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Millennium Cohort Study

Consent to linkage to child health data

Peter Shepherd

February 2013

Centre for Longitudinal Studies
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First published in February 2013 by the
Centre for Longitudinal Studies,
Institute of Education, University of London
20 Bedford Way
London WC1H 0AL
www.cls.ioe.ac.uk

ISBN 978-1-906929-59-6

The Centre for Longitudinal Studies (CLS) is an Economic and Social Research Council (ESRC) Resource Centre based at the Institution of Education (IOE), University of London. It manages three internationally-renowned birth cohort studies: the 1958 National Child Development Study, the 1970 British Cohort Study and the Millennium Cohort Study. For more information, visit www.cls.ioe.ac.uk.

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Contents

Acknowledgements

The UK Millennium Cohort Study (MCS) is funded by the Economic and Social Research Council (ESRC) and a consortium of UK government departments. It is managed by the Centre for Longitudinal Studies (CLS). This work was funded by the Wellcome Trust (grant 084686/Z/08/A).

Many people were involved in the work reported here. Particular thanks are due to CLS staff - George Andrew, Denise Brown, Robert Browne, Peter Deane, Jane Elliott, Jon Johnson, Rachel Rosenberg and Mary Ukah; CLS temporary staff - Elizabeth Aribisala, Kitt Dines, Gemma Hanvey, Pavan Jhoot, Melody Laffy and Jade Summers; and Carol Dezateux from the MRC Centre of Epidemiology for Child Health at the Institute of Child Health, University College London.

Professors Carol Dezateux and Jane Elliott also made helpful comments on drafts of this manuscript.

Summary

S1. In order to enhance the data available for the children in the Millennium Cohort Study (MCS), the Centre for Longitudinal Studies (CLS) has sought written consent from parents to link the MCS data to other records, including health records, that are routinely collected by government departments or agencies, and other public sector organisations.

S2. The main aim of this report is to demonstrate to those responsible for the health records in England, Scotland, Wales and Northern Ireland that all reasonable efforts have been made to ensure that data will only be linked for children whose legal guardians have consented.

S3. A secondary aim of the report is to advise those who may use the data in the future about the total number of cases that are available to link to health data in each of the four UK countries. This will determine the total sample available for analysis and could also be used to inform the construction of weights, or estimation of models, to take account of the response biases and consent biases in the data.

S4. The report describes the different steps that have been taken to ensure that the electronic records of consent are as accurate as possible. This work was funded by Wellcome Trust, as part of a project that aims to use health record linkage in the MCS to investigate childhood obesity, asthma and infections.

S5. During the MCS age 7 survey, interviewers recorded the signatory's reference number on the consent form so that CLS could check that they were in fact the cohort child's legal guardian. Interviewers were instructed that, if at all possible, they should ask the child's natural mother to sign these forms.

S6. When the survey was completed, initial checks were carried out by the survey contractor to ensure that all necessary consent forms had been returned and were correctly completed. Information on the forms was cross-checked with information obtained during the interviews to ensure that forms were signed by the correct respondents. Problems were referred back to the interviewer to be rectified.

S7. The vast majority of parents (13,047 - 92.9%) gave consent for their child's health records to be accessed.

S8. The review of the consents was based on intensive clerical work seeking to verify the electronic record of consents provided by the survey contractor against signatures and other information on the paper consent forms. This work was necessary to confirm that consent was given and by whom. These verifications are essential for ethical and governance reasons.

S9. Legally, consent for the cohort child's health records to be linked should be obtained from a person with 'parental responsibility'. In addition to the natural mother, a number of others may also have parental responsibility. The information on the consent form regarded as enough for legal consent is: a) child name; b) parent/adult name; c) consent box ticked; d) parent/adult signature; and e) parent/adult considered to have parental responsibility.

S10 Following pilot checks, CLS is reviewing the child health record consents for: a) all cases where the mother is not the main respondent (433 cases); b) a 10% random sample of cases where the mother is the main respondent (1,228 cases) – as a quality check; c) all twins (328 cases, ie: 164 sets of twins); and d) all triplets (33 cases, ie: 11 sets of triplets)

S11. As a result of the checking process, the total number of cases that are available for data linkage has been reduced from 13,047 to 12,517, or 89.1 per cent of the total number of cohort children surveyed as part of the age 7 survey. These comprise: 8,029 children in England; 1,745 in Wales; 1,511 in Scotland; and 1,232 in Northern Ireland.

Introduction

1. In order to enable the enhancement of data available for the children who are the subjects of the Millennium Cohort Study (MCS), written consent has been sought from parents to obtain additional information from records that are routinely collected by government departments or agencies, and other public sector organisations. These include health records and the main aim of this report is to demonstrate to those responsible for these records in the four countries of the UK that all reasonable efforts have been made to ensure that linkage will only be sought for children where consent has been given by someone with legal parental responsibility.

2. The report describes and documents the different steps that have been taken to ensure that the electronic records of consent to linkage to child health data are as accurate as possible.

3. The work was funded by Wellcome Trust as part of a project that aims to use health record linkage in Millennium Cohort Study (MCS) to investigate childhood obesity, asthma and infections.[1]

4. As a result of the checking process the total number of cases that are available for data linkage has been reduced from 13,047 to 12,736. This corresponds to 90.7 per cent of the total number of cohort children surveyed as part of sweep 4 of MCS.

5. A secondary aim of the report is to advise future researchers, and users of the data, about the total numbers of cases that are available for linkage to health data in each of the four countries of the UK. This will determine the total sample available for analysis and could also be used to inform the construction of weights, or estimation of models, to take account of the response biases and consent biases in the data.

6. Below, a brief summary of MCS will be followed by a detailed account of account of the work that has been undertaken to check the record of consents to child health linkage obtained during the survey carried out when the members of the birth cohort were aged 7 years.

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[1] The Principal Investigator of this project is Professor Carol Dezateux (Institute of Child Health University College London [ICH]) with co-investigators from ICH including Dr. Helen Bedford, Dr Tito Castillo and Dr Mario Cortina-Borja, from the Centre for Longitudinal Studies (CLS) Professor Jane Elliott and from Imperial College Dr Mitch Blair.

Millennium Cohort Study

7. The Centre for Longitudinal Studies (CLS) is responsible for MCS. It is a multi-disciplinary research project following the lives of around 19,000 children born in the UK in 2000/1. It is the most recent of Britain's world-renowned national longitudinal birth cohort studies. The study has been tracking the Millennium children through their early childhood years and plans to follow them into adulthood. The four surveys of MCS cohort members carried out so far – at age nine months, three, five and seven years – have built up a uniquely detailed portrait of the children of the new century. They have also amassed a vast amount of information on the children's siblings and parents. The study was commissioned by the Economic and Social Research Council (ESRC), whose funding has been supplemented by a consortium of Government departments and by the above grant from the Wellcome Trust. The next sweep of the study is being carried out in 2012.

Consents

8. The review of the consents to linkage to child health records was based on an intensive clerical task seeking to verify the electronic record of consents provided by the survey contractor against signatures and other information on the paper consent form completed during the seven-year survey in 2008 (MCS4). This work was necessary to confirm that consent was given and by whom. These verifications are essential for ethical and governance reasons.

9. The MCS4 sweep was developed by CLS in consultation with scientific advisers from a variety of disciplines and the survey contractor - the National Centre for Social Research (NatCen). It gathered information from parents, children and teachers. The various elements of are outlined below (Box 1). For more details see the *Millennium Cohort Study Sweep 4 Technical Report* available at: http://www.cls.ioe.ac.uk/core/documents/download.asp?id=1441&log_stat=1

10. An important requirement for the MCS4 survey was that all adult respondents had to give informed consent in writing to take part in the study. Written consent was also required from a parent or guardian for the participation of a child. The survey received ethical approval from the Northern and North Yorkshire Research Ethics Committee (Ref: 07/MRE03/32)

11. In addition, consent was also sought to obtain additional information about the cohort children from their teachers and about the family from records that are routinely collected by government departments or agencies, and other public sector organisations – see Appendix 1. A leaflet, *Information from other sources,* explained in detail what information was being sought. Interviewers gave, or sent, this leaflet to MCS family when making an appointment to visit so the parents could read the information before the interview. A copy of the leaflet can be found in Appendix 2.

Box 1: Elements of the MCS4 sweep

Household questionnaire
Main respondent interview (CAPI and CASI)*
Partner interview (CAPI and CASI)*
Child cognitive assessments
Sally and Anne
Word reading or Our Adventures
Progress in Maths
Pattern Construction
Child physical measurements
Height

Weight and body fat
Waist
Physical activity monitoring
Interviewer observation of the conditions in which the cognitive assessments were conducted

Child paper self-completion questionnaire
Collection of consents
Data collection
Information from other sources (ie: permission for the teacher survey, and release of education, health and economic records
Teacher survey

* CAPI=Computer-Assisted Personal Interviewing (face-to-face interview); CASI= Computer-Assisted Self Interviewing (self-completion)

Five MCS4 consents

12. There are five consent forms associated with MCS4:

Consent 1: Main respondent - The purpose of this form was to gain consent to administer the survey, and also to gain permission to access information from other sources for the main respondent.

The consent form was split into two parts:

> **_Part A_** was used to gain consent to administer the CAPI and CASI for the main respondent, and it was necessary for this part of the form to be completed before the interviewer started to administer the CAPI to the main respondent.
>
> **_Part B_** was used to gain permission to release the main respondent’s routine health and economic records; this part was completed at the end of the main respondent interview.

Consent 2: Cohort child data collection - This form was used to gain consent from either the main respondent or partner for the administration of the cohort child data-collection elements: cognitive assessments and physical measurements, physical activity monitoring and child self-completion questionnaire. All sections of this consent form had to be completed by the same parent or guardian.

There were several opportunities to complete this consent form. Consents for the assessments and measurements were asked immediately after information about the household was collected (using the household grid) and again at the end of the main questionnaire (if not collected after the household grid included in the *Household questionnaire* above). CAPI also asked interviewers to confirm that written consent had been obtained prior to administering each of the child elements.

For the child self-completion questionnaire, interviewers were asked to collect consent immediately after the household grid or at the end of the main questionnaire. For the activity monitor interviewers were prompted to explain it and collect consent after the physical measurements were taken.

Consent 3: Cohort child - information from other sources - In the main respondent questionnaire there were many questions about the cohort child's experiences at school and their health and education. To supplement this information, permission was asked to send a questionnaire to the cohort child's school teacher, and to access information held in routine records on education and health:

> ***Part A*** of this consent form sought consent to administer the teacher questionnaire. Details of the Teacher Survey are contained in a separate technical report.
>
> ***Part B*** of this consent form asked for parental consent to access information held in routine records on education and health.

Interviewers were prompted to collect this consent at the end of the main respondent interview, although the form could be signed by either the main respondent or the partner.

Consent 4: Siblings - health and education records - This form was used to gain permission from either the main respondent or partner to access the routine health and education records of the cohort child's siblings in order to gain further insights into the cohort child's development in relation to their siblings.

All types of siblings were eligible to be selected (natural, step, foster, adoptive, half) and up to four children were selected by the CAPI, and their names and other details will be shown on the consent screen. If there were more than four siblings, the four youngest were to be selected.

Interviewers were prompted to collect this consent at the end of the main respondent interview, although the form could be signed by either the main respondent or the partner.

Consent 5: Partner respondent - The purpose of this form was to gain consent from the partner to administer the survey, and also to gain permission to access information from other sources.

> ***Part A*** of this form was used to obtain consent from the partner respondent to administer the survey (CAPI and CASI), and interviewers were prompted to collect this consent before administering the CAPI to the partner.
>
> ***Part B*** was used to gain permission to release the partner's routine health and economic records; this part was completed at the end of the partner interview.

13. The consent forms were carbon-backed and printed in triplicate. One copy was retained by the respondent, and the other two copies returned by interviewers to NatCen's operations department. Copies of the consent forms can be found in Appendix 1.

Who could consent?

14. Any parent or parent-figure was able to give consent for the data collection elements relating to the cohort child, regardless of their relationship to the child. So for example, a step-parent could give consent for the cohort child cognitive assessments and physical measurements, placement of the cohort child self-completion questionnaire, and physical activity monitoring (Consent 2). This is because these consents were an ethical rather than a legal requirement, so it was not necessary for the person signing the form to have legal parental responsibility for the child. However, in general, if natural parents were available, interviewers were advised to seek the consent of that parent.

15. In relation to gathering information about the cohort child from other sources and linking to health and education records (Consent 3), there were legal restrictions about who could give permission. Interviewers were therefore required to ensure they recorded the reference number of the person who signed the form correctly on this consent form in order that their relationship to the cohort child could be checked by CLS to establish whether or not they were legally able to give permission for the information to be released. Interviewers were instructed that, if at all possible, they should ask the child's natural mother to sign these forms.

16. A person whose mother tongue was English but who could not read and understand the advance leaflets or consent forms for themselves because of literacy problems or poor vision could have the leaflets and consent forms read out to them. Large-type copies of the leaflets and consent forms were available on request.

17. Interviewers were reminded that consent from a parent or guardian did not imply consent from the child, who retained the right to decide whether or not to take part in the survey.

Checks undertaken by the survey contractor

18. Following the completion of the survey, initial checks were carried out by NatCen, including those to ensure that all necessary consent forms had been returned and were correctly completed. The information written on the forms was cross-checked with the sample data contained in the MCS4 survey interviews to ensure that the forms were signed by the correct respondents. If any problems came to light during the checking, the interviewer was contacted so the problems could be rectified as soon after the interview was completed as possible.

Consent rates for data linkage

19. Overall, the majority of respondents gave permission for information from routine records to be accessed. The focus of the health record linkage project is on the MCS4 Consent 3 which includes consent to linkage to child health records. The records of the survey agency show that the vast majority of parents (92.9%) gave consent for their child's health records to be accessed. (Table 1)

Table 1: Consent rates for child health data linkage recorded during the MCS4 survey

	UK	%
Base: Total cohort children in productive households	14043	100.0
Parents recorded as consenting to child health data linkage	13047	92,9

20. A revised table indicating the estimated number of legal consents is to be found at paragraph 72 below.

Electronic data supplied to CLS

21. Once the survey contractor had completed all initial data preparation and checks, electronic data for all elements of the MCS4 survey were supplied to CLS. It is important to note that the data made available for Consent 3 only recorded whether or not consent had been given to the teacher survey, to linkage to health and to education records. Other information as it appeared on the consent form was not included on the electronic record, for example, the name of the child, the name and person number of the adult giving consent and the presence of a signature.

22. Separately, electronic data taken from the MCS address database and the household grid completed before the main MCS4 interview were available for the cohort child and the respondents to the main and partner interview, including names, sex, relationships and person numbers.

Verifying consents

23. It follows that, as noted at 4 above, an important initial phase of the project is an intensive clerical task seeking to verify the electronic record of consents provided by the survey contractor against the information on the paper consent form completed during the MCS4 survey. This work is necessary to confirm that consent was given by an adult deemed to have parental responsibility and to identify the participants whose data will be linked now and in the future up to the age of 14 years. These verifications are essential for ethical and governance reasons.

24. The information on the consent form, or derived from it, that must be verified against existing electronic data is

a) Child name on form
b) Parent/adult name on form
c) Consent box ticked on form
d) Consent on form consistent with electronic data provided by survey contractor
e) Parent/adult signature on form
f) Parent/adult signature dated on the form
g) Parent/adult person number on form
h) Relationship of the parent/adult consenting to the child
i) If not the natural mother, the relationship to the natural mother of the person consenting
j) If parent/adult has parental responsibility

NB: Items a), b), c), e) and j) are required in order to confirm that legal consent to child health data linkage has been obtained.

25. To achieve this, a number of steps have been taken:

a) MCS4 consent forms have been scanned and indexed so that that verification will not require the handling of large volumes of paper. The processing of some 62,000 consent forms took over 800 hours.
b) Existing electronic data have been extracted for the cohort child and the respondents to the main and partner interview, including names, sex, relationships and person numbers.
c) A pilot exercise has been carried out on a sample of cases comparing the data CLS already hold about consents against the information on the consent forms.
d) In the light of the findings from the pilot, additional, more detailed checks have been carried out on a larger number of cases selected from the existing CLS electronic record.

Pilot checking

26. The pilot exercise comparing the data CLS already hold about consents against the information on the consent forms for a small sample of cases was designed to provide

insight into the practicalities of verifying the consents and an indication of the quality of the electronic data on consent. Further details are given in Appendix 4.

