

# Collecting saliva samples for DNA extraction from children and parents

Evidence from the UK Millennium Cohort Study

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CLS Cohort Studies

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**Collecting saliva samples for DNA  
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Cohort Study**

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## Abstract

In recent years there has been a substantial increase in the collection of biological data on social surveys. Biological data has hitherto been primarily collected by medically trained personnel in a clinic or laboratory setting or using specialist nurse interviewers in a home-visit setting. However, improvements in technology and the development of minimally or non-invasive data collection methods have made it increasingly feasible to collect bio-measures in a home setting using non-medically trained field interviewers. In the field of genetic research, recent advances have meant that it has become possible to extract DNA from saliva samples as well as from blood samples. This paper provides an account of a pilot study investigating the feasibility of collecting saliva samples for DNA extraction from mothers, fathers and children aged around 11 years old using field interviewers on the UK Millennium Cohort Study. To our knowledge, this is the first time that saliva sample collection for DNA has been trialled for fathers as well as mothers and children on a major longitudinal study, and the first time that saliva sample collection for DNA extraction had been trialled for children this age on a large-scale survey in the UK. We demonstrate that it is indeed viable to collect saliva samples for DNA extraction from 11-year-old children and co-resident biological fathers and mothers using field interviewers in a home setting.

## Key words

Saliva samples; bio-measures; DNA; interviewer training; Millennium Cohort Study; longitudinal.

## Non-technical summary

Surveys usually find out things about people by asking questions. But it is also possible to find out things by measuring them directly. For example, instead of asking people how much they weigh, we can find this out by weighing them using a set of scales. This usually gives a more accurate answer, as people often don't know exactly how much they weigh or might be embarrassed to give a true answer. Similarly, we can find out things from taking biological tissue samples like blood and saliva. Collecting DNA, which can be extracted from blood or saliva, allows us to find out about people's genes. Genes are the instructions which help determine the growth and development of all living things. Everyone has a slightly different set of genes – so they are like our own personal recipe book. Studying the relative importance of genes and other factors helps researchers to better understand differences in health, behaviour and learning. It is particularly beneficial to collect DNA on longitudinal surveys because combining information collected over a period of time with genetic information can improve our understanding of people's lives.

However, generally speaking, asking questions is easier and cheaper than taking measurements and collecting biological samples. And people are usually more willing to answer questions than to be measured and give their blood and saliva. But, saliva

samples are much easier to collect than blood. They just involve spitting into a tube, which is a bit unpleasant but, unlike blood, it doesn't involve any needles. Blood samples can only be taken by specially trained nurses, whereas interviewers can collect saliva samples. This means that more people are willing to give saliva than blood.

This paper provides an account of a pilot study looking into whether it is possible to collect saliva samples for DNA extraction from mothers, fathers and children aged around 11 using interviewers. A number of large-scale longitudinal surveys have collected saliva for DNA extraction from adults. But we know of only one other longitudinal survey in the world that has done this with children. And to our knowledge, our pilot study was the first time that the collection of saliva samples from fathers as well as mothers and children has been tried on a major longitudinal survey. The pilot was part of the development work for the fifth wave of the Millennium Cohort Study, a nationally representative longitudinal study which follows over 19,000 children born in 2000-2001. It provided new evidence for the UK about the practicalities of collecting saliva from minors and from multiple family members using interviewers. We demonstrate that it is indeed viable to collect saliva samples for DNA extraction from 11-year-old children and co-resident biological fathers and mothers using interviewers in a home setting. Our experience of piloting this will help other surveys who wish to do something similar to design their leaflets, consent forms, sample collection and despatch procedures and interviewer training.

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## Introduction

In recent years there has been a substantial increase in the collection of biological data on social surveys. This has been driven by growing scientific interest in the interplay between social and biological factors in explaining human behaviour (Hobcraft, 2007; Kumari et al., 2006) and facilitated by technological developments which have greatly improved the feasibility of collecting such data, particularly in large-scale, population-based surveys (Lindau and McDade, 2007).

Biological data is relatively expensive to collect as it requires specialist measurement or sample collection equipment; and for tissue samples, such as hair, blood or saliva, laboratory processing and storage costs are necessary. There are also particular ethical concerns surrounding the collection of bio-measures. There are specific challenges in gaining informed consent, particularly for the ongoing use of stored samples. There can be additional risks associated with carrying out the measurements themselves, and there may be unintended consequences resulting from feeding back 'abnormal' results to respondents. For surveys of children, there are additional ethical and practical issues in obtaining informed consent and carrying out the measurements. In part for these reasons, biological data has hitherto been primarily collected by medically trained personnel in a clinic or laboratory setting or using specialist nurse interviewers in a home-visit setting.

However, improvements in technology and the development of minimally or non-invasive methods for collecting biological data have made it increasingly feasible to collect bio-measures in a home setting using non-medically trained field interviewers. The main advantages of using field interviewers are cost and that higher response rates can typically be achieved in a home visit where the sample is collected at the same point as other survey data. However, interviewer-administered bio-measure collection requires additional training and quality control procedures. It also involves consideration of the acceptability of this approach among participants and of interviewers' own perceptions of and reactions to being asked to collect this kind of data.

