, and will not be released in any way that enables you to be identified. We shall be pleased to send you some of the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

BCS70 2008 – Leaflet accompanying the Advance Letter

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: bc570@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.

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