Main checking

27. There are some 13,000 MCS4 consent forms and given the project timetable and available resources it was decided to check a representative sample of consent forms. Hence, in the light of the findings from the pilot, additional, more detailed checks have been carried out on a larger number of cases selected from the existing CLS electronic record. The MCS4 consents selected are described below, together with the reasons for their selection (Table 2):

Table 2: Selection of cases for verification and checking of consent forms

Selected cases	*Reason selected*
a) All cases where the mother is not the main respondent (433 cases)	Concern to check that the person who gave consent was legally entitled to do so
b) A ten per cent random sample of cases where the mother is the main respondent (1,228 cases)	Concern to check the quality of the existing data on consent and that consent was given by the natural mother or another person with parental responsibility
c) All twins (328 cases, ie: 164 sets of twins) d) All triplets (33 cases, ie: 11 sets of triplets)	Concern to check that: • the person who gave consent was legally entitled to do so • in the light of the pilot checking exercise, if a consent form had been completed for each child

28. Initial checking relied on comparing the information that CLS already hold on MCS4 parental consent to health record linkage for the cohort child against the information on the consent forms that have been scanned. Information on the former was placed in an Access database and checked against the content of the later. Relying on the experience gained in the pilot exercise most information was pre-filled for each sample case to minimise the time taken. More details of this checking procedure can be found in Appendix 5.

29. Following these initial checks, additional work to verify the consents to child health linkage was undertaken as outlined in Table 3.

Table 3: Additional verification and checking of consent forms

Cases	*Additional checks*
a) Where scan is missing	Search for paper consent form
b) Where scan is illegible	Reference to paper consent form

Cases	*Additional checks*
c) Where the mother is not the main respondent	Relationship to the natural mother of the person giving consent and their legal status in relation to parental responsibility
d) Where the mother is the main respondent	Where the person giving consent is found to be not the natural mother, their relationship to the mother and their legal status in relation to parental responsibility
e) Twins	Where the person giving consent is not the natural mother, their relationship to the mother and their legal status in relation to parental responsibility; and where consent for 1 twin is missing, further checks among scans and/or contact with parents
f) Triplets	Where the person giving consent is not the natural mother, their relationship to the mother and their legal status in relation to parental responsibility; and where consent for 1 or more triplets is missing, further checks among scans and/or contact with parents

Parental responsibility

30. Legally, consent to record linkage for the cohort child should be obtained from a person with ‘parental responsibility’. As noted at 11 above, interviewers were instructed that, if at all possible, they should ask the child’s natural mother to complete Consent 3. Appendix 3 identifies others who may also have parental responsibility. These are summarised in Table 4.

Table 4: Identification of adults considered to have parental responsibility

Those with parental responsibility	*Can be identified from existing data?*
a) Natural mother	Yes
b) Natural father married to the natural mother	Yes
c) Adoptive mother	Yes
d) Adoptive father	Yes
e) Natural father not married to the natural mother but who has a court registered parental responsibility agreement with the mother or a parental responsibility order or a residence order from the courts.	No
f) Married step-parent or registered civil partner who has a parental responsibility order or a residence order from the courts.	No

Those with parental responsibility	***Can be identified from existing data?***
g) Unmarried step-parent who has adopted the child or has a parental responsibility order, a residence order; or special guardianship	No
h) A testamentary guardian will acquire parental responsibility if no one with parental responsibility survives the testator.	No
i) A guardian appointed by a court	No

31. The checks carried out for each of the groups of cases identified at 23 above are summarised below.

Legal consent to data linkage

32. As noted above (paragraph 23), the information on the consent form regarded as enough for legal consent is:

a) Child name on form
b) Parent/adult name on form
c) Consent box ticked on form
d) Parent/adult signature on form
e) If parent/adult has parental responsibility

Cases where the mother is not the main respondent

33. As noted at 23 above, the main concern with this group of consents (from 433 respondents) relates to the status of those who gave consent to the linkage to child health records. Although the child's mother is not recorded as the main respondent, given the guidance to interviewers to seek out the mother's signature (see 11 above), it is possible that the natural mother of the child did sign the consent form.

34. Appendix 6 summarises the initial review of the scanned consent forms for these cases and shows that scans of consent forms were found for almost all cases and that most information had been completed. However, there were a small number of cases where key elements considered necessary for legal consent to child health linkage – *ie:* the name of the cohort child, a tick in the consent to linkage box or parent signature – were missing.

35. As noted at 11 above, interviewers were required to ensure they recorded the reference number of the person who signed the form correctly on the form so that their relationship to the cohort child could be checked by CLS to establish whether or not they were legally able to give permission for the information to be released. Although the majority of the person numbers recorded on the consent form are those of the main or partner respondent, in a minority of cases these appeared to relate to some other person.

36. Fortunately, the clerical checking included a comparison of the name of the parent giving consent recorded on the consent forms against the existing electronic data provided by the survey contractor. This reveals that in over 9 out of 10 cases, consent to child health linkage was given by the person who completed the main interview or the partner interview during the MCS4 survey.

37. Further analysis reveals that most consent forms were completed by the natural mother or father; or by the grandmother of the child. The majority of natural fathers consenting to health record linkage were either married (to the natural mother or lone parents) (Table 5).

Table 5: Relation to the cohort child of person giving consent to health linkage and relationship between parents where the mother is not the main respondent*

	Single parent	Married	Cohabiting	Neither	Unknown	NA	Total
Natural mother	0	25	5	0	0	0	30
Natural father	87	179	25	22	0	0	313
Adoptive mother	4	6	1	0	0	0	11
Adoptive father	0	2	0	0	0	0	2
Foster mother	0	0	0	1	0	0	1
Step mother	0	1	2	0	0	0	3
Step father	0	0	5	0	0	0	5
Grandmother	0	0	0	0	0	36	36
Grandfather	0	0	0	0	0	1	1
Other, female	0	0	0	0	0	3	3
Other, male	0	0	0	0	0	1	1
No name on form	0	0	0	0	4	0	4
Needs further review	0	0	0	0	8	0	8
No scan	0	0	0	0	15	0	15
TOTAL	**91**	**213**	**38**	**23**	**27**	**41**	**433**

* Figures for those with parental responsibility are shown in bold

38. This analysis also shows that legal status (in relation to parental responsibility) of the person giving consent is uncertain or unlikely or consent inadequate in nearly 50 percent of cases (Table 6).

Table 6: Parental responsibility and consent to child health record linkage where the mother is not the main respondent

Parental and consent status	Number	%
Those with parental responsibility and adequate consent*		
a) Natural mother	30	6.9
b) Natural father married to mother	179	41.3
c) Adoptive mother	11	2.5
d) Adoptive father	2	0.5
All with parental responsibility and adequate consent	222	51.3
Those where parental responsibility is uncertain despite adequate consent*		
e) Natural father and lone parent, etc	87	20.1
f) Step mother	3	0.7
g) Step father	5	1.2
h) Grandmother	36	8.3
i) Grandfather	1	0.2
j) Other female	3	0.7
k) Other male	1	0.2
l) Other	61	14.1
m) No scan	8	1.8
All where parental responsibility is uncertain despite adequate consent	205	47.4
Those where parental responsibility is unlikely despite adequate consent*		
n) Foster mother	1	0.2
All where parental responsibility is unlikely despite adequate consent	1	0.2

Parental and consent status	Number	%
Those where consent is inadequate irrespective of parental responsibility*		
o) No child name on form	0	0.0
p) No consent tick	3	0.7
q) No parental signature	2	0.5
All where consent is inadequate irrespective of parental responsibility	5	1.2
TOTAL	**433**	**100.0**

***** The following are required to confirm that adequate consent to child health data linkage has been obtained: (a) child name on form; (b) parent/adult name on form; (c) consent box ticked on form; (d) parent/adult signature on form; and (e) parent/adult giving consent has parental responsibility

39. In those cases where parental responsibility is uncertain, valid consent was deemed not to exist precluding seeking of health record linkage.

Cases where the mother is the main respondent

40. As noted at paragraph 26 above, the main concern with this group of consents is to establish the quality of the existing data on consent for these cases and that consent was given by the natural mother or, failing this, some other person with parental responsibility. As the majority of consents are attributed to the main respondent to the survey, and the majority of main respondents are mothers (>12,000), the verification of consents was based on a ten per cent random sample of cases (1,228 cases) to ensure that the work could be carried out within the timescale and resources available.

41. Appendix 7 summarises the initial review of the scanned consent forms for these cases and shows that scans of consent forms were found for all but 3 cases and that most information had been completed. However, there were a small number of cases where key elements considered necessary for legal consent to child health linkage – *ie:* a tick in the consent to linkage box or parent signature – were missing.

42. As noted above, interviewers were required to ensure the reference number of the person who signed the form was correctly recorded on the consent form so that their relationship to the cohort child could be checked by CLS to establish whether or not they were legally able to give permission for the information to be released. Again, although the majority of the person numbers recorded on the consent forms are those of the main or partner respondent, an important minority appear to relate to some other person.

43. Fortunately, the clerical checking included a comparison of the name of the parent giving consent as recorded on the consent forms against the existing electronic data provided by the survey contractor. This reveals that in almost every case consent to child

health linkage was given by the person who completed the main interview during the MCS4 survey.

44. Further analysis reveals that all but a very few consent forms were completed by the natural mother. It also shows that a small number of consents were given by natural fathers or stepfathers (Table 7).

Table 7 Relation to the cohort child of person giving consent to health linkage and relationship between parents for the 10% sample of cases where the mother is the main respondent*

	Single parent	**Married**	**Cohabiting**	**Neither**	**Unknown**	**Total**
Natural mother	236	715	177	54	30	1212
Natural father	3	7	0	0	1	11
Step father	0	1	1	0	0	2
No scan	0	0	0	0	3	3
TOTAL	**239**	**723**	**178**	**54**	**34**	**1228**

* Figures for those with parental responsibility are shown in bold

45. This analysis also shows that legal status (in relation to parental responsibility) of the person giving consent is uncertain or unlikely or consent inadequate in nearly is uncertain in just over 2 percent of cases (Table 8).

Table 8: Parental responsibility and consent to child health record linkage for the 10% sample of cases where the mother is the main respondent

Parental and consent status	Number	%
Those with parental responsibility and adequate consent*		
a) Natural mother	1192	97.1
b) Natural father married to the natural mother	6	0.5
All with parental responsibility and adequate consent	1198	97.6
Those where parental responsibility is uncertain despite adequate consent*		
c) Natural father and lone parent/unknown	4	0.3
d) Step father	2	0.2
e) No scan	3	0.2
All where parental responsibility is uncertain despite adequate consent	9	0.7
Those where consent is inadequate irrespective of parental responsibility*		
f) No child name on form	3	0.2
g) No consent tick	9	0.7
h) No parental signature	9	0.7
All where consent is inadequate irrespective of parental responsibility	21	1.6
TOTAL	**1228**	**100.0**

***** The following are required to confirm that adequate consent to child health data linkage has been obtained: (a) child name on form; (b) parent/adult name on form; (c) consent box ticked on form; (d) parent/adult signature on form; and (e) parent/adult giving consent has parental responsibility

Twins

46. As noted at paragraph 26 above, the main concern with this group of consents is to establish that consent to access the child's health records was given by the natural mother or, failing this, some other person with parental responsibility. In addition, the pilot checking exercise showed that a separate consent form was not always completed for each child. Both children were sometimes named on a single form. Accordingly, checks were carried out for all twins.

47. Appendix 6 summarises the initial review of the scanned consent forms for these cases and shows that, once again, scans of consent forms were found for almost all cases and that most information had been completed. However, there were a small number of cases where key elements considered necessary for legal consent to child health linkage – *ie:* the name of the cohort child, a tick in the consent to linkage box or parent signature – were missing.

48. As noted above, interviewers were required to ensure they correctly recorded on the consent form the reference number of the person who signed the form so that their relationship to the cohort child could be checked by CLS to establish whether or not they were legally able to give permission for the information to be released. Again, although the majority of the person numbers recorded on the consent form are those of the main or partner respondent, an important minority are appear to relate to some other person.

49. Fortunately, the clerical checking included a comparison of the name of the parent giving consent as recorded on the consent forms against the existing electronic data provided by the survey contractor. This reveals that in over 9 out of 10 cases, consent to child health linkage was given by the person who completed the main interview during the MCS4 survey.

50. As noted above, the pilot checking exercise showed that a consent form was not always completed for each twin. Both children were sometimes named on a single form. Accordingly, checks were carried out for all twins and these show that, in a significant number of cases, both children were named on a single consent form – 108 (35.46%) of the 305 children for whom a consent form was found. (Table 9)

Table 9: Twins - Children named per form

	Number	**%**
One form per twin child	197	60.1
Both children named on one form	108	32.9
No scan	23	7.01
TOTAL	**328**	**100.0**

51. Further analysis reveals that all but a very few consent forms were completed by the natural mother. It also shows that a small number of consents were given by natural fathers or stepfathers. (Table 10)

Table 10: Twins - Relation to the cohort child of person giving consent to health linkage and relationship between parents*

	Single parent	Married	Cohabiting	Neither	Unknown	Total
Natural mother	53	221	14	6	0	294
Natural father	0	5	0	0	5	10
Grandmother	0	1	0	0	0	1
No scan	0	0	0	0	23	23
TOTAL	**53**	**227**	**14**	**6**	**15**	**328**

* Figures for those with parental responsibility are shown in bold

52. This analysis also shows that legal status (in relation to parental responsibility) of the person giving consent is uncertain or unlikely or consent inadequate in slightly less than 9 per cent of cases (Table 11)

Table 11: Twins - Parental responsibility and consent to child health record linkage

Parental and consent status	Number	%
Those with parental responsibility and adequate consent*		
a) Natural mother	294	89.6
b) Natural father married to mother	5	1.5
All with parental responsibility and adequate consent	299	91.2
Those where parental responsibility is uncertain despite adequate consent*		
c) Grandmother	3	0.9
d) No scan	23	7.0
All where parental responsibility is uncertain despite adequate consent	26	7.9

Parental and consent status	Number	%
Those where consent is inadequate irrespective of parental responsibility*		
e) No child name on form	0	0.0
f) No consent tick	0	0.0
g) No parental signature	3	0.9
All where consent is inadequate irrespective of parental responsibility	3	0.9
TOTAL	**328**	**100.0**

***** The following are required to confirm that adequate consent to child health data linkage has been obtained: (a) child name on form; (b) parent/adult name on form; (c) consent box ticked on form; (d) parent/adult signature on form; and (e) parent/adult giving consent has parental responsibility

Triplets

53. As noted at 23 above, the main concern with this group of consents is to establish that consent to access the child's health records was given by the natural mother or, failing this, some other person with parental responsibility. In addition, the pilot checking exercise showed that a separate consent form was not always completed for each triplet child. All three were sometimes named on a single form. Accordingly, checks were carried out for all triplets.

54. Appendix 6 summarises the initial review of the scanned consent forms for these cases and shows that, once again, scans of consent forms were found for almost all cases and that, for this group, all information had been completed.

55 As noted above, interviewers were required to ensure the reference number of the person who signed the form was correctly recorded on the consent form so that their relationship to the cohort child could be checked by CLS to establish whether or not they were legally able to give permission for the information to be released. Again, although the majority of the person numbers recorded on the consent forms are those of the main respondent, there are some that appear to relate to some other person.

56. Fortunately, the clerical checking included a comparison of the name of the parent giving consent as recorded on the consent forms against the existing electronic data provided by the survey contractor. This reveals that in over 8 out of 10 cases, consent to child health linkage was given by the person who completed the main interview during the MCS4 survey.

57. As noted above, the pilot checking exercise showed that a consent form was not always completed for each triplet child. All three children were sometimes named on a single form. Accordingly, checks were carried out for all triplets and these show that, in a

significant number of cases, all the children were named on a single consent form – 13 (46.4%) of the 28 children for whom a consent form was found. (Table 12)

Table 12: Triplets - Children named per form

	Number	%
One form per triplet child	15	45.5
All children named on one form	13	39.4
Needs further review	5	15.2
TOTAL	**33**	**100.0**

58. Further analysis reveals that all but a very few consent forms were completed by the natural mother. It also shows that a small number of consents were given by natural fathers or stepfathers. (Table 13)

Table 13: Triplets - Relation to the cohort child of person giving consent to health linkage and relationship between parents*

	Single parent	Married	Neither	Unknown	Total
Natural mother	6	18	1	0	25
Natural father	3	0	0	0	3
No scan	0	0	0	5	5
TOTAL	**9**	**18**	**1**	**5**	**33**

* Figures for those with parental responsibility are shown in bold

59. This analysis also shows that legal status (in relation to parental responsibility) of the person giving consent is uncertain or unlikely or consent inadequate in around 1 in 4 cases (Table 14).