In the field of genetic research, recent advances have meant that it has become possible to extract DNA from saliva samples as well as from blood samples. Saliva sample collection is straightforward and non-invasive, and can be easily carried out by field interviewers or by respondents themselves. As it is non-invasive, co-operation rates are typically higher than for blood samples taken using venipuncture, which can only be carried out by phlebotomists or other medically trained personnel. The key disadvantage of collecting DNA through saliva rather than blood is that the genetic resource that can be extracted from the sample is finite, i.e. it cannot be used to create immortalised cell lines which are self-replicating, and has a more limited range of research uses.

There are many advantages to collecting biological samples in general and DNA in particular on longitudinal surveys (Kumari, 2006; Manolio et al., 2006). The wealth of background information available opens up a wide range of analytical possibilities



and, on established longitudinal surveys, co-operation rates tend to be high due to participants' existing commitment to the study. By collecting data prospectively over time, longitudinal surveys are able to explore how later outcomes are associated with earlier circumstances. Supplementing longitudinal surveys with genetic information means that genetic variants can be used as instrumental variables in Mendelian randomisation analyses (Lawlor et al., 2008) to make causal inferences about the relationships between outcome variables and background characteristics.

This paper provides an account of a pilot study investigating the feasibility of collecting saliva samples for DNA extraction from mothers, fathers and children aged around 11 years old using field interviewers. The pilot study formed part of the development work for the fifth wave of the Millennium Cohort Study (MCS), a large, nationally representative, multi-disciplinary longitudinal study of a cohort of children born in 2000-2001 who have been followed over time. It provides new evidence for the UK of the issues and practicalities of collecting saliva from minors and multiple family members using lay interviewers.

## Experience from other surveys

Internationally many cross-sectional and longitudinal surveys collect physical measurements such as height, weight, infant head circumference, waist, hip and arm measurements, grip strength and walking speed. Examples include the Health Survey for England, the English Longitudinal Study of Ageing (ELSA) and the Health and Retirement Study (HRS) in the USA. It is well established that, with appropriate training, field interviewers are able to carry out these measurements in a home setting. The collection of medical measurements such as blood pressure, ECG, lung function, and biological samples such as blood, saliva, urine, teeth and hair, has typically been carried out either by medically trained personnel in a clinic setting, such as in the Avon Longitudinal Study of Parents and Children, or by nurse interviewers in a home-visit setting, as in the Health Survey for England, the UK National Diet and Nutrition Survey, the 1958 British Cohort Study (National Child Development Study) and *Understanding Society*: the UK Household Longitudinal Study (UKHLS).

However, a major drawback of clinic or nurse follow-up visits is the large drop-out rate. Clemens, Given and Purdon (2012) looked at the response rates to the follow-up nurse visit on a range of surveys carried out by the National Centre for Social Research (NatCen), a UK survey research agency, and showed that these ranged from 65 per cent (on UKHLS) to 86 per cent (on ELSA) of those who completed an interview. They also showed that follow-up clinic visits can suffer from even higher rates of drop-out. For example on the Diet and Nutrition Survey of Infants and Young children, only 44 per cent of those interviewed took part in a clinic visit.

Increasingly, therefore, field interviewers in countries including the UK, Germany and the USA are beginning to carry out medical measurements, such as blood pressure, and to collect biological samples, such as dried blood spots and saliva; typically with high success rates (Clemens, Given and Purdon, 2012; McFall, Conolly and Burton, 2012; Schonlau et al., 2010; Jaszczak, Lundeen and Smith, 2009; Erickson and Mierzwa, 2012; Guyer and Ofstedal, 2012). ALSPAC and NCDS in the UK and the Wisconsin Longitudinal Study in the USA have also included self-administered saliva sample collection which is posted back by respondents.

To our knowledge, however, the only example of a major longitudinal study which has included the collection of saliva samples for DNA from children is the Fragile Families and Child Well-Being Study in the USA. Field interviewers collected saliva samples from both children and their mothers during the home visit for the age 9 follow-up wave of data collection, and achieved collection rates of 86 per cent for children and 80 per cent for biological mothers. This evidence suggests that collection from children as well as mothers is both feasible and acceptable. However, such an approach has not been tested in the UK context. Moreover, there was no attempt to collect samples from biological fathers in Fragile Families, only from the biological mother and child.

The Millennium Cohort Study proposed to collect saliva for DNA extraction from children and both their biological parents, where co-resident, at the age 11 sweep. There are particular benefits from collecting DNA from parents as well as children in exploring genetic inheritance and in epigenetic research, which the study aimed to exploit by seeking funding to provide DNA from saliva as a resource to the research community. On the basis of the evidence summarised above, it was concluded that there was sufficient basis to trial saliva collection for DNA extraction using lay interviewers but that it would be important to test the feasibility more fully. The UK context (including lack of financial incentives for participants in the MCS) differs from the Fragile Families precedent in the USA. In addition, we aimed to collect from co-resident biological fathers as well as mothers and we anticipated that there might be additional sensitivities in relation to paternal participation, particularly around paternity testing.

In the remainder of this paper we describe the feasibility study and the learning involved. We demonstrate that it is indeed viable to collect saliva samples for DNA extraction from 11-year-old children and co-resident biological fathers and mothers.