Table 14: Triplets - Parental responsibility and consent child health record linkage

Parental and consent status	Number	%
Those with parental responsibility and adequate consent		
a) Natural mother	25	75.8
All with parental responsibility and adequate consent	25	75.8
Those where parental responsibility is uncertain despite adequate consent		
b) Natural father and single parent	3	9.1
c) No scan	5	15.2
All where parental responsibility is uncertain despite adequate consent	8	24.2
Those where consent is inadequate irrespective of parental responsibility***		
d) No child name on form	0	0.0
e) No consent tick	0	0.0
f) No parental signature	0	0.0
All where consent is inadequate irrespective of parental responsibility	0	0.0
TOTAL	**33**	**100.0**

***** The following are required to confirm that adequate consent to child health data linkage has been obtained: (a) child name on form; (b) parent/adult name on form; (c) consent box ticked on form; (d) parent/adult signature on form; and (e) parent/adult giving consent has parental responsibility.

Differences between the countries of the UK

60. Tables 15 to 18 below reveal that for the four groups of cases identified above, there are some differences between the four countries of the UK in the relationship to the cohort child of the person giving consent to child health linkage and in their associated parental responsibility.

61. In practice, it will be necessary to arrange any linkage of child health records with the responsible authority in each of the four countries of the UK,

Table 15: Cases where the mother is not the main respondent – parental responsibility by country

	England	Wales	Scotland	N. Ireland	Total
Those with parental responsibility and adequate consent*					
a) Natural mother	22 6.3%	4 11.5%	3 10.9%	1 4.2%	30 6.9%
b) Natural father married to the natural mother	158 45.6%	5 15.0%	7 25.3%	9 36.1%	179 41.3%
c) Adoptive mother	10 2.90%	1 2.60%	0 0.00%	0 0.00%	11 2.50%
d) Adoptive father	1 0.30%	0 0.00%	0 0.00%	1 4.20%	2 0.50%
All with parental responsibility and adequate consent	191 55.1%	10 28.6%	10 37.0%	11 45.8%	222 51.3%
Those where parental responsibility is uncertain despite adequate consent*					
e) Natural father and lone parent, etc	62 17.8%	10 29.9%	9 31.5%	6 26.4%	87 20.1%
f) Step mother	3 0.9%	0 0.0%	0 0.0%	0 0.0%	3 0.7%
g) Step father	5	0	0	0	5

	England	Wales	Scotland	N. Ireland	Total
	1.4%	0.0%	0.0%	0.0%	1.2%
h) Grandmother	26 7.4%	6 16.4%	4 13.8%	1 3.9%	36 8.3%
i) Grandfather	1 0.3%	0 0.0%	0 0.0%	0 0.0%	1 0.2%
j) Other female	3 0.9%	0 0.0%	0 0.0%	0 0.0%	3 0.7%
k) Other male	0 0.0%	0 0.0%	1 3.6%	0 0.0%	1 0.2%
l) Other	49 14.1%	5 14.8%	3 11.1%	4 16.7%	61 14.1%
m) No scan	5 1.4%	2 6.1%	0 0.0%	1 4.4%	8 1.8%
All where parental responsibility is uncertain despite adequate consent	154 44.3%	23 66.6%	17 63.0%	12 50.3%	205 47.4%
Those where parental responsibility is unlikely despite adequate consent*					
n) Foster mother	0 0.00%	0 0.00%	0 0.00%	1 4.20%	1 0.20%
All where parental responsibility is unlikely despite adequate consent	0 0.00%	0 0.00%	0 0.00%	1 4.20%	1 0.20%
Those where consent is inadequate irrespective of parental responsibility*					
o) No child name on form	0 0.0%	0 0.0%	0 0.0%	0 0.0%	0 0.0%
p) No consent tick	2	0	0	0	3

	England	Wales	Scotland	N. Ireland	Total
	0.6%	0.0%	0.0%	0.0%	0.7%
q) No parental signature	0 0.0%	2 5.7%	0 0.0%	0 0.0%	2 0.5%
All where consent is inadequate irrespective of parental responsibility	2 0.6%	2 5.7%	0 0.0%	1 4.2%	5 1.2%
TOTAL	**347** **100.00%**	**35** **100.00%**	**27** **100.00%**	**24** **100.00%**	**433** **100.00%**

***** The following are required to confirm that adequate consent to child health data linkage has been obtained: (a) child name on form; (b) parent/adult name on form; (c) consent box ticked on form; (d) parent/adult signature on form; and (e) parent/adult giving consent has parental responsibility.

Table 16: Ten percent sample of cases where the mother is the main respondent – parental responsibility by country

	England	Wales	Scotland	N. Ireland	Total
Those with parental responsibility and adequate consent*					
a) Natural mother	758 96.3%	170 98.8%	146 97.3%	118 99.2%	1192 97.1%
b) Natural father married to mother	6 0.8%	0 0.0%	0 0.0%	0 0.0%	6 0.5%
All with parental responsibility and adequate consent	764 97.1%	170 98.8%	146 97.3%	118 99.2%	1198 97.6%
Those where parental responsibility is uncertain despite adequate consent*					
c) Natural father and lone parent, etc	3 0.4%	0 0.0%	1 0.7%	0 0.0%	4 0.3%
d) Step father	1 0.1%	1 0.6%	0 0.0%	0 0.0%	2 0.2%
e) No scan	2	0	0	1	3

	England	Wales	Scotland	N. Ireland	Total
	0.3%	0.0%	0.0%	0.8%	0.2%
All where parental responsibility is uncertain despite adequate consent	6 0.8%	1 0.6%	1 0.7%	1 0.8%	9 0.7%
Those where consent is inadequate irrespective of parental responsibility*					
f) No child name on form	2 0.3%	0 0.0%	1 0.7%	0 0.0%	3 0.2%
g) No consent tick	8 1.0%	1 0.6%	0 0.0%	0 0.0%	9 0.7%
h) No parental signature	7 0.9%	0 0.0%	2 1.3%	0 0.0%	9 0.7%
All where consent is inadequate irrespective of parental responsibility	17 2.2%	1 0.6%	3 2.0%	0 0.0%	21 1.7%
TOTAL	**787** **100.0%**	**172** **100.0%**	**150** **100.0%**	**119** **100.0%**	**1228** **100.0%**

***** The following are required to confirm that adequate consent to child health data linkage has been obtained: (a) child name on form; (b) parent/adult name on form; (c) consent box ticked on form; (d) parent/adult signature on form; and (e) parent/adult giving consent has parental responsibility.

Table 17: Twins – parental responsibility by country

	England	Wales	Scotland	N. Ireland	Total
Those with parental responsibility and adequate consent*					
a) Natural mother	192 89.8%	31 93.3%	33 86.8%	38 88.3%	294 89.6%
b) Natural father married to mother	1 0.5%	0 0.0%	2 5.2%	2 4.7%	5 1.5%
All with parental responsibility and adequate consent	193 90.2%	31 93.9%	35 92.1%	40 93.0%	299 91.2%

	England	**Wales**	**Scotland**	**N. Ireland**	**Total**
Those where parental responsibility is uncertain despite adequate consent*					
c) Grandmother	3 0.5%	0 0.0%	0 0.0%	0 0.0%	3 0.9%
d) No scan	15 6.9%	2 6.7%	3 8.0%	3 7.1%	23 7.0%
All where parental responsibility is uncertain despite adequate consent	18 9.8%	2 6.1%	3 7.9%	3 7.0%	26 7.9%
Those where consent is inadequate irrespective of parental responsibility*					
e) No child name on form	0 0.0%	0 0.0%	0 0.0%	0 0.0%	0 0.0%
f) No consent tick	0 0.0%	0 0.0%	0 0.0%	0 0.0%	0 0.0%
g) No parental signature	3 1.4%	0 0.0%	0 0.0%	0 0.0%	3 0.9%
All where consent is inadequate irrespective of parental responsibility	3 214	0 33	0 38	0 43	3 0.9
TOTAL	**214 100.0%**	**33 100.0%**	**38 100.0%**	**43 100.0%**	**328 100.0%**

***** The following are required to confirm that adequate consent to child health data linkage has been obtained: (a) child name on form; (b) parent/adult name on form; (c) consent box ticked on form; (d) parent/adult signature on form; and (e) parent/adult giving consent has parental responsibility.

Table 18: Triplets – parent status by country

	England	Wales	Scotland	N. Ireland	Total
Those with parental responsibility and adequate consent*					
a) Natural mother	11 67.40%	5 84.50%	7 84.50%	2 84.50%	25 75.80%
All with parental responsibility and adequate consent	11 67.40%	5 84.50%	7 84.50%	2 84.50%	25 75.80%
Those where parental responsibility is uncertain despite adequate consent*					
b) Natural father and lone parent, etc	3 17.80%	0 0.00%	0 0.00%	0 0.00%	3 9.10%
c) No scan	3 14.80%	1 15.50%	1 15.50%	0 15.50%	5 15.20%
All where parental responsibility is uncertain despite adequate consent	6 35.30%	1 20.00%	1 12.50%	0 0.00%	8 24.20%
Those where consent is inadequate irrespective of parental responsibility***					
d) No child name on form	0	0	0	0	0
	0.0%	0.0%	0.0%	0.0%	0.0%
e) No consent tick	0	0	0	0	0
	0.0%	0.0%	0.0%	0.0%	0.0%
f) No parental signature	0	0	0	0	0
	0.0%	0.0%	0.0%	0.0%	0.0%
All where consent is inadequate irrespective of parental responsibility	0 0.0%	0 0.0%	0 0.0%	0 0.0%	0 0.0%
TOTAL	**17** **100.00%**	**5** **100.00%**	**8** **100.00%**	**3** **100.00%**	**33** **100.00%**

***** The following are required to confirm that adequate consent to child health data linkage has been obtained: (a) child name on form; (b) parent/adult name on form; (c) consent box ticked on form; (d) parent/adult signature on form; and (e) parent/adult giving consent has parental responsibility.

Discussion

62 As noted above, an important initial phase of this Wellcome-funded project is an intensive clerical task seeking to verify the electronic record of consents provided by the survey contractor against the information on the paper consent form completed during the MCS4 survey. This work is necessary to confirm that consent was given and by whom, and will form the basis of all linkages to 7 years as well as for future linkages to age 14. These verifications are essential for ethical and governance reasons.

63. It follows that the main concern was to establish that consent to access the child's health records was:

a) given by the natural mother or, failing this, some other person with parental responsibility – see paragraph 30 above; and
b) adequate – the consent form holds: child name; parent name; ticked consent box; and parental signature. See also paragraph 31 above

64. In addition, the early pilot checking exercise showed that, for twins and triplets, a separate consent form was not always completed for each child. All the children were sometimes named on a single form. Accordingly, checks were carried out to see if the consent form had been appropriately completed for each child.

Consents found

65. Scans of consent forms were found for almost all cases and most information had been completed. However, there were a small number of cases where consent forms have not (yet) been found or where key elements - the name of the cohort child, a tick in the consent to linkage box, parent signature or parent person number – were missing. See Table 19 below and Appendices 6-9.

Table 19: Consents found and information available

	Mother is not the main respondent	Mother is the main respondent*	Twins	Triplets
Scan found	425 98.2%	1225 99.8	305 93.0%	28 84.8%
Child name present	423 97.7%	1222 99.5	305 93.0%	28 84.8%
Parent name present	418 96.5%	1219.0 99.3	305 93.0%	28 84.8%

	Mother is not the main respondent	Mother is the main respondent*	Twins	Triplets
Consent to health data linkage ticked	420 97.0%	1216 99.0	305 93.0%	28 84.8%
Parent signature present	423 97.7%	1216 99.0	302 92.1%	28 84.8%
Parent person number present	390 90.1%	1156 94.1	294 89.6%	28 84.8%
TOTAL	**433** **100.0%**	**1228** **100.0%**	**328** **100.0%**	**33** **100.0%**

* 10% sample of cases

66. The absence of any consent form or, where a form exists, the lack of the child's name, a tick in the consent box or the signature of the parent means that valid consent does not exist and health data linkage should not be sought.

Who consented?

67. As noted above, interviewers were required to ensure the reference number of the person who signed the form was correctly recorded on the consent form so that their relationship to the cohort child could be checked by CLS to establish whether or not they were legally able to give permission for the information to be released. Again, although the majority of the person numbers recorded on the consent forms are those of the main or partner respondent, a minority appear to relate to some other person. Further checking suggests that a significant number are incorrect. – being the person number of the cohort child or a number not allocated within the MCS family concerned.

68. Fortunately, the clerical checking included a comparison of the name of the parent giving consent as recorded on the consent forms against the existing electronic data provided by the survey contractor. This reveals that, in most cases, consent to child health linkage was given by the person who completed the main interview during the MCS4 survey (Table 20).

Table 20: Person who consented to child health record linkage

	Mother is not the main respondent	Mother is the main respondent*	Twins	Triplets
Main MCS4 respondent	380 87.8%	1209 98.5%	300 91.5%	28 84.8%
Partner MCS4 respondent	38 8.8%	10 0.8%	5 1.5%	0 0.0%
Other person	2 0.5%	4 0.3%	0 0%	0 0.0%
No name on form	5 1.2%	2 0.2%	0 0.0%	0 0.0%
Needs further review	8 1.8%	3 0.2%	23 7.0%	5 15.2%
TOTAL	**433** **100,0%**	**1228** **100,0%**	**328** **100,0%**	**33** **100,0%**

* 10% sample of cases

Consent from those with parental responsibility

69. The verification of consents to child health records summarised above also shows that, on most occasions, consent to link child health records was provided by the natural mother or another adult who has legal parental responsibility (Table 20). Nevertheless, this leaves a number of cases – especially where the mother is not the main respondent – where parental responsibility is uncertain or unlikely, or the consent inadequate.

Table 20: Consent from those with parental responsibility

	Mother is not the main respondent	Mother is the main respondent*	Twins	Triplets
Those with parental responsibility and adequate consent	222 51.3%	1198 97.6%	299 91.2%	25 75.8%
Those where parental responsibility is uncertain despite adequate consent	205 47.4%	9 0.7%	26 7.9%	8 24.2%
Those where parental responsibility is unlikely despite adequate consent	1 0.2%	0 0.0%	0 0.0%	0 0.0%

	Mother is not the main respondent	Mother is the main respondent*	Twins	Triplets
Those where consent is inadequate irrespective of parental responsibility	5 1.2%	21 1.6%	3 0.9%	0.0% 0.%
TOTAL	**433** **100.0.0%**	**1228** **100.0%**	**328** **100.0%**	**33** **100.0%**

* 10% sample of cases

70. It is important to remember that, while the verification undertaken was based on a review of all MCS4 cases where the mother is not the main respondent and all multiple births, the work to verify the consents for cases where the mother is the main respondent was based on a ten per cent sample of cases. As the majority of consents are attributed to the main respondent to the survey, and the majority of main respondents are mothers (>12,000), this sample was taken in order to ensure that the verification could be carried out within the timescale and resources available. In Table 21 below, information regarding parental responsibility for cases where the mother is not the main respondent and for all multiple births is repeated. It also includes: estimates, based on findings for the ten percent sample, for all cases where the mother is the main respondent; and an estimate for all cases.

Table 21: Consent from those with parental responsibility

	Total	Mother is not the main respondent	Mother is the main respondent*	Twins	Triplets
All with parental responsibility and adequate consent	12517 95.9%	222 51.3%	11971 97.6%	299 91.2%	25 75.8%
All where parental responsibility is uncertain despite adequate consent	325 2.5%	205 47.4%	86 0.7%	26 7.9%	8 24.2%
All where parental responsibility is unlikely despite adequate consent	1 0.0%	1 0.2%	0 0.0%	0 0.0%	0 0.0%
All where consent is inadequate irrespective of parental responsibility	204 1.6%	5 1.2%	196 1.6%	3 0.9%	0 0.0%
TOTAL	**13047** **100.0%**	**433** **100.0%**	**12253** **100.0%**	**328** **100.0%**	**33** **100.0%**

* Estimate based on a review of a 10% sample of cases

71. The estimated number (and proportion) of cases for which consent for linkage to child health data is likely to have been given by the natural mother or another adult who has legal parental responsibility is very encouraging - 12,517 (95.9%). However, there are a number of consents where parental responsibility is unclear or unlikely or the consent inadequate (530).

72. Table 1 above shows that, during the MCS4 survey, consent to health record linkage was recorded as being given for the vast majority of children (92.9%). The review of consent forms described here suggests that on nearly all occasions this consent was given by the natural mother or some other adult who had legal parental responsibility (95.9%) – see Table 22.

Table 22: Consent for child health data linkage and parental responsibility

	UK	%	%
Base: Total cohort children in productive households	14043	100.0	-
Parents recorded as consenting to child health data linkage at MCS4	13047	92,9	100.0
Consent from those with parental responsibility*	12517	89.1	95.9

* Estimate based on the review of scanned consent forms

Consent forms for twins and triplets

73. A remaining issue relates to twins and triplets where pilot checking showed that a separate consent form was not always completed for each child and that all the children were sometimes named on a single form. The checks carried out during the verification of consents showed that, in a significant number of cases, twin and triplet children were indeed named on a single consent form – 108 (35.46%) of the 305 twin children for whom a consent form was found and 13 (46.4%) of the 28 triplet children. (Table 23)

Table 23: Consent forms for twins and triplets

	Twins	Triplets
One form per child	197 60.1%	15 45.5%
All children named on one form	108 32.9%	13 39.4%
Needs further review	23 7.01%	5 15.2%
TOTAL	**328** **100.0**	**33** **100.0**

74. In all cases, the children were clearly named and this suggests that valid consent to linkage to child health data exists.

Differences between the countries of the UK

75. As noted above, the verification of consents to linkage to child health records shows that, on most occasions, consent was provided by the natural mother or another adult who has legal parental responsibility (Table 20). Nevertheless, this leaves a number of cases – especially where the mother is not the main respondent – where parental responsibility is uncertain or unlikely.

76. The differences overall between the four countries of the UK as established by the verification outlined above are summarised in below (Table 24).

Table 24: Summary of consent to child health record linkage and parental responsibility by country*

	England	Wales	Scotland	N. Ireland	Total
Those with parental responsibility and adequate consent	1159 84.9%	216 88.2%	198 88.8%	171 90.5%	1744 86.3%
Those where parental responsibility is uncertain despite adequate consent	184 13.5%	27 11.0%	22 9.9%	16 8.5%	248 12.3%
Those where parental responsibility is unlikely despite adequate consent	0 0.0	0 0.0	0 0.0	1 0.0	1 0.0
Those where consent is inadequate irrespective of parental responsibility	22 1.6%	3 1.2%	3 1.3%	1 0.5%	29 1.4%
TOTAL	**1365** **100.0%**	**245** **100.0%**	**223** **100.0%**	**189** **100.0%**	**2022** **100.0%**

* Verification of consents in cases where the mother is the main respondent was based on a 10% sample of cases

77. Once again, it is important to remember that, while the verification undertaken was based on a review of all MCS4 cases where the mother is not the main respondent and all multiple births, the work to verify the consents for cases where the mother is the main respondent was based on a ten per cent sample of cases. As the majority of consents are attributed to the main respondent to the survey, and the majority of main respondents are

mothers (>12,000), this sample was taken in order to ensure that the verification could be carried out within the timescale and resources available. In Table 25 below, information regarding parental responsibility for cases where the mother is not the main respondent and for all multiple births is repeated. It also includes: estimates, based on findings for the ten percent sample, for all cases where the mother is the main respondent; and an estimate for all cases.

Table 25: Summary of estimates of consent to child health record linkage and parental responsibility by country*

	England	Wales	Scotland	N. Ireland	UK
Those with parental responsibility and adequate consent	8029 95.3%	1745 97.4%	1511 96.3%	1232 97.9%	12517 95.9%
Those where parental responsibility is uncertain despite adequate consent	235 2.8%	36 2.0%	31 1.9%	25 1.9%	325 2.5%
Those where parental responsibility is unlikely despite adequate consent	0 0.0	0 0.0	0 0.0	1 0.0	1 0.0
Those where consent is inadequate irrespective of parental responsibility	164 1.9%	11 0.6%	28 1.8%	1 0.1%	204 1.6%
TOTAL	**8428** **100.0%**	**1791** **100.0%**	**1569** **100.0%**	**1259** **100.0%**	**13047** **100.0%**

***** Includes and estimate for based on a 10% sample of cases where the mother is the main respondent

78. A more detailed breakdown of consents and parental responsibility is given in Table 26 for each of the groups of cases reviewed. Table 27 provides similar information but incorporates estimates of overall numbers for all cases where the mother is the main respondent. The latter are based on findings for the ten percent sample of this group of cases that were reviewed.

Table 26: Consent to child health record linkage and parental responsibility for each group of cases reviewed by country

	Mother is not the main respondent					Mother is the main respondent*					Twins					Triplets				
	England	**Wales**	**Scotland**	**N. Ireland**	**Total**	**England**	**Wales**	**Scotland**	**N. Ireland**	**Total**	**England**	**Wales**	**Scotland**	**N. Ireland**	**Total**	**England**	**Wales**	**Scotland**	**N. Ireland**	**Total**
All with parental responsibility and adequate consent	191 55.1%	10 28.6%	10 37.0%	11 45.8%	222 51.3%	764 97.1%	170 98.8%	146 97.3%	118 99.2%	1198 97.6%	193 90.2%	31 93.9%	35 92.1%	40 93.0%	299 91.2%	11 67.4%	5 84.5%	7 84.5%	2 84.5%	25 75.8%
All where parental responsibility is uncertain despite adequate consent	154 44.3%	23 66.6%	17 63.0%	12 50.3%	205 47.4%	6 0.8%	1 0.6%	1 0.7%	1 0.8%	9 0.7%	18 9.8%	2 6.1%	3 7.9%	3 7.0%	26 7.9%	6 35.3%	1 20.0%	1 12.5%	0 0.0%	8 24.2%
All where parental responsibility is unlikely despite adequate consent	0 0.0	0 0.0	0 0.0	1 0.0	1 0.0	0 0.0	0 0.0	0 0.0	0 0.0	0 0.0	0 0.0	0 0.0	0 0.0	0 0.0	0 0.0	0 0.0	0 0.0	0 0.0	0 0.0	0 0.0
All where consent is inadequate irrespective of parental responsibility	2 0.6%	2 5.7%	0 0.0%	1 4.2%	5 1.2%	17 2.2%	1 0.6%	3 2.0%	0 0.0%	21 1.7%	3 1.4%	0 0.00%	0 0.00%	0 0.00%	3 0.9	0 0.0%	0 0.0%	0 0.0%	0 0.0%	0 0.0%
TOTAL	**347** **100.0%**	**35** **100.0%**	**27** **100.0%**	**24** **100.0%**	**433** **100.0%**	**787** **100.0%**	**172** **100.0%**	**150** **100.0%**	**119** **100.0%**	**1228** **100.0%**	**214** **100.0%**	**33** **100.0%**	**38** **100.0%**	**43** **100.0%**	**328** **100.0%**	**17** **100.0%**	**5** **100.0%**	**8** **100.0%**	**3** **100.0%**	**33** **100.0%**

* Verification of consents in cases where the mother is the main respondent was based on a 10% sample of cases

Table 27: Estimates of consent to child health record linkage and parental responsibility for each group of cases reviewed by country

	Mother is not the main respondent					Mother is the main respondent*					Twins					Triplets				
	England	**Wales**	**Scotland**	**N. Ireland**	**Total**	**England**	**Wales**	**Scotland**	**N. Ireland**	**Total**	**England**	**Wales**	**Scotland**	**N. Ireland**	**Total**	**England**	**Wales**	**Scotland**	**N. Ireland**	**Total**
All with parental responsibility and adequate consent	191 55.1%	10 28.6%	10 37.0%	11 45.8%	222 51.3%	7634 97.2%	1699 98.9%	1459 97.5%	1179 99.2%	11971 97.7%	193 90.2%	31 93.9%	35 92.1%	40 93.0%	299 91.2%	11 67.4%	5 84.5%	7 84.5%	2 84.5%	25 75.8%
All where parental responsibility is uncertain despite adequate consent	154 44.3%	23 66.6%	17 63.0%	12 50.3%	205 47.4%	57 0.7%	10 0.6%	10 0.6%	10 0.8%	86 0.7%	18 9.8%	2 6.1%	3 7.9%	3 7.0%	26 7.9%	6 35.3%	1 20.0%	1 12.5%	0 0.0%	8 24.2%
All where parental responsibility is unlikely despite adequate consent	0 0.0	0 0.0	0 0.0	1 0.0	1 0.0	0 0.0	0 0.0	0 0.0	0 0.0	0 0.0%	0 0.0	0 0.0	0 0.0	0 0.0	0 0.0	0 0.0	0 0.0	0 0.0	0 0.0	0 0.0
All where consent is inadequate irrespective of parental responsibility	2 0.6%	2 5.7%	0 0.0%	1 4.2%	5 1.2%	159 2.0%	9 0.5%	28 1.9%	0 0.0%	196 1.6%	3 1.4%	0 0.00%	0 0.00%	0 0.00%	3 0.9	0 0.0	0 0.0%	0 0.0%	0 0.0%	0 0.0%
TOTAL	**347** **100.0%**	**35** **100.0%**	**27** **100.0%**	**24** **100.0%**	**433** **100.0%**	**7850** **100.0%**	**1718** **100.0%**	**1496** **100.0%**	**1189** **100.0%**	**12253** **100.0%**	**214** **100.0%**	**33** **100.0%**	**38** **100.0%**	**43** **100.0%**	**328** **100.0%**	**17** **100.0%**	**5** **100.0%**	**8** **100.0%**	**3** **100.0%**	**33** **100.0%**

***** Includes an estimate of overall numbers based on a 10% sample of cases where the mother is the main respondent

Cases available for child health record linkage

79. Drawing together the information that has been revealed by the review reported above, it is estimated that there would be some 12,517 cases where written consent is available from those with parental responsibility. The breakdown for the selected groups of cases is shown in Table 28 below.

80. There would be 530 cases that would not be available for linkage because parental responsibility is unlikely or uncertain; or because consent is inadequate irrespective of parental responsibility.

Table 28: Consent from those with parental responsibility

	Total	Mother is not the main respondent	Mother is the main respondent*	Twins	Triplets
All with parental responsibility and adequate consent	12517 95.9%	222 51.3%	11971 97.6%	299 91.2%	25 75.8%
All where parental responsibility is uncertain despite adequate consent	325 2.5%	205 47.4%	86 0.7%	26 7.9%	8 24.2%
All where parental responsibility is unlikely despite adequate consent	1 0.0%	1 0.2%	0 0.0%	0 0.0%	0 0.0%
All where consent is inadequate irrespective of parental responsibility	204 1.6%	5 1.2%	196 1.6%	3 0.9%	0 0.0%
TOTAL	**13047** **100.0%**	**433** **100.0%**	**12253** **100.0%**	**328** **100.0%**	**33** **100.0%**

* Estimate based on a review of a 10% sample of cases
Source: Table 21 above

81. It is also estimated that there would be adequate consent for 8,029 MCS children in England, 1.745 in Wales, 1,511 in Scotland and 1,232 in N. Ireland. Further details of the distribution across the four UK countries are shown below.

Table 29: Summary of estimates of consent to child health record linkage and parental responsibility by country*

	England	Wales	Scotland	N. Ireland	UK
Those with parental responsibility and adequate consent	8029 95.3%	1745 97.4%	1511 96.3%	1232 97.9%	12517 95.9%
Those where parental responsibility is uncertain despite adequate consent	235 2.8%	36 2.0%	31 1.9%	25 1.9%	325 2.5%
Those where parental responsibility is unlikely despite adequate consent	0 0.0	0 0.0	0 0.0	1 0.0	1 0.0
Those where consent is inadequate irrespective of parental responsibility	164 1.9%	11 0.6%	28 1.8%	1 0.1%	204 1.6%
TOTAL	**8428** **100.0%**	**1791** **100.0%**	**1569** **100.0%**	**1259** **100.0%**	**13047** **100.0%**

***** Includes and estimate for based on a 10% sample of cases where the mother is the main respondent
Source: Table 25 above

82. It should be stressed that these are necessarily estimates because the review detailed above is, in part, based on a 10% sample of those cases where the mother is the main respondent.

Appendix 1: MCS4 Consents

There are 5 consent forms associated with MCS4:

Consent 1: Main respondent (usually mother), covers:
- Interview and self-completion
- Health and economic records

Consent 2: Child (cohort member), covers:
- Assessments and Measurements
- Physical activity and monitoring
- Self-completion questionnaire

Consent 3: Child (cohort member), covers:
- Teacher survey
- Health and education records,

Consent 4: Siblings of cohort child, covers:
- Health and education records of up to 4 siblings

Consent 5: Partner respondent (usually father), covers:
- Interview and self-completion
- Health and economic records

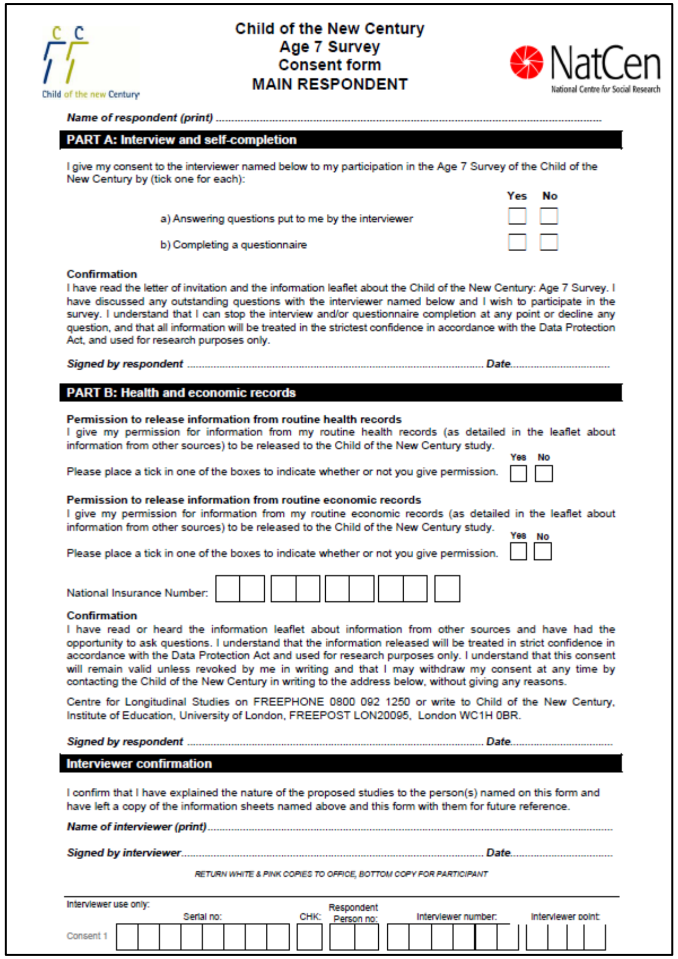
Further details are given overleaf.

Consent 1	**Consent 2[b]**	**Consent 3**	**Consent 4**	**Consent 5**
Name of respondent **Part A: Interview and self-completion** a) Answering questions put to me by the interviewer Yes/No b) Completing a questionnaire Signature of respondent Date **Part B: Health and economic records** Permission to release information from routine health records Yes/No Permission to release information from routine economic records Yes/No NINO Signature of respondent Date	Name of child Name of parent **Age 7 Child: Assessments and Measurements** a) Story of Sally & Anne b) Word Reading c) Progress in Maths d) Pattern Construction e) Height f) Weight g) Waist circumference against skin OR i) Body fat percentage h) Waist circumference over clothing **Age 7 Child: Physical activity and monitoring** Consent to wear an activity monitor to have their physical activity measured **Age 7 Child: Self-completion questionnaire** Parental confirmation Signature by parent Date	Name of child Name of parent **Part A: Teacher survey** Name of class teacher Parental confirmation Signature by parent Date **Part B: Health and education records** information from health records information from education records Parental confirmation Signature by parent Date	Name of parent **Health and education records - SIBLINGS** For up to 4 children: Person number DOB Name of child Parental confirmation Signature by parent Date	Name of partner **Part A: Interview and self-completion** a) Answering questions put to me by the interviewer Yes/No b) Completing a questionnaire Signature of partner Date **Part B: Health and economic records** Permission to release information from routine health records Permission to release information from routine economic records Yes/No NINO Signature of respondent
Interviewer confirmation Name of interviewer Signature of interviewer Date Serial number CHK Respondent person no: Interviewer number Interviewer point	**Interviewer confirmation** Name of interviewer Signature of interviewer Date Serial number CHK Respondent person no: Interviewer number Interviewer point	**Interviewer confirmation** Name of interviewer Signature of interviewer Date Serial number CHK Respondent person no: Interviewer number Interviewer point	**Interviewer confirmation** Name of interviewer Signature of interviewer Date Serial number CHK Respondent person no: Interviewer number Interviewer point	**Interviewer confirmation** Name of interviewer Signature of interviewer Date Serial number CHK Respondent person no: Interviewer number Interviewer point

a: Consent forms were also available in Welsh, Urdu, Punjabi, Gujarati, Hindi, Bengali, Somali, Tamil, Turkish, Kurdish and Arabic

b: For multiple births (and families with >1 CM child) additional forms were provided relating to 2 further children

MCS age 7 survey consent forms



Child of the New Century
Age 7 Survey
Consent form
MAIN RESPONDENT

Name of respondent (print) ....