## Design and methods

### Survey context

The MCS is a birth cohort study following over 19,000 UK children born in 2000/1. The data collection for the study takes place in the home and involves face-to-face interviews with multiple informants in each family. Four waves of the study have been carried out so far, at 9 months (2001/2), age 3 (2003/4), age 5 (2006) and age 7 (2008). The fifth wave (age 11) is taking place during 2012, and development work began in 2010. The data collection for the study is competitively tendered and sub-contracted to a reputable and suitably experienced fieldwork agency. For wave 5, the contracted agency is Ipsos MORI. The interviewers who work on the study receive special training and the data collection is carried out to high standards.

The home visits for the age 11 survey consist of a number of different survey elements: a computerised interview containing a self-completion element with the main carer of the child (usually the mother) and partner (usually the father); direct assessments of the child's cognitive function; measurements of height, weight and body-fat, and a paper self-completion questionnaire for the child. Previous waves of the survey have included biological samples: oral fluid via mouth swabs (but not for the purposes of DNA extraction) at age 3; and shed milk teeth for environmental lead exposure at age 7.

The development work for the age 11 survey included an initial pilot of all survey elements, consents and materials. The feasibility of saliva collection was tested in this first pilot, building on prior development work. The sample for the pilot was recruited from five areas in the UK representing a diversity of types of region. Five interviewers worked on the pilot, one in each area. None of the interviewers had prior experience of saliva sample collection. Quotas were set to ensure a cross-section of different child and family types and the fieldwork period was three weeks. None of the families had taken part in the MCS previously.

In total, interviews were carried out with 45 families (including one set of twins), as detailed in Table 1.

**Table 1: MCS5 pilot sample profile**

Demography	Sub-group	Number of interviews achieved
School year (and age) of child	Child in Year 6 / Primary 7 (aged 10 or 11)	46
Gender of child	Boys	26
	Girls	20
Social grade of parent <sup>1</sup>	AB (highest)	11
	C1	9
	C2	9
	DE (lowest)	16
Ethnicity of child	Black or other minority ethnic	5 (3 in London)
Family composition	Single parent household	16

## Data collection procedures

The fieldwork procedures for the saliva sample collection were adapted from those used successfully on ALSPAC and Fragile Families. All of the protocols were reviewed and approved by a medical research ethics committee. Interviewers were required to attend a three-day, face-to-face briefing session, where they received training on all elements of the survey, including the requirements for collecting the saliva samples.

## Gaining informed consent and securing co-operation

Interviewers were required to gain informed consent, from both parents and children, for the saliva sample collection. Parents were required to give written consent for the collection of their own sample and one parent was asked to give written consent for the collection of the sample from the child. Children were also required to consent verbally to the sample collection. Information leaflets were developed for both parents and children explaining the saliva sample collection. The content of these leaflets, and our approach to interviewer training, was informed by pre-pilot

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<sup>1</sup> Social grade is a system of social classification based on occupation that is used widely in market research. It is derived from the occupation of the head of the household. AB refers to those in higher managerial, administrative or professional, or intermediate managerial, administrative or professional occupations. C1 refers to those in supervisory or clerical and junior managerial, administrative or professional occupations. C2 refers to skilled manual workers, and D includes semi and unskilled manual workers. Those in social grade E are casual or the lowest grade workers, pensioners and others who depend on the welfare state for their income

qualitative interviews and focus groups carried out with parents and children exploring the acceptability of, and concerns surrounding the request to collect a sample of saliva for DNA extraction.

The information sheet for parents covered the following areas:

- what genes and DNA are,
- why it's important to study genes,
- what research would be done with the samples,
- what other research the samples would be used for,
- why we wanted to collect DNA from natural parents as well as children,
- ensuring that the parents understood that they didn't have to provide a saliva sample if they didn't want to,
- what giving the sample would involve,
- what would happen to the samples,
- how the samples would be used,
- restrictions on how the samples would be used,
- what would happen if the parents or the children changed their minds in the future,
- funding, ethical approval and feedback on results.

As parents were giving consent for their children, it was important that the leaflet explained whether parental consent would remain valid when the children became adults, and at what age the child would acquire 'rights' over the ongoing storage and use of their own DNA.

For the child leaflet the explanation of why the saliva sample was being collected was kept quite basic, with more focus on the practicalities involved. Given their age and the fact that parental consent was also required, this level of information was sufficient for informed consent from children.

Interviewers were instructed to give these leaflets to parents and children in advance of the survey visit and to encourage the respondents to read them prior to their visit. At the visit, interviewers had to ensure that the respondents had read and understood the letters and leaflets, and that they had explained the procedure clearly before they attempted to carry it out. They were not allowed to attempt to collect samples from anyone until they had gained the appropriate consents. In addition, the interviewer had to establish whether or not the co-resident parent was the natural parent of the study child, as only biological resident parents were eligible for the saliva sample collection. This was done through the household composition questionnaire, which had to be completed first in order to identify the eligible parent respondents. Once eligibility was established, the process for gaining consent from the natural parents to provide their own sample was relatively straightforward, and involved the interviewer and respondent working through a paper consent form, using a CAI script to guide them, and using the leaflet described above to ensure that the parents fully understood the process.