PART A: Interview and self-completion

I give my consent to the interviewer named below to my participation in the Age 7 Survey of the Child of the New Century by (tick one for each):

	Yes	No
a) Answering questions put to me by the interviewer	☐	☐
b) Completing a questionnaire	☐	☐

Confirmation
I have read the letter of invitation and the information leaflet about the Child of the New Century: Age 7 Survey. I have discussed any outstanding questions with the interviewer named below and I wish to participate in the survey. I understand that I can stop the interview and/or questionnaire completion at any point or decline any question, and that all information will be treated in the strictest confidence in accordance with the Data Protection Act, and used for research purposes only.

Signed by respondent .... **Date**..............................

PART B: Health and economic records

Permission to release information from routine health records
I give my permission for information from my routine health records (as detailed in the leaflet about information from other sources) to be released to the Child of the New Century study.

Please place a tick in one of the boxes to indicate whether or not you give permission. Yes ☐ No ☐

Permission to release information from routine economic records
I give my permission for information from my routine economic records (as detailed in the leaflet about information from other sources) to be released to the Child of the New Century study.

Please place a tick in one of the boxes to indicate whether or not you give permission. Yes ☐ No ☐

National Insurance Number: ☐☐ ☐☐ ☐☐ ☐☐ ☐

Confirmation
I have read or heard the information leaflet about information from other sources 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 unless revoked by me in writing and that I may withdraw my consent at any time by contacting the Child of the New Century in writing to the address below, without giving any reasons.

Centre for Longitudinal Studies on FREEPHONE 0800 092 1250 or write to Child of the New Century, Institute of Education, University of London, FREEPOST LON20095, London WC1H 0BR.

Signed by respondent .... **Date**..............................

Interviewer confirmation

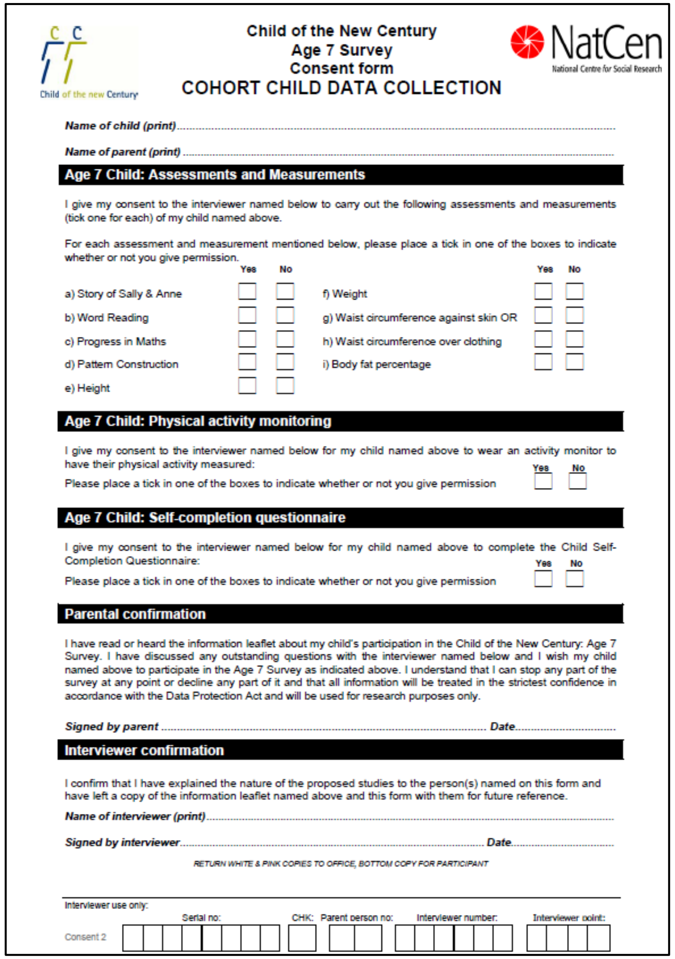
I confirm that I have explained the nature of the proposed studies to the person(s) named on this form and have left a copy of the information sheets named above and this form with them for future reference.

Name of interviewer (print)..

Signed by interviewer.. **Date**..............................

RETURN WHITE & PINK COPIES TO OFFICE, BOTTOM COPY FOR PARTICIPANT

Interviewer use only:
Consent 1 Serial no: ☐☐☐☐☐☐☐☐ CHK: ☐ Respondent Person no: ☐☐ Interviewer number: ☐☐☐☐☐☐ Interviewer point: ☐☐☐☐



Child of the New Century
Age 7 Survey
Consent form
COHORT CHILD DATA COLLECTION

Name of child (print)..

Name of parent (print) ....

Age 7 Child: Assessments and Measurements

I give my consent to the interviewer named below to carry out the following assessments and measurements (tick one for each) of my child named above.

For each assessment and measurement mentioned below, please place a tick in one of the boxes to indicate whether or not you give permission.

	Yes	No		Yes	No
a) Story of Sally & Anne	☐	☐	f) Weight	☐	☐
b) Word Reading	☐	☐	g) Waist circumference against skin OR	☐	☐
c) Progress in Maths	☐	☐	h) Waist circumference over clothing	☐	☐
d) Pattern Construction	☐	☐	i) Body fat percentage	☐	☐
e) Height	☐	☐			

Age 7 Child: Physical activity monitoring

I give my consent to the interviewer named below for my child named above to wear an activity monitor to have their physical activity measured:

Please place a tick in one of the boxes to indicate whether or not you give permission Yes ☐ No ☐

Age 7 Child: Self-completion questionnaire

I give my consent to the interviewer named below for my child named above to complete the Child Self-Completion Questionnaire:

Please place a tick in one of the boxes to indicate whether or not you give permission Yes ☐ No ☐

Parental confirmation

I have read or heard the information leaflet about my child's participation in the Child of the New Century: Age 7 Survey. I have discussed any outstanding questions with the interviewer named below and I wish my child named above to participate in the Age 7 Survey as indicated above. I understand that I can stop any part of the survey at any point or decline any part of it and that all information will be treated in the strictest confidence in accordance with the Data Protection Act and will be used for research purposes only.

Signed by parent .... **Date**..............................

Interviewer confirmation

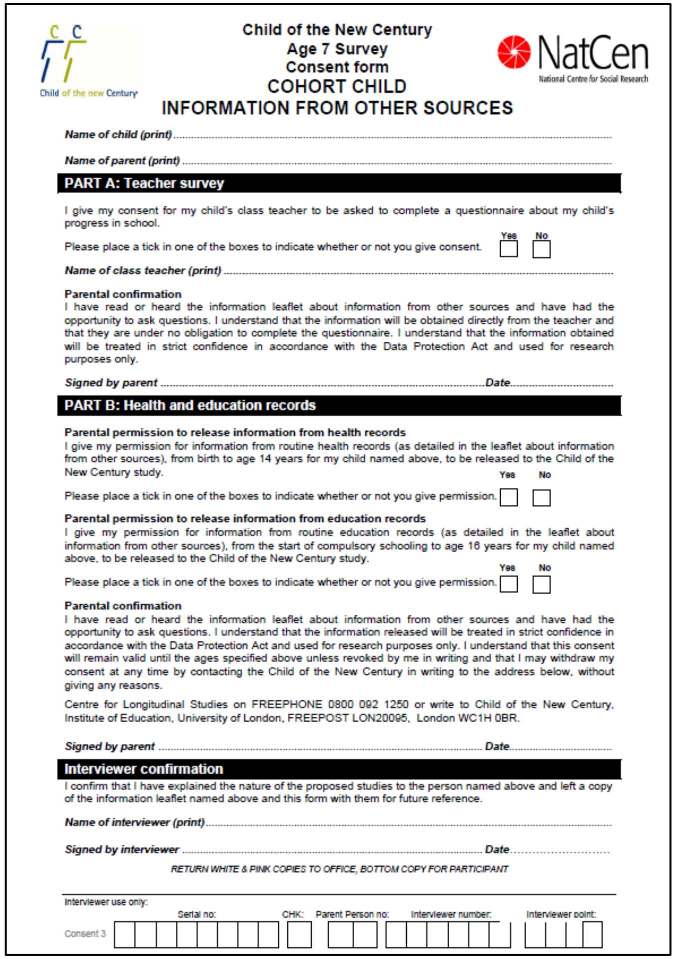
I confirm that I have explained the nature of the proposed studies to the person(s) named on this form and have left a copy of the information leaflet named above and this form with them for future reference.

Name of interviewer (print)..

Signed by interviewer.. **Date**..............................

RETURN WHITE & PINK COPIES TO OFFICE, BOTTOM COPY FOR PARTICIPANT

Interviewer use only:
Consent 2 Serial no: ☐☐☐☐☐☐☐☐ CHK: ☐ Parent person no: ☐☐ Interviewer number: ☐☐☐☐☐☐ Interviewer point: ☐☐☐☐



Child of the New Century
Age 7 Survey
Consent form
COHORT CHILD
INFORMATION FROM OTHER SOURCES

Name of child (print)..

Name of parent (print) ....

PART A: Teacher survey

I give my consent for my child's class teacher to be asked to complete a questionnaire about my child's progress in school.

Please place a tick in one of the boxes to indicate whether or not you give consent. Yes ☐ No ☐

Name of class teacher (print) ....

Parental confirmation
I have read or heard the information leaflet about information from other sources and have had the opportunity to ask questions. I understand that the information will be obtained directly from the teacher and that they are under no obligation to complete the questionnaire. I understand that the information obtained will be treated in strict confidence in accordance with the Data Protection Act and used for research purposes only.

Signed by parent ....**Date**..............................

PART B: Health and education records

Parental permission to release information from health records
I give my permission for information from routine health records (as detailed in the leaflet about information from other sources), from birth to age 14 years for my child named above, to be released to the Child of the New Century study.

Please place a tick in one of the boxes to indicate whether or not you give permission. Yes ☐ No ☐

Parental permission to release information from education records
I give my permission for information from routine education records (as detailed in the leaflet about information from other sources), from the start of compulsory schooling to age 16 years for my child named above, to be released to the Child of the New Century study.

Please place a tick in one of the boxes to indicate whether or not you give permission. Yes ☐ No ☐

Parental confirmation
I have read or heard the information leaflet about information from other sources 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 until the ages specified above unless revoked by me in writing and that I may withdraw my consent at any time by contacting the Child of the New Century in writing to the address below, without giving any reasons.

Centre for Longitudinal Studies on FREEPHONE 0800 092 1250 or write to Child of the New Century, Institute of Education, University of London, FREEPOST LON20095, London WC1H 0BR.

Signed by parent .... **Date**..............................

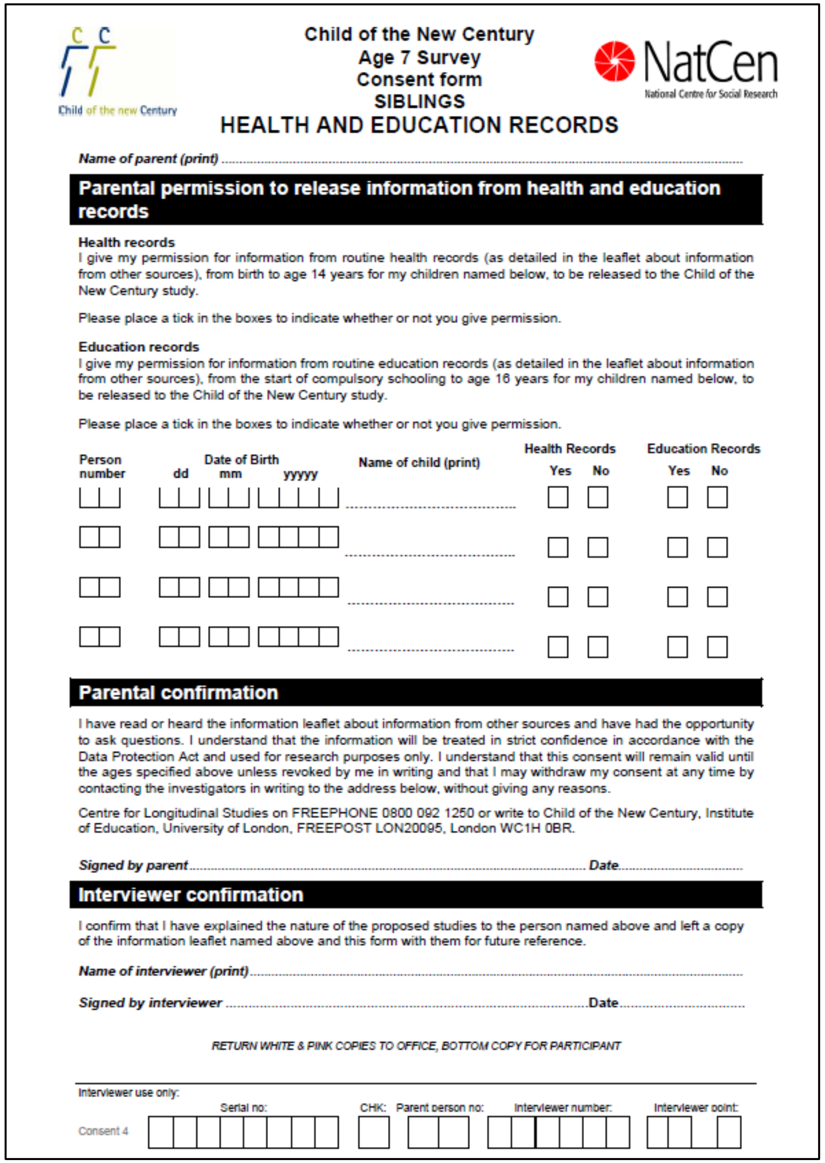
Interviewer confirmation
I confirm that I have explained the nature of the proposed studies to the person named above and left a copy of the information leaflet named above and this form with them for future reference.

Name of interviewer (print)..

Signed by interviewer .... **Date**..............................

RETURN WHITE & PINK COPIES TO OFFICE, BOTTOM COPY FOR PARTICIPANT

Interviewer use only:
Consent 3 Serial no: ☐☐☐☐☐☐☐☐ CHK: ☐ Parent Person no: ☐☐ Interviewer number: ☐☐☐☐☐☐ Interviewer point: ☐☐☐☐



Child of the New Century
Age 7 Survey
Consent form
SIBLINGS
HEALTH AND EDUCATION RECORDS

Name of parent (print) ....

Parental permission to release information from health and education records

Health records
I give my permission for information from routine health records (as detailed in the leaflet about information from other sources), from birth to age 14 years for my children named below, to be released to the Child of the New Century study.

Please place a tick in the boxes to indicate whether or not you give permission.

Education records
I give my permission for information from routine education records (as detailed in the leaflet about information from other sources), from the start of compulsory schooling to age 16 years for my children named below, to be released to the Child of the New Century study.

Please place a tick in the boxes to indicate whether or not you give permission.

Person number	Date of Birth dd	mm	yyyyy	Name of child (print)	Health Records Yes	Health Records No	Education Records Yes	Education Records No
				....	☐	☐	☐	☐
				....	☐	☐	☐	☐
				....	☐	☐	☐	☐
				....	☐	☐	☐	☐

Parental confirmation

I have read or heard the information leaflet about information from other sources and have had the opportunity to ask questions. I understand that the information 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 until the ages specified above unless revoked by me in writing and that I may withdraw my consent at any time by contacting the investigators in writing to the address below, without giving any reasons.

Centre for Longitudinal Studies on FREEPHONE 0800 092 1250 or write to Child of the New Century, Institute of Education, University of London, FREEPOST LON20095, London WC1H 0BR.

Signed by parent.. ***Date***...................................

Interviewer confirmation

I confirm that I have explained the nature of the proposed studies to the person named above and left a copy of the information leaflet named above and this form with them for future reference.