The process for gaining consent from a parent to approach the child to provide a sample was somewhat more complicated. Unlike other survey elements, consent to collect a saliva sample from the child could only be given by someone with legal parental responsibility, and not all parents have this. Interviewers therefore had to first ascertain who had legal responsibility with the help of the CAPI script. Natural mothers, natural fathers who are married to the natural mother and adoptive parents all automatically have legal parental responsibility. But for other parents, e.g. step-parents and cohabiting natural fathers, it was necessary for the interviewer to ask a series of questions to ascertain whether they had legal parental responsibility. If they did not, they were not allowed to give consent for the child to provide a sample. If there was no-one in the household with legal parental responsibility, it would not be possible to collect a sample. Once the interviewer had established who was able to give consent, they then worked through the consent form for the child's sample with the designated parent, using the saliva sample collection leaflet, in order to ensure fully informed consent for the child to provide a sample.

After consent was obtained from a parent with legal parental responsibility to collect a sample from the child, the next step was for the interviewer to gain the child's consent. The child retained the right to refuse, even if a parent had consented for them to give a sample. The process for gaining consent from the child was to ensure that they read their leaflet, and that they understood that they didn't have to provide a sample if they did not want to. It was vital that, not only did the child understand why the sample was being taken, but what the process itself would be like. The CAPI script guided the interviewer through a series of questions in order to check this. The child was not required to sign anything, but the interviewer had to sign a form to confirm the child's informed consent.

### **Collection of saliva samples**

Samples were collected using an Oragene 500 DNA self-collection kit. This equipment has been widely used on other surveys. Respondents were instructed, both in the saliva collection leaflet, and by the interviewers, not to eat, drink, smoke or chew gum in the 30 minutes prior to providing the sample.

Interviewers gave a saliva collection tube to the respondent and asked them to spit into the funnel attached to the top of it until the amount of liquid saliva reached the fill line marked on the side of the tube. This should take about 5 minutes, but interviewers were told to encourage respondents to complete the collection within 30 minutes of beginning it, should they need more time. If respondents were having difficulty producing enough saliva, interviewers were told to tell them to close their mouths and wiggle their tongue, or rub their cheeks.

When the amount of liquid had reached the fill line, respondents were asked to pass the tube back to the interviewer, who then had to hold the tube upright in one hand, and close the lid with the other hand by firmly pushing the lid until they heard a loud click. The preservative liquid that was stored in the lid would then be released into the tube for the interviewer to mix in with the saliva. They did this by unscrewing the

funnel from the top of the tube and replacing it with a small cap. They were told to screw the cap on firmly, and then shake the capped tube for five seconds.

### **Sending samples back to the laboratory**

Once the sample was provided, interviewers were meant to write the time and date that the sample was collected on the side of the tube. They were provided with a set of barcodes for each family, colour coded for different respondents (pink for the natural mother, blue for the natural father and yellow for the child), and were told to attach the relevant barcode to the side of the tube. No identifying information was recorded on the sample. Interviewers also had to enter the serial number and respondent ID number onto a despatch note. The despatch note was for the laboratory to cross check the samples against it as they arrived.

Interviewers were instructed to place the tubes into individual plastic bags (to prevent leakages) and place both the tubes and the completed despatch note into a padded envelope. They returned all of the samples that they had collected to the laboratory twice a week. Interviewers did not need to wait until they had received a complete set of samples from a family before sending them to the laboratory. As the samples are stable at room temperature, they were instructed that they should not store them in a fridge in the meantime.

### **Reconciliation of consent forms and samples**

It was essential that only samples for which consent had been obtained for collection were processed in the laboratory. The Ipsos MORI Field Department and the processing laboratory therefore had to design systems that enabled this check to be carried out. Although consent was recorded electronically by the interviewers in CAPI, this was insufficient and needed to be cross-checked against the hard-copy of the consent form. Interviewers posted consent forms back to Ipsos MORI where they were booked in on a spreadsheet generated from the CAPI data. It detailed successful serial numbers, interviewer reference numbers, and details of whether the child, mother and/or father had provided a sample. A visual check was carried out to confirm that the names on the consent forms corresponded with the names of the individuals interviewed in each household who had been recorded as the child's parent. Checks were not, however, carried out against the CAPI data to ascertain that the person giving the signature was in fact someone with legal parental responsibility.

When the samples arrived at the laboratory, the serial numbers were recorded, and this list was sent at regular intervals to the Ipsos MORI Field department. This enabled the Field department to chase up any interviewers who had yet to send back a consent form for that respondent. This also meant that the Field Department was able to chase up interviewers who had returned the consent form but where the sample had not been received by the laboratory. At the end of fieldwork, Ipsos MORI sent a full list to the laboratory of all valid consents received. Any samples for which consent had not been obtained would have had to have been discarded, although this did not actually occur.



## Findings

### Gaining informed consent and securing co-operation

The interviewers were very successful at gaining informed consent and securing co-operation from respondents, and achieved high rates of sample collection. As illustrated in Table 2, samples were collected and processed from 73 per cent of mothers, 76 per cent of eligible fathers, and 74 per cent of children.