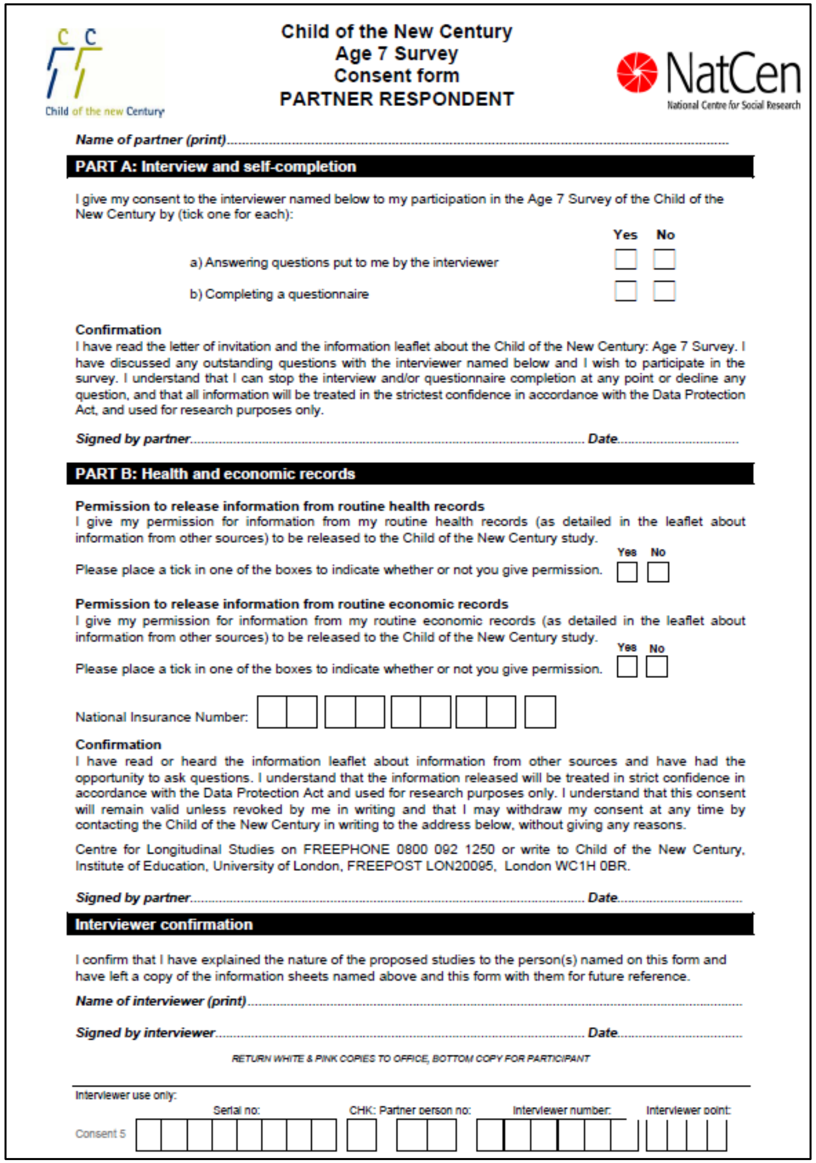
Name of interviewer (print)..

Signed by interviewer ....***Date***...................................

RETURN WHITE & PINK COPIES TO OFFICE, BOTTOM COPY FOR PARTICIPANT

Interviewer use only:

Consent 4 | Serial no: | CHK: | Parent person no: | Interviewer number: | Interviewer point:



Child of the New Century
Age 7 Survey
Consent form
PARTNER RESPONDENT

Name of partner (print)..

PART A: Interview and self-completion

I give my consent to the interviewer named below to my participation in the Age 7 Survey of the Child of the New Century by (tick one for each):

	Yes	No
a) Answering questions put to me by the interviewer	☐	☐
b) Completing a questionnaire	☐	☐

Confirmation
I have read the letter of invitation and the information leaflet about the Child of the New Century: Age 7 Survey. I have discussed any outstanding questions with the interviewer named below and I wish to participate in the survey. I understand that I can stop the interview and/or questionnaire completion at any point or decline any question, and that all information will be treated in the strictest confidence in accordance with the Data Protection Act, and used for research purposes only.

Signed by partner.. ***Date***...................................

PART B: Health and economic records

Permission to release information from routine health records
I give my permission for information from my routine health records (as detailed in the leaflet about information from other sources) to be released to the Child of the New Century study.

Please place a tick in one of the boxes to indicate whether or not you give permission. Yes ☐ No ☐

Permission to release information from routine economic records
I give my permission for information from my routine economic records (as detailed in the leaflet about information from other sources) to be released to the Child of the New Century study.

Please place a tick in one of the boxes to indicate whether or not you give permission. Yes ☐ No ☐

National Insurance Number:

Confirmation
I have read or heard the information leaflet about information from other sources 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 unless revoked by me in writing and that I may withdraw my consent at any time by contacting the Child of the New Century in writing to the address below, without giving any reasons.

Centre for Longitudinal Studies on FREEPHONE 0800 092 1250 or write to Child of the New Century, Institute of Education, University of London, FREEPOST LON20095, London WC1H 0BR.

Signed by partner.. ***Date***...................................

Interviewer confirmation

I confirm that I have explained the nature of the proposed studies to the person(s) named on this form and have left a copy of the information sheets named above and this form with them for future reference.

Name of interviewer (print)..

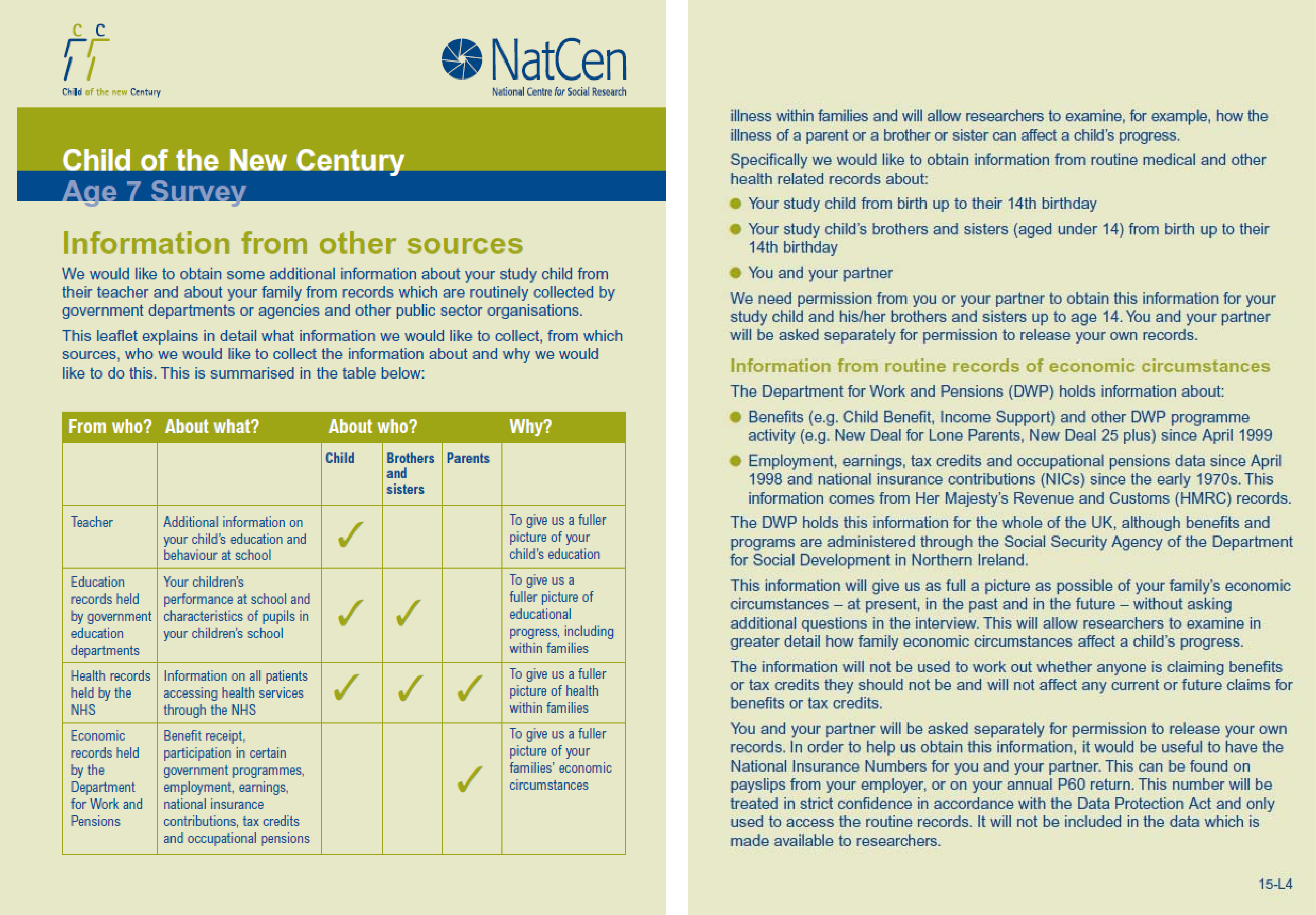
Signed by interviewer.. ***Date***...................................

RETURN WHITE & PINK COPIES TO OFFICE, BOTTOM COPY FOR PARTICIPANT

Interviewer use only:

Consent 5 | Serial no: | CHK: | Partner person no: | Interviewer number: | Interviewer point:

Appendix 2: MCS4 Information from other sources leaflet



Child of the new Century

NatCen
National Centre for Social Research

Child of the New Century
Age 7 Survey

Information from other sources

We would like to obtain some additional information about your study child from their teacher and about your family from records which are routinely collected by government departments or agencies and other public sector organisations.

This leaflet explains in detail what information we would like to collect, from which sources, who we would like to collect the information about and why we would like to do this. This is summarised in the table below:

From who?	About what?	About who?			Why?
		Child	**Brothers and sisters**	**Parents**	
Teacher	Additional information on your child's education and behaviour at school	✓			To give us a fuller picture of your child's education
Education records held by government education departments	Your children's performance at school and characteristics of pupils in your children's school	✓	✓		To give us a fuller picture of educational progress, including within families
Health records held by the NHS	Information on all patients accessing health services through the NHS	✓	✓	✓	To give us a fuller picture of health within families
Economic records held by the Department for Work and Pensions	Benefit receipt, participation in certain government programmes, employment, earnings, national insurance contributions, tax credits and occupational pensions			✓	To give us a fuller picture of your families' economic circumstances

illness within families and will allow researchers to examine, for example, how the illness of a parent or a brother or sister can affect a child's progress.

Specifically we would like to obtain information from routine medical and other health related records about:

- Your study child from birth up to their 14th birthday
- Your study child's brothers and sisters (aged under 14) from birth up to their 14th birthday
- You and your partner

We need permission from you or your partner to obtain this information for your study child and his/her brothers and sisters up to age 14. You and your partner will be asked separately for permission to release your own records.

Information from routine records of economic circumstances

The Department for Work and Pensions (DWP) holds information about:

- Benefits (e.g. Child Benefit, Income Support) and other DWP programme activity (e.g. New Deal for Lone Parents, New Deal 25 plus) since April 1999
- Employment, earnings, tax credits and occupational pensions data since April 1998 and national insurance contributions (NICs) since the early 1970s. This information comes from Her Majesty's Revenue and Customs (HMRC) records.

The DWP holds this information for the whole of the UK, although benefits and programs are administered through the Social Security Agency of the Department for Social Development in Northern Ireland.

This information will give us as full a picture as possible of your family's economic circumstances – at present, in the past and in the future – without asking additional questions in the interview. This will allow researchers to examine in greater detail how family economic circumstances affect a child's progress.

The information will not be used to work out whether anyone is claiming benefits or tax credits they should not be and will not affect any current or future claims for benefits or tax credits.

You and your partner will be asked separately for permission to release your own records. In order to help us obtain this information, it would be useful to have the National Insurance Numbers for you and your partner. This can be found on payslips from your employer, or on your annual P60 return. This number will be treated in strict confidence in accordance with the Data Protection Act and only used to access the routine records. It will not be included in the data which is made available to researchers.

15-L4

We need your written permission to approach the child's teacher or to obtain information from routine records. The interviewer will ask you for your permission for each of these sources separately. **It is completely up to you which permissions you choose to give.** You can withdraw your permission at any time in the future. Choosing not to give your permission or withdrawing in the future will not affect your participation in the study.

All information obtained from these sources will be treated in strict confidence in accordance with the Data Protection Act and used for research purposes only.

In order to access these routine records, we will provide a limited amount of information about your family to the holders of the records (e.g. full name, sex, date of birth, address). This information will only be used for accessing the records. No information that you have provided in the Child of the New Century study will be disclosed to these sources for any other purpose.

Information from your child's school teacher

We would like to contact your child's class teacher to find out more about your child's education and behaviour at school.

We would like to ask your child's teacher to complete a questionnaire on various aspects of your child's education. The questionnaire covers some details about your child's teacher, their teaching methods and class groupings and the other children in your child's class. There are some questions about your child's behaviour, abilities and any special educational needs/additional support needs and your involvement with the school. This information will provide a fuller picture of your child's education.

It is entirely up to the teacher whether they complete the questionnaire, but we require your written permission to approach them. The questionnaire will be sent to them at school by post a few months after the interview. The interviewer will ask you for the teacher's full name and the name and address of the school. We will also write to the head teacher of the school to let them know that one of the teachers in their school has been asked to take part in this study.

The information that the teacher gives about your child will be treated in strict confidence in accordance with the Data Protection Act. This means that you will not be able to access the information they give about your child.

Information from routine records on education

We would like to collect information from routine records on education about your children's performance at school and the characteristics of pupils in your children's school, throughout their compulsory education.

By performance at school, we mean the results that they get when they do national tests or the formal assessments that their teachers make about their performance in different subjects at the end of particular years. The exact information varies but we mean things like Key Stage assessments and GCSEs in England, Wales and Northern Ireland and 5-14 levels and Standard Grades in Scotland.

The information on the characteristics of pupils in your children's school also varies by country but may include ethnicity, special educational needs/additional support needs, eligibility for free school meals, absences, home postcode and date pupil first entered and left the school. This information will be collected for your children as well as other pupils in the school. We may be able to use this information to help keep in touch with your family if you move in the future.

For England, this information is held by the Department for Children, Schools and Families (DCSF), and for Wales by the Local Government Data Unit of the Welsh Assembly. In Northern Ireland, some of this information is held by the schools themselves and some is held by the Department of Education. From 2009 onwards, some of this information will be held by a new statutory organisation called the Education and Skills Authority (ESA) in Northern Ireland. For Scotland, some of this information is held by local education authorities and some is held by the Education Directorate of the Scottish Government.

We would like to obtain this information from these routine education records about:

- Your study child from the start of their compulsory education up to the end of their compulsory education at age 16
- Your study child's brothers and sisters (aged under 14) from the start of their compulsory education up to the end of their compulsory education at age 16

We will ask you or your partner for permission to obtain this information for your study child and his/her brothers and sisters up to age 16, as this is the end of compulsory full-time schooling. Having such information enables us to draw a more complete picture of educational progress within families and will allow researchers to examine, for example, what impact the educational progress of a brother or sister has on your study child's progress.

Information from routine medical and other health related records

The National Health Service (NHS) maintains information on all patients accessing the health services through routine medical and other health-related records. These health records are held within statistical health databases, which may 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

We would like to get information from these routine medical and other health-related records about you, your partner and your child's brothers and sisters **as well as** your study child. This will mean we have a much more complete picture of health and

Appendix 3: Parental responsibility and consent

Who should consent in relation to children?

1. The approach adopted in surveys where information is gathered from children and/or permission for record linkage is sought is often vague with reference to gaining consent from ‘parents’ or ‘care givers’ or ‘guardians’ or those in ‘loco parentis’ without any real guidance on who these people might be or how they might be identified.

2. Consent should be obtained from a person with ‘parental responsibility’.

Parental responsibility

3. Parental responsibility is defined in the Children Act 1989 as '...all the rights, duties, powers, responsibilities and authority which by law a parent of a child has in relation to the child and his property...'[2]. While the law does not define in detail what parental responsibility is, the following list sets out the key roles[3]:

- providing a home for the child
- having contact with and living with the child
- protecting and maintaining the child
- disciplining the child
- choosing and providing for the child's education
- determining the religion of the child
- agreeing to the child's medical treatment
- naming the child and agreeing to any change of the child's name
- accompanying the child outside the UK
- agreeing to the child's emigration, should the issue arise
- being responsible for the child's property
- appointing a guardian for the child, if necessary
- allowing confidential information about the child to be disclosed

4. Parental responsibility is afforded not only to parents, however, and not all parents have parental responsibility, despite, it could be argued, having equal moral rights to make decisions for their children where they have been equally involved in their care.

Who possesses parental responsibility?

5. The law in relation to parental responsibility has been revised relatively recently:

(a) For a child whose birth was registered from 15 April 2002 in Northern Ireland, 1 December 2003 in England and Wales and 4 May 2006 in Scotland, both of the child's parents have parental responsibility if they are registered on the child's birth certificate.

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[2] http://www.childtrustfund.gov.uk/templates/Page____1329.aspx

[3] http://www.direct.gov.uk/en/Parents/ParentsRights/DG_4002954

(b) Throughout the United Kingdom, a mother automatically acquires parental responsibility at birth. However, the acquisition of parental responsibility by a natural father varies according to where and when the child's birth was registered:

(c) For births registered in England, Wales or Northern Ireland - A natural father acquires parental responsibility if he is married to the mother at the time of the child's birth or subsequently. An unmarried father will acquire parental responsibility if he is recorded on the child's birth certificate (at registration or upon re-registration) from 1 December 2003 in England or Wales and from 15 April 2002 in Northern Ireland.

(d) For births registered in Scotland - A natural father acquires parental responsibility if he is married to the mother at the time of the child's conception or subsequently. An unmarried natural father will acquire parental responsibility if he is recorded on the child's birth certificate (at registration or upon re-registration) from 4 May 2006.

(e) For births registered outside the United Kingdom -The above rules for the UK country where the child resides apply.

(f) An unmarried natural father, whose child's birth was registered before the dates mentioned above, or afterwards if he is not recorded on the child's birth certificate, does not have parental responsibility even if he has lived with the mother for a long time. However, the natural father can acquire parental responsibility by way of a court registered parental responsibility agreement with the mother or by obtaining a parental responsibility order or a residence order from the courts. See diagram on page 4 below.

(g) Married step-parents and registered civil partners can acquire parental responsibility in the same ways.

(h) Unmarried step-parents can get parental responsibility through adoption, a parental responsibility order, a residence order; or special guardianship

(i) Others can also acquire parental responsibility for a child:

  (i) A testamentary guardian will acquire parental responsibility if no one with parental responsibility survives the testator.
  (ii) A guardian appointed by a court will also acquire parental responsibility.
  (iii) When a child is adopted, the adoptive parents are the child's legal parents and automatically acquire parental responsibility.
  (iv) A local authority acquires parental responsibility (shared with anyone else with parental responsibility) while the child is subject to a care or supervision order.
  (v) Foster parents rarely have parental responsibility.
  (vi) For a child born under a surrogacy arrangement, parental responsibility will lie with the surrogate mother (and husband if married) until the intended parents either (a) obtain a parental order from a court under the Human Fertilisation and Embryology Act 1990 or (b) adopt the child.

6. Parents do not lose parental responsibility if they divorce – neither can a separated or divorced parent relinquish parental responsibility. This is true even if the parent without custody does not have contact with the child and does not make any financial contribution.

7. Parental responsibility awarded by a court can only be removed by a court.

8. In England, Wales and Northern Ireland, parental responsibilities may be exercised until a young person reaches 18 years. In Scotland, only the aspect of parental responsibilities concerned with the giving of "guidance" endures until 18 years, guidance meaning the provision of advice. The rest is lost when the young person reaches 16 years.

Some useful URLs

http://www.direct.gov.uk/en/Parents/ParentsRights/DG_4002954

http://www.yourrights.org.uk/yourrights/the-rights-of-children-and-young-people/parental-responsibility-and-childrens-rights/index.html

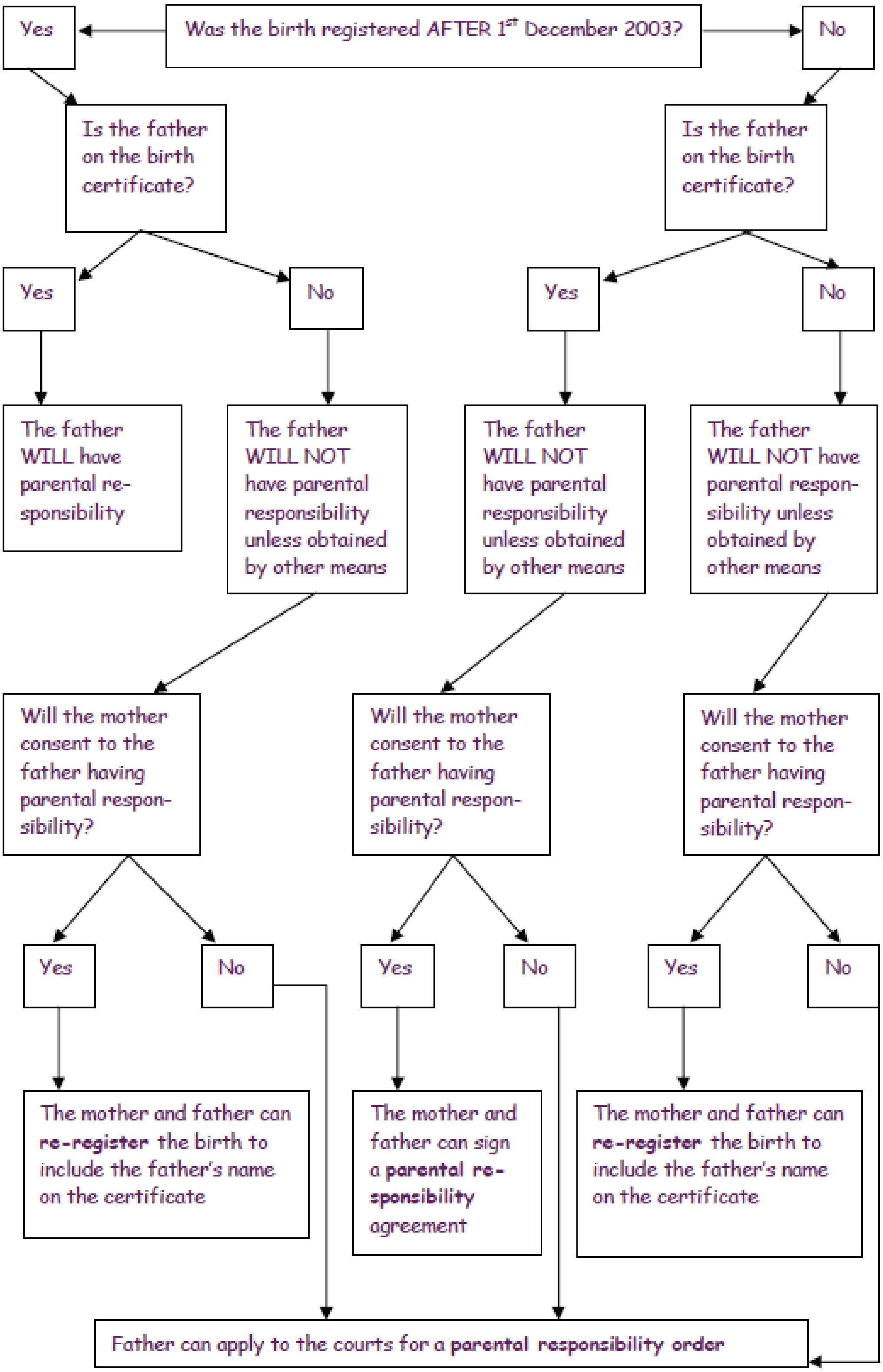
http://www.fnf.org.uk/law-and-information/parental-responsibility

http://www.scotland.gov.uk/Publications/2006/04/27135238/1

http://www.nidirect.gov.uk/index/information-and-services/parents/parents-and-childrens-rights/parental-rights-and-responsibilities.htm

http://www.childrenslegalcentre.com/Legal+Advice/Child+law/ParentalResponsibility/

How can an unmarried father obtain parental responsibility?



Source: Children's Legal Centre leaflet - 'Parental Responsibility' 'http://www.childrenslegalcentre.com/Resources/CLC/Documents/PDF%20N-Z/Parental%20Responsibility%20leaflet.pdf

Appendix 4: Pilot checking of MCS4 consents

Pilot checking

A4.1. The pilot exercise comparing the data CLS already hold about consents against the information on the consent forms was designed to provide insight into the practicalities of verifying the consents and an indication of the quality of the electronic data on consent. It was based on 5 samples identified from the existing survey data on consent, namely:

A. 50 consents where the main respondent WAS NOT the natural mother
B. 50 consents where main respondent WAS the natural mother:
C. All 15 consents where the natural mother was main respondent but there is no main interview
D. 2 cases (4 consents) where twin CMs have different consent flag (eg: one yes, one no)
E. 1 case (3 consents) where triplet CMs have different consent flags

A4.2. Preliminary analysis of the pilot showed:

a) General agreement between the electronic consent data already held by CLS and the information on the consent forms:

SCAN: Consent to link to child health records	**MCS4 Data: Consent to link to child health records**		
	Yes	**Form NOT received**	**Total**
Yes	112	0	112
No	1	0	1
No consent form scan	5	4	9
TOTAL	**118**	**4**	**122**

b) Natural mothers and natural fathers are in the majority in giving consent, but further analysis is needed of the status of the latter, and of the others recorded as giving consent to record linkage but who are not natural mothers.

	Number	**%**
Natural mother	69	56.6
Natural father	21	17.2
Adoptive mother	3	2.5
Grandmother	3	2.5
Someone else	13	10.7
No person number on consent form	4	3.3
No scan	9	7.4
TOTAL	**122**	**100.0**

Appendix 5: Checking of MCS4 consents – an extract from a guide to the tasks

The task

1. The task is to check the information that we already hold on MCS4 parental consent to health record linkage for the cohort child against the information on the consent forms that have been scanned.

Access database

2. Information on MCS4 consents, selected from that we already hold, has been placed in an Access database and must be checked against the content of the relevant MCS4 consent form.

3. The data entry form you will use (see below) has three columns:

a) The **left-hand column** is prefilled with information taken from CLS existing records as follows:

Information	Format	Source
Serial number	Number	Prefilled from existing data
Singleton/Twin/Triplet	Tick	Prefilled from existing data
CM person number	Number	Prefilled from existing data
CM first name	Text	Prefilled from existing data
CM middle name	Text	Prefilled from existing data
CM last name	Text	Prefilled from existing data
Main person number	Number	Prefilled from existing data
Main first name	Text	Prefilled from existing data
Main middle name	Text	Prefilled from existing data
Main last name	Text	Prefilled from existing data
Partner person number	Number	Prefilled from existing data
Partner first name	Text	Prefilled from existing data
Partner middle name	Text	Prefilled from existing data
Partner last name	Text	Prefilled from existing data
Consent to health linkage	Tick	Prefilled from existing data
Main interview date	Date	Prefilled from existing data

b) The **middle column** is also mostly prefilled but must be updated by you where necessary after comparing the contents of the consent form with the prefilled information in the left-hand column. Mostly you should only need to make a few changes as follows:

Information	Format	Source
Scan found	Tick	Prefilled - Yes. Leave/update after review of scan
Scan legible	Tick	Prefilled - Yes. Leave/update after review of scan

Information	Format	Source
Language of form English?	Tick	Prefilled - Yes. Leave/update after review of scan
Language of form (if not English)	Text	Scan*
CM name on form	Tick	Prefilled - Yes. Leave/update after review of scan
CM name same as existing data	Tick	Prefilled - Yes. Leave/update after review of scan
CM name if different	Text	Scan
Parent name on form	Tick	Prefilled - Yes. Leave/update after review of scan
Parent name same as Main respondent on existing data	Tick	Prefilled - Yes. Leave/update after review of scan
Parent name same as Partner respondent on existing data	Tick	Scan
Parent name if different	Text	Scan
Consent box ticked on form	Tick	Prefilled - Yes. Leave/update after review of scan
Consent same as existing data	Tick	Prefilled - Yes. Leave/update after review of scan
Consent if different	Tick	Scan
Parental signature on form	Tick	Prefilled - Yes. Leave/update after review of scan
Parental signature dated	Tick	Prefilled - Yes. Leave/update after review of scan
Date of parental signature	Date	Prefilled – Date. Leave/update after review of scan
Date same as main interview	Tick	Prefilled - Yes. Leave/update after review of scan
Date earlier than main interview	Tick	Comparison of scan & prefilled data
Date later than main interview	Tick	Comparison of scan & prefilled data
Parental person number on form	Tick	Prefilled - Yes. Leave/update after review of scan
Parental person number	Number	Scan

* Consent forms were also available in Welsh, Urdu, Punjabi, Gujarati, Hindi, Bengali, Somali, Tamil, Turkish, Kurdish and Arabic

c) The **right-hand column** is to be completed by you after completing the middle column and contains:

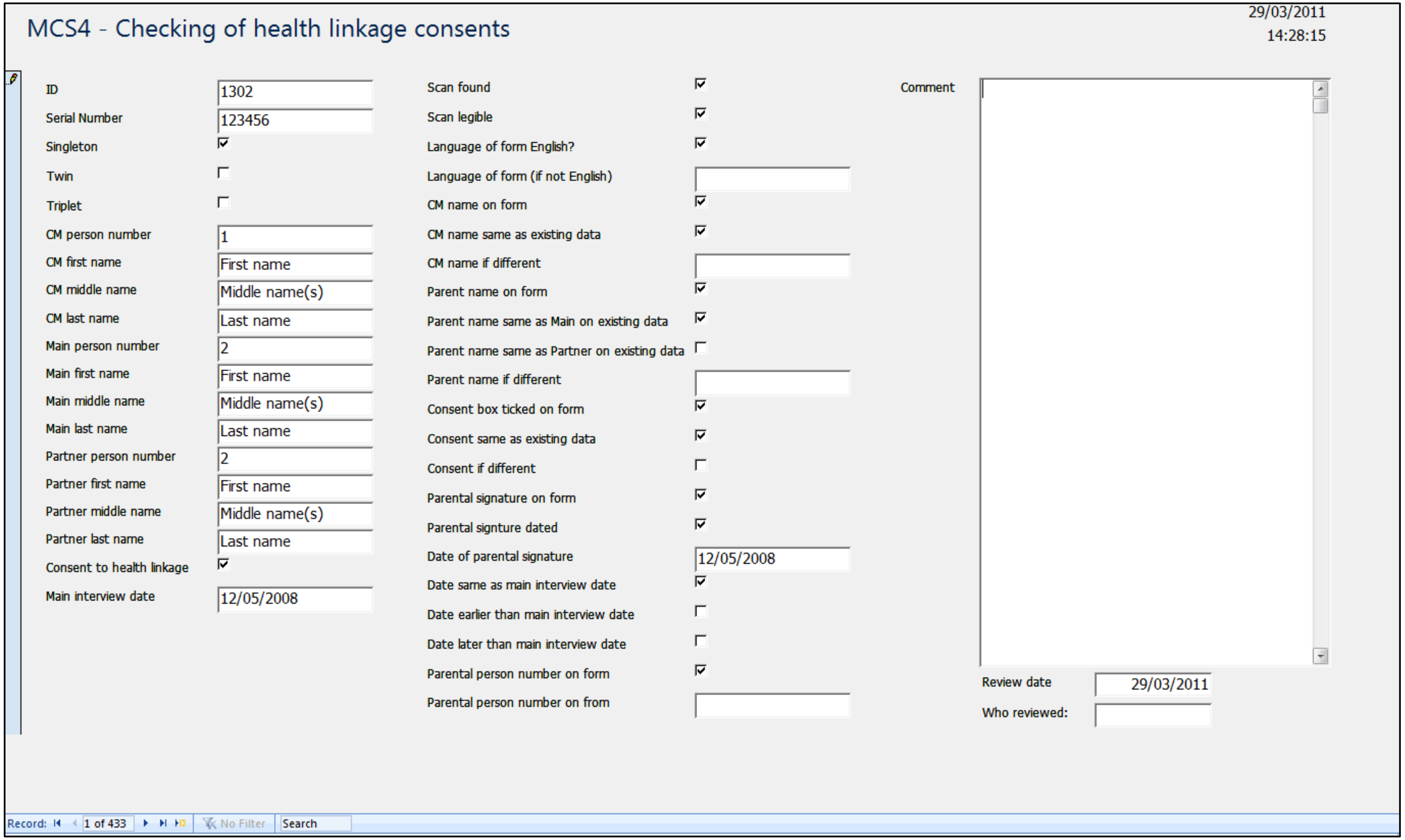
Information	Format	Source
Comment	Text	You reflecting on the above
Review date	Date	You
Who reviewed	Text	You

The ‘Comment’ box is large but you are not expected to make an entry for every case, only those to which you wish to draw attention.