**Table 2: Saliva sample collection response rates**

Saliva Sample	Number interviewed	Number collected	% of respondents providing sample
Children	46	34	74
Mothers	45	33	73
Fathers	25	19	76

The majority of respondents were therefore happy to participate in this element of the survey. It was clear that the leaflets managed to reassure the majority of respondents, and that the training given to interviewers about how to deal with queries and concerns was valuable. Feedback from interviewers during the pilot debrief also indicated that, for many respondents, providing a saliva sample was not viewed as either onerous or a concern, but just another part of the survey.

Of all of the elements of the survey, however, this attracted the most controversy during the visit, and refusals from a significant minority of respondents. This was either due to worries about what would be done with the samples, or distaste for the actual process involved. Additionally, in one or two cases consent was initially given but the respondent changed their mind when it came to actually carrying out the process. This was particularly the case for some of the children who, when faced with the tube, found the actual process too 'yucky' to complete.

Some parents and children refused because they did not like the idea of spitting into a tube. One or two commented that they would be happy to give a sample via another means, such as a swab. Some found the idea embarrassing, especially in front of a stranger. In some cases, interviewers found that some people were more willing to provide the sample if they could go away and produce it on their own without others watching.

In addition, a number of parents refused because they were worried and uncertain about the uses that the data would be put to. Some were concerned that data might end up on police or government databases and be used to check up on them, or to identify them in relation to criminal activities. Although the leaflet did contain assurances regarding this, a small number of parents refused point blank for these reasons; their views were so strong and fixed that interviewers felt that no further

information or persuasion techniques were likely to be effective, because they had a fundamental mistrust of the whole concept of DNA databases and data security. This attitude seemed more common among parents with lower levels of education, but not exclusively; one parent who refused for himself but consented for the study child was a university academic familiar with data handling for research purposes. One parent queried whether any reassurances about security given now would still hold in future, for example, if the law changed.

Other issues were raised by individual respondents. One parent refused, not because she had worries about how data would be handled on this study, but because of a previous bad experience when a sample of her DNA had been taken without her permission. One or two did not like the thought of not being able to access the data for themselves. One parent queried why it was necessary to collect data from the child and both parents. The leaflet did explain this, but the fact that the query was raised made it clear that interviewers needed to be prepared for questions.

In terms of administering the consent procedures, none of the interviewers had difficulty with defining legal parental responsibility. However, one respondent was unsure of how we were defining natural/biological parents and whether mothers who had conceived using a donor egg would be included (as the respondent considered herself as the child's natural parent). In this case, the sample that the respondent gave was returned to them, but the interviewer had already recorded in CAPI that a sample had been given. It became clear, therefore that the process needs to be designed to record that certain samples will not be sent to the lab, even though collection has taken place.

Although none of the respondents asked for further information about the laboratory where the data would be stored or how the data would be linked, interviewers felt that should this have arisen they would not have been sufficiently informed to respond confidently.

## **Collection of saliva samples**

Interviewers reported that the saliva samples took between 5 and 10 minutes per sample to complete. However, it is worth noting that some interviewers found it difficult to record timings accurately, particularly in cases where not all saliva samples were taken at the same time.

A number of children reported finding it hard to spit into the tube and found the process a bit awkward. Parents were generally happy with the process but some also found it difficult to produce enough saliva (especially just after they had been interviewed). Having said that, all respondents who gave consent to give saliva completed the donation.

The order in which saliva samples were taken varied from interviewer to interviewer and from household to household. Most interviewers found it helpful to introduce or

reintroduce this element of the survey later in the appointment once a rapport had been established. This resulted in some initial refusals being converted into successful outcomes. This highlights the importance of flexibility in timing.

In terms of the equipment, interviewers did not report any significant problems with the testing kit. However, in some cases saliva was present on the outside of the tubes when the interviewers were handling the samples. As a result, the majority of interviewers felt that disposable gloves should have been provided. Another issue raised was that interviewers were unable to write in the space provided on the tubes. As this information was captured in the despatch note, this did not have a significant impact on the pilot survey.

### **Reconciliation of consent forms and samples**

In total, 86 saliva samples were collected, and all were received by the laboratory. A reconciliation process was carried out four times during the three week fieldwork period. This involved the laboratory sending Ipsos MORI the serial numbers of the samples they had received to date. Ipsos MORI field staff then cross-checked this list with the consent forms received and updated the sheet to confirm that consent had been received for each individual sample. The sheet was then returned to the laboratory.

During the final check it came to light that, although Ipsos MORI had received consent forms for 86 samples, one interviewer had clearly got confused when using the barcode labels and whilst the correct label was stuck onto the saliva sample, an incorrect label (for another respondent) was used on the consent form.

At the briefings one or two interviewers had been confused about which barcode labels to use, and how they should identify which labels belonged to each respondent. This was partly because the titles on the barcode sheet, designed to inform the interviewers which labels they should use for which material/sample, did not match the wording used on the consent forms. However, feedback at the debrief suggested that, when they got out into the field, the majority of interviewers did understand which labels to use, and the colour coding system worked well.

There were two cases where respondents initially gave consent to provide a saliva sample but then withdrew their consent at a later time. Interviewers were unsure how to record this situation.

When the samples arrived at the laboratory, sample identifiers from the tubes obtained from the mothers and children were scanned successfully using a barcode scanner; but those of the fathers (blue background) could not be scanned and needed to be logged manually.

## Quality of the samples

The total yields obtained from the samples are shown in Table 3. Over 81 per cent of samples gave yields of at least 20 µg, sufficient DNA for a range of genetic studies. However there was a large range of variation in the amount obtained from different individuals. To some extent this is reflected in the initial size of the saliva sample, as shown in Table 4, with smaller samples giving a lower yield.

**Table 3: Total DNA yield**

	Number collected	Mean total yield (µg)	Std dev	Range (µg)	% with total yield > 20 µg
Children	34*	58.81	38.2	0.03-238.2	82.9%
Mothers	33	119.6	103.6	0.1- 390.4	81.8%
Fathers	19	99.6	77.1	4.0 – 254.7	89.5%

\* includes one set of twins

**Table 4: DNA yield related to sample volume**

	Number collected	Mean total yield (µg)	Std dev	Range (µg)	Mean yield per ml of sample
≤2ml	13	31.2	83.3	0.03 -306.9	15.6
2.1 to 3ml	39	98.3	86.6	0.1-390.4	105.2
3.1 to 4ml	28	97.8	69.0	21.0 – 258.1	52.1
4.1 to 5ml	6	141.3	45.9	79.1 – 290.8	45.9

The smallest samples (≤2ml) had a much lower yield per ml of sample which indicated that DNA extraction was not as efficient from these samples. Since the majority of these small volume samples were collected by one interviewer on one particular day, it suggests that the collection instructions had not been followed properly. Upon investigation, it was found that one interviewer had shaken the sample before taking off the funnel and putting on the cap. It is likely that 2ml of saliva were collected in this instance, but that it effectively spilled. Samples collected by the same interviewer at a later date were of the correct volume and gave higher yields of DNA, reflecting the fact that they had received further training on the correct use of the kits. Table 5 shows total DNA yields when samples collected incorrectly are excluded from the data and is a better indication of the yields that can be obtained. In this case over 92 per cent of samples yielded more than 20 µg of DNA.

**Table 5: Total DNA yield excluding samples collected incorrectly**

	Number collected	Mean total yield (µg)	Std dev	Range (µg)	% with total yield > 20 µg
Children	28*	61.4	35.6	12.0-171.6	92.9%
Mothers	27	142.9	99.9	0.1- 390.4	92.6%
Fathers	11	110.7	73.8	21.0 – 254.7	100%

\* includes one set of twins

At the analysis stage it was discovered that some samples were turbid and discoloured suggesting that the instructions regarding not eating, drinking, smoking or chewing gum for 30 minutes before providing the sample were not consistently adhered to. This can result in lower quality DNA.

## Conclusions

Our findings show that it is clearly feasible to get good quality, analytical samples of saliva from both young children and their parents using simple kits administered by interviewers in a household setting on a population-based survey in the UK. Importantly, we have shown for the first time that it is feasible to collect saliva samples from resident natural fathers as well as natural mothers and children.

Although our co-operation rates were not as high as in the Fragile Families study, they were sufficiently high for us to reasonably expect that large proportions of families would take part if this element was included in the main stage of the survey. It should also be noted that we would expect co-operation rates to be higher amongst the study members themselves, as they have a pre-existing commitment to and experience of the study, including provision of samples and a range of consents.

In terms of maximising response to the saliva sample collection, interviewers fed back to us that provision of greater clarity and further information about the following issues would provide respondents with reassurance and potentially encourage participation:

- That the data would not be put on the “police DNA database”.
- That the data would be held in its own separate database that would *always* be kept separate from any other database, and never linked with data that was not generated via the MCS study itself (with families’ permission).
- How data would be used (as well as information about how it would not be used), and in particular giving specific examples of socially beneficial uses of the data explained clearly and in simple, non-technical language.
- Clarification about what would happen if there was a change in the law regarding access to data. For example, would it be appropriate to provide reassurance that families would be re-contacted to re-consent if changes to the law resulted in changes in the purposes to which data could be used?

The information leaflet could easily be revised to cover these areas.

In common with other surveys, we found that respondents did not raise concerns that the sample collection was carried out by lay interviewers rather than medically-qualified personnel. This is not surprising given the non-invasive nature of saliva sample collection. Similarly, although the interviewers had no prior experience of collecting saliva samples, they were all willing and able to do this.

However, it became clear during the pilot that a considerable amount of time needs to be spent during the interviewer training to ensure that interviewers follow the procedures accurately and feel adequately equipped to deal in a confident manner with any questions that might be raised by respondents. The pilot debrief provided a great deal of information in terms of the areas that interviewers were most frequently asked about, and future training could be designed to cover these areas in more detail. Additionally, some interviewers felt that, given the nature of the research, they

did not always have the specialist knowledge required to answer questions accurately and therefore suggested that further information and answers to more detailed questions could be provided on a website.

As we had only five interviewers on our pilot study, we did not examine interviewer effects on co-operation rates; but there is evidence from other surveys that there can be significant interviewer variation in consent rates for bio-measures (e.g. Korbmacher and Kreiger, 2012). Although this is in part due to differences in respondent characteristics between interviewer assignments, it is likely that interviewer attitudes to the sample collection also play a part. In this context, it is important that interviewer training addresses any negative attitudes or inaccurate perceptions about bio-measure collection among interviewers in order that they are better able to persuade reluctant participants.