4. The prefilled information for each sample case is to be checked against the information on Consent 3 for that case.

5. Images of the data entry form and Consent Form 3 are provided below.

Data Entry form*



MCS4 - Checking of health linkage consents

29/03/2011
14:28:15

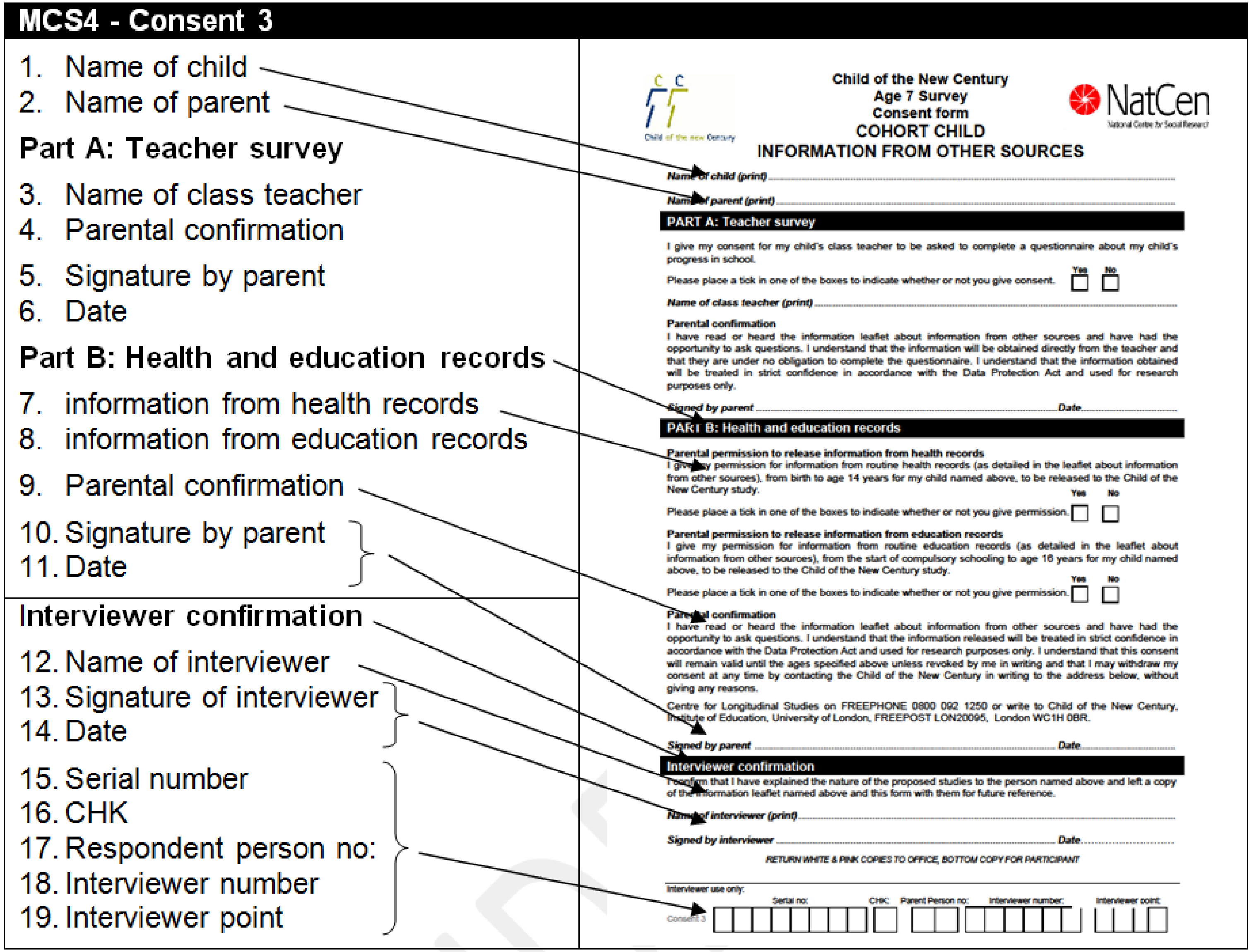
ID	1302
Serial Number	123456
Singleton	☑
Twin	☐
Triplet	☐
CM person number	1
CM first name	First name
CM middle name	Middle name(s)
CM last name	Last name
Main person number	2
Main first name	First name
Main middle name	Middle name(s)
Main last name	Last name
Partner person number	2
Partner first name	First name
Partner middle name	Middle name(s)
Partner last name	Last name
Consent to health linkage	☑
Main interview date	12/05/2008

Scan found	☑
Scan legible	☑
Language of form English?	☑
Language of form (if not English)	
CM name on form	☑
CM name same as existing data	☑
CM name if different	
Parent name on form	☑
Parent name same as Main on existing data	☑
Parent name same as Partner on existing data	☐
Parent name if different	
Consent box ticked on form	☑
Consent same as existing data	☑
Consent if different	☐
Parental signature on form	☑
Parental signture dated	☑
Date of parental signature	12/05/2008
Date same as main interview date	☑
Date earlier than main interview date	☐
Date later than main interview date	☐
Parental person number on form	☑
Parental person number on from	

Comment	
Review date	29/03/2011
Who reviewed:	

* The data entry form was slightly modified to allow for the verification of consents for twins and triplets.

Consent form 3



MCS4 - Consent 3

1. Name of child
2. Name of parent

Part A: Teacher survey

3. Name of class teacher
4. Parental confirmation
5. Signature by parent
6. Date

Part B: Health and education records

7. information from health records
8. information from education records
9. Parental confirmation
10. Signature by parent
11. Date

Interviewer confirmation

12. Name of interviewer
13. Signature of interviewer
14. Date
15. Serial number
16. CHK
17. Respondent person no:
18. Interviewer number
19. Interviewer point

Child of the New Century

NatCen
National Centre for Social Research

Child of the New Century
Age 7 Survey
Consent form
COHORT CHILD
INFORMATION FROM OTHER SOURCES

Name of child (print) ....

Name of parent (print) ....

PART A: Teacher survey

I give my consent for my child's class teacher to be asked to complete a questionnaire about my child's progress in school.

Please place a tick in one of the boxes to indicate whether or not you give consent. Yes ☐ No ☐

Name of class teacher (print) ....

Parental confirmation
I have read or heard the information leaflet about information from other sources and have had the opportunity to ask questions. I understand that the information will be obtained directly from the teacher and that they are under no obligation to complete the questionnaire. I understand that the information obtained will be treated in strict confidence in accordance with the Data Protection Act and used for research purposes only.

Signed by parent .... ***Date***..........................

PART B: Health and education records

Parental permission to release information from health records
I give my permission for information from routine health records (as detailed in the leaflet about information from other sources), from birth to age 14 years for my child named above, to be released to the Child of the New Century study.

Please place a tick in one of the boxes to indicate whether or not you give permission. Yes ☐ No ☐

Parental permission to release information from education records
I give my permission for information from routine education records (as detailed in the leaflet about information from other sources), from the start of compulsory schooling to age 16 years for my child named above, to be released to the Child of the New Century study.

Please place a tick in one of the boxes to indicate whether or not you give permission. Yes ☐ No ☐

Parental confirmation
I have read or heard the information leaflet about information from other sources 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 until the ages specified above unless revoked by me in writing and that I may withdraw my consent at any time by contacting the Child of the New Century in writing to the address below, without giving any reasons.

Centre for Longitudinal Studies on FREEPHONE 0800 092 1250 or write to Child of the New Century, Institute of Education, University of London, FREEPOST LON20095, London WC1H 0BR.

Signed by parent .... ***Date***..........................

Interviewer confirmation

I confirm that I have explained the nature of the proposed studies to the person named above and left a copy of the information leaflet named above and this form with them for future reference.

Name of interviewer (print) ....

Signed by interviewer .... ***Date***..........................

RETURN WHITE & PINK COPIES TO OFFICE, BOTTOM COPY FOR PARTICIPANT

Interviewer use only:

Consent 3 Serial no: ☐☐☐☐☐☐☐☐ CHK: ☐ Parent Person no: ☐☐ Interviewer number: ☐☐☐☐☐☐ Interviewer point: ☐☐☐☐

Appendix 6: Summary of the initial review of the scanned consent forms for cases where the mother is not the main respondent

A6.1. As noted at 23 above, the main concern with this group of consents relates to the status of those who gave consent to the linkage to child health records. Although the child's mother is not recorded as the main respondent, given the exhortation to interviewers to seek out the mother's signature (see 11 above), it is possible that the natural mother of the child did sign the consent form.

A6.2. The summary below of the initial review of the scanned consent forms for these cases shows that scans of consent forms were found for almost all cases and that most information had been completed. However, there were a small number of cases key elements considered necessary for legal consent to child health linkage – *ie:* the name of the cohort child, a tick in the consent to linkage box or parent signature – were missing (Table A6.1).

Table A6.1: Cases where the mother is not the main respondent – Summary of the initial review of scans

	Yes	No	Needs further review	Total
Scan found	425	8	na	433
Scan legible	425	0	8	433
Child name present	423	2	8	433
Child name same as on existing data record	423	2	8	433
Parent name same as 'Main' on existing data record	380	45	8	433
Parent name same as 'Partner' on existing data record	38	387	8	433
Consent to health data linkage ticked	420	5	8	433
Parent signature present	423	2	8	433
Parent signature dated	417	8	8	433
Parent person number present	390	35	8	433

A6.3. As noted at 11 above, interviewers were required to ensure they correctly recorded the reference number on the form of the person who signed the form so that their relationship to the cohort child could be checked by CLS to establish whether or not they were legally able to give permission for the information to be released. Although the majority of the person numbers recorded on the consent form are those of the main or partner respondent, an important minority are appear to relate to some other person (Table A6.2).

Table A6.2: Person number on consent form

	Number	%
Same as main	216	49.9
Same as partner	92	21.3
Other	82	18.9
No person number on form	35	8.1
Needs further review	8	1.8
TOTAL	**433**	**100.0**

A6.4. The clerical checking included a comparison of the name of the parent giving consent recorded on the consent forms against the existing electronic data provided by the survey contractor. This reveals that in over 9 out of 10 cases, consent to child health linkage was given by the person who completed the main interview or the partner interview during the MCS4 survey (Table A6.3).

Table A6.3: Who consented to child health linkage?

	Number	%
Main	380	87.8
Partner	38	8.8
Other person	2	.5
No name on form	5	1.2
Needs further review	8	1.8
TOTAL	**433**	**100.0**

Appendix 7: Summary of the initial review of the scanned consent forms for cases where the mother is the main respondent

A7.1. As noted at 23 above, the main concern with this group of consents is to establish that consent to access the child's health records was given by the natural mother or, failing this, some other person with parental responsibility. As the majority of consents are attributed to main respondent to the survey, and the majority of main respondents are mothers (>12,000), the verification of consents was based on a ten percent random sample of cases (1,228 cases) to ensure that the work could be carried out within the timescale and resources available.

A7.2. The summary below of the initial review of the scanned consent forms for these cases shows that scans of consent forms were found for all but 3 cases and that most information had been completed. However, there were a small number of cases where key elements considered necessary for legal consent to child health linkage – *ie:* a tick in the consent to linkage box or parent signature – were missing (Table A7.1).

Table A7.1: Cases where the mother is the main respondent – Summary of the initial review of scans

	Yes	No	Needs further review	Total
Scan found	1225	3	na	1228
Scan legible	1225	0	3	1228
Child name present	1222	3	3	1228
Child name same as on existing data record	1222	2	3	1228
Parent name same as 'Main' on existing data record	1210	15	3	1228
Parent name same as 'Partner' on existing data record	10	1215	3	1228
Consent to health data linkage ticked	1216	9	3	1228
Parent signature present	1216	9	3	1228
Parent signature dated	1218	7	3	1228
Parent person number present	1156	69	3	1228

A7.3 As noted above, interviewers were required to ensure the reference number of the person who signed the form was correctly recorded on the consent form so that their relationship to the cohort child could be checked by CLS to establish whether or not they were legally able to give permission for the information to be released. Again, although the majority of the person numbers recorded on the consent form are those of the main or partner respondent, an important minority are appear to relate to some other person (Table A7.2).

Table A7.2: Person number on consent form

	Number	%
Same as main	1067	86.9
Same as partner	54	4.4
Other	35	2.9
No person number	69	5.6
No scan	3	0.2
TOTAL	**1228**	**100.0**

A7.4. Fortunately, the clerical checking included a comparison of the name of the parent giving consent as recorded on the consent forms against the existing electronic data provided by the survey contractor. This reveals that in almost every case consent to child health linkage was given by the person who completed the main interview during the MCS4 survey (Table A7.4).

Table A7.4: Who consented to child health linkage?

	Number	%
Main	1209	98.5
Partner	10	.8
Other person	4	.3
No name on form	2	.2
No scan	3	.2
TOTAL	**1228**	**100.0**

Appendix 8:Summary of the initial review of the scanned consent forms for twins

A8.1. As noted at 23 above, the main concern with this group of consents is to establish that consent to access the child's health records was given by the natural mother or, failing this, some other person with parental responsibility. In addition, the pilot checking exercise showed that a consent form was not always completed for each twin child. Both children were sometimes named on a single form. Accordingly, checks were carried out for all twins.

A8.2. The summary below of the initial review of the scanned consent forms for these cases shows that, once again, scans of consent forms were found for almost all cases and that most information had been completed. However, there were a small number of cases where key elements considered necessary for legal consent to child health linkage – *ie:* the name of the cohort child, a tick in the consent to linkage box or parent signature – were missing (Table A8.1).

Table A8.1: Twins – Summary of the initial review of scans

	Yes	No	Needs further review	Total
Scan found	305	23	na	328
Scan legible	305	0	23	328
Child name present	305	0	23	328
Child name same as on existing data record	305	0	23	328
Parent name same as 'Main' on existing data record	300	5	23	328
Parent name same as 'Partner' on existing data record	5	300	23	328
Consent to health data linkage ticked	305	9	23	328
Parent signature present	302	3	23	328
Parent signature dated	301	4	23	328
Parent person number present	294	11	23	328

A8.3 As noted above, interviewers were required to ensure they correctly recorded on the consent form the reference number of the person who signed the form so that their relationship to the cohort child could be checked by CLS to establish whether or not they were legally able to give permission for the information to be released. Again, although the majority of the person numbers recorded on the consent form are those of the main or partner respondent, an important minority are appear to relate to some other person (Table A8.2).

Table A8.2: Person number on consent form

	Number	%
Same as main	280	85.4
Same as partner	10	3.1
Other	15	4.6
Further checks	23	7.0
TOTAL	**328**	**100.0**

A8.4. Fortunately, the clerical checking included a comparison of the name of the parent giving consent as recorded on the consent forms against the existing electronic data provided by the survey contractor. This reveals that in over 9 out of 10 cases, consent to child health linkage was given by the person who completed the main interview during the MCS4 survey (Table A8.3).

Table A8.3: Who consented to child health linkage?

	Number	%
1 Main	300	91.5
2 Partner	5	1.5
5 Needs further review	23	7.0
TOTAL	**328**	**100.0**

A8.5 As noted above, the pilot checking exercise showed that a consent form was not always completed for each twin. Both children were sometimes named on a single form. Accordingly, checks were carried out for all triplets and these show that, in a significant number of cases, both children were named on a single consent form – 108 (35.46%) of the 305 children for whom a consent form was found (Table A8.4).

Table A8.4: Twins - Children named per form

	Number	%
One form per twin child	197	60.1
Both children named on one form	108	32.9
Needs further review	23	7.02
TOTAL	**328**	**100.0**

Appendix 9: Summary of the initial review of the scanned consent forms for triplets

A9.1. As noted at 23 above, the main concern with this group of consents is to establish that consent to access the child's health records was given by the natural mother or, failing this, some other person with parental responsibility. In addition, the pilot checking exercise showed that a consent form was not always completed for each triplet child. All three were sometimes named on a single form. Accordingly, checks were carried out for all triplets.

A9.2. The summary below of the initial review of the scanned consent forms for these cases shows that, once again, scans of consent forms were found for almost all cases and that, for this group, all information had been completed (Table A9.1).

Table A9.1: Triplets – Summary of the initial review of scans

	Yes	No	Needs further review	Total
Scan found	28	5	Na	33
Scan legible	28	0	5	33
Child name present	28	0	5	33
Child name same as on existing data record	28	0	5	33
Parent name same as 'Main' on existing data record	28	0	5	33
Parent name same as 'Partner' on existing data record	0	28	5	33
Consent to health data linkage ticked	28	0	5	33
Parent signature present	28	0	5	33
Parent signature dated	28	0	5	33
Parent person number present	28	0	5	33

A9.3 As noted above, interviewers were required to ensure they correctly recorded on the consent form the reference number of the person who signed the form so that their relationship to the cohort child could be checked by CLS to establish whether or not they were legally able to give permission for the information to be released. Again, although the majority of the person numbers recorded on the consent forms are those of the main respondent, there are some that appear to relate to some other person (Table A9.1).

Table A9.2: Person number on consent form

	Number	%
Same as main	26	78.8
Other	2	6.1
Further checks	5	15.2
TOTAL	**33**	**100.0**

A9.4. Fortunately, the clerical checking included a comparison of the name of the parent giving consent as recorded on the consent forms against the existing electronic data provided by the survey contractor. This reveals that in over 8 out of 10 cases, consent to child health linkage was given by the person who completed the main interview during the MCS4 survey (Table A9.3).

Table A9.3: Who consented to child health linkage?

	Number	%
Main	28	84.8
Needs further review	5	15.2
TOTAL	**33**	**100.0**

A9.5 As noted above, the pilot checking exercise showed that a consent form was not always completed for each triplet child. All three children were sometimes named on a single form. Accordingly, checks were carried out for all triplets and these show that, in a significant number of cases, all the children were named on a single consent form – 13 (46.4%) of the 28 children for whom a consent form was found (Table A9.4).

Table A9.4: Children named per form

	Number	%
One form per triplet child	15	45.5
All children named on one form	13	39.4
Needs further review	5	15.2
TOTAL	**33**	**100.0**

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