Parents and children were generally happy with the collection process, and interviewers reported few problems with the collection kit itself, leading us to conclude that both the kit and the method of sample collection can be recommended for similar studies. In terms of the process of collection itself, we would recommend ensuring that interviewers are aware of the potential for respondent embarrassment being a barrier to participation, and the benefit of facilitating privacy in this context. We also believe that it is important to provide interviewers with gloves or some other way of sanitising should saliva be present on the tubes when handed back, and we would emphasise at the briefings when to shake the tubes (as doing this prematurely led to fluid leaking from the tubes in some cases). We would also recommend that interviewers are trained to remind respondents about the requirement not to eat, drink, smoke or chew gum for 30 minutes prior to the sample collection, as the analysis of the samples carried out by the lab showed that this had not always been observed.

The despatch and reconciliation processes used at the pilot enabled us to keep track of interviewer's progress, reconcile consent forms and successfully identify who the samples belonged to. However, it is important to bear in mind the small sample size for the pilot. The process, which involved the exchange of spreadsheets between the Ipsos MORI field department and the laboratory, may be more difficult to replicate on a much larger scale involving hundreds of interviewers and thousands of samples. Given the importance of accurate real-time specimen tracking, developing a database which can be shared between the field department and the laboratory, and that identifies problems in an automated way, may be worth investigating. Some surveys involving multiple specimens being shipped to multiple laboratories have taken this approach (e.g. Jaszczack, O'Doherty and McPhillips, 2012). However, the costs and benefits of this would depend on the survey context and would need to be carefully considered.

The analysis by the lab and the booking-in processes also revealed that some interviewers had not been following the procedures for sample collection and dispatch correctly. As these processes are important for ensuring that high quality samples are collected and that the identification and reconciliation of samples can be carried out accurately, these findings indicated that further interviewer training would

be beneficial. It is becoming increasingly common for surveys to adopt formal interviewer accreditation procedures for the collection of bio-measures, and we would recommend that this approach is taken on surveys which include saliva sample collection. A number of minor improvements to the processes were also identified: providing barcode labels for an individual household alongside other personalised materials during the despatch process to minimise the risk of mixing up the labels across households; using titles for barcodes that are consistent with the terms used on the consent forms and despatch notes to help ensure that the correct barcodes are used; changing the colour used on the father's barcode label in order that it can be read by the barcode scanners at the laboratory; and verifying at the booking-in stage that valid consent was given by a parent with legal parental responsibility.

Overall, we felt that the pilot survey clearly demonstrated that the collection of saliva samples on the MCS was feasible, and could be expected to provide high quality data. Although a number of areas for improvement were identified, this was expected and demonstrates the value of pre-testing new data collection elements, even where they have been successfully incorporated on other surveys. Saliva sample collection was not included on the main stage of the fifth wave of the MCS as funding was not secured. However, it remains an aim for future sweeps, and these findings can be used to inform the development of fieldwork procedures. Our findings are also relevant to other surveys planning to incorporate saliva sample collection for DNA extraction, particularly for those involving children.



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## Appendix: Information leaflets

# CHILD OF THE NEW CENTURY

AGE 11 SURVEY PILOT



## WHAT ELSE WOULD WE LIKE YOU AND YOUR CHILD TO DO?

We are inviting you and your child to give a sample of your saliva in order that we can extract a sample of your DNA to be used for research about genes.

### WHAT ARE GENES AND DNA?

Genes are the instructions which help determine the growth and development of all living things. For example, genes determine eye-colour. Genes are made up of sections of DNA, which is the language our bodies use to write these instructions. Genes are inherited from our parents and they are the biological way parents pass on traits to their children. Everyone has a slightly different set of genes - so they are like our own personal recipe book.



### WHY IS IT IMPORTANT TO STUDY GENES?

Researchers will be able to use the DNA sample to look at whether you and your child have certain types of genes. Studying the relative importance of genes and other factors will help researchers to understand better differences in children's development, health, behaviour, growth and learning. It is important to understand the different influences on children's lives so that policy aimed at improving their lives can be informed by this research evidence.

## CHILD OF THE NEW CENTURY

### WHAT RESEARCH WILL BE DONE WITH THE SAMPLES?

Initially researchers will be looking at specific genes which have been shown to influence children's growth and learning. The measurements and assessments that children are doing in the study provide detailed information on their growth and learning. The researchers will use this alongside both the information collected about your child's genes, and the other information collected in the survey questionnaires, to help understand what things are most important in influencing growth and learning.

This initial research will be carried out by researchers at the University of Bristol and the University of Cambridge.



### WHAT OTHER RESEARCH WILL THE SAMPLES BE USED FOR?

The DNA that is extracted from the saliva samples may be used to look at other genes in the future. Researchers who want to use the DNA to look at a particular gene will have to apply for permission to an independent committee which oversees access to the samples.

### WHY DO YOU WANT TO COLLECT DNA FROM PARENTS AS WELL AS CHILDREN?

Parents influence their children in many ways and parents are themselves influenced by their genes. Collecting DNA from parents as well as children will help us to understand genetic influences on parent behaviour which may also have an effect on their children. We would like to collect a saliva sample for DNA from natural (biological) parents who are living with the study child. As children inherit their genes from their parents, we are only collecting saliva samples from parents who are biologically related to the study child.

### DO WE HAVE TO GIVE SALIVA SAMPLES?

No. Your participation in this part of the study is entirely voluntary and you or your child can choose not to give a saliva sample. This will not affect your participation in the pilot study. The interviewer will ask for your written permission before asking you or your child to give the saliva sample. We will also ask your child for their agreement.





#### WHAT WILL GIVING A SALIVA SAMPLE INVOLVE?

You and your child will be asked to do the same thing. You will be given a small container and asked to spit your saliva into the container. You should not eat, drink, smoke or chew gum for 30 minutes before giving a saliva sample. About half a teaspoon of saliva is needed. This typically takes about 5 minutes. When finished, the interviewer will place a cap on the container. There is no risk of harm to you or others when giving a saliva sample.



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#### WHAT WILL HAPPEN TO THE SALIVA SAMPLES?

The interviewer will post the saliva samples to a research laboratory at the University of Bristol. A sample of DNA will be extracted from your saliva. The saliva sample and DNA samples will be stored securely and anonymously. The saliva sample and DNA sample will be stored indefinitely unless you or your child withdraws consent in the future. Small portions of the DNA samples (with an anonymous number) may also be sent to other specialist research laboratories in the UK and elsewhere for analysis. The samples are returned to Bristol.

Your name and address will not be attached to the saliva sample when it is sent to the University of Bristol. The University of Bristol, other research laboratories to which the DNA may be sent and researchers using the DNA will not have access to your name and address.

## CHILD OF THE NEW CENTURY

### HOW WILL THE DNA SAMPLES BE USED?

The DNA will be used for research purposes only and will be treated in strict confidence in accordance with the Data Protection Act. The DNA samples provided for the pilot will only be used to inform the design of the main survey.

### ARE THERE ANY ADDITIONAL RESTRICTIONS ON HOW THE DNA WILL BE USED?

It will not be tested for the HIV (AIDS) virus and will not be available for paternity testing, life insurance, mortgage applications or police records.

### WHAT IF I CHANGE MY MIND IN THE FUTURE?

You can withdraw your consent for the storage and ongoing use of your DNA at any time, without giving any reasons, by writing to the Centre for Longitudinal Studies. They will inform the Bristol laboratory and the stocks of your samples will be destroyed. You can also withdraw your consent for the storage and ongoing use of your child's DNA in this way until your child is an adult. When your child is an adult (or earlier if he or she can demonstrate that he or she is old enough to understand), he or she can withdraw permission for the storage and ongoing use of his or her DNA and you will no longer be able to do this on their behalf.

### WHO IS PAYING FOR THIS RESEARCH?

The collection of saliva samples, DNA extraction and the initial analysis of growth and learning is being paid for by the Medical Research Council.

### WHO HAS APPROVED THIS RESEARCH?

All research which includes the collection of biological samples is looked at by an independent group of people, called a Research Ethics Committee to protect your safety, rights, well being and dignity. This study has been reviewed and approved by one of these committees.

### WILL I GET ANY FEEDBACK ON THE RESULTS?

We are not able to send you any individual's specific results as we will only be examining group trends. If you have any concerns about health or development, including any concerns about genetic or inherited diseases, we recommend that you speak to your GP.

### HOW CAN I FIND OUT MORE ABOUT THIS PART OF THE STUDY?

If you have any questions you can ask the interviewer or contact one of the Ipsos MORI researchers listed below:

#### Kirsty Burston

020 7347 3980  
kirsty.burston@ipsos.com

#### Tom Frere-Smith

020 7347 3131  
tom.frere-smith@ipsos.com

For further information about the study in general, you can visit the study website: **[www.childnc.net](http://www.childnc.net)**

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**Ipsos MORI**



## Do I have to do these four things?

You don't have to help us with these things if you don't want to. The interviewer will ask you about them one at a time, and you can say yes or no to each. You can miss out any questions you don't want to answer and stop at any time.

£

## Will I get anything for doing it?

Your family will be given a voucher for £25. The interviewer will give you a small present to thank you for taking part.

## What will happen to the information about me?

It will be used to help decide what happens in the main survey. The information about you will always be kept completely separate from your name and address. The interviewer will not show or tell your answers or measurements to anyone. You do not have to show or tell your answers or measurements to anyone, including your parent(s). The booklet you fill in and the saliva sample that you give will not have your name and address on them. This means that no-one who sees them will know whose answers they are or whose saliva sample it is.



The interviewer is looking forward to meeting you. **Thank you for your help!**  
Ipsos MORI

## How can I help with the Child of the New Century?



### What is it?

It is an important survey of lots of children. The children have been in the survey since they were born. The next time they take part will be when they are 11.

### What's it for?

It's to find out what it's like to be growing up in England, Scotland, Wales and Northern Ireland today. This will help to make things better for children in the future.

### Why me?

We want to test the survey of 11 year olds to make sure it is working. We are asking a small number of children living in a few different places to help us with this.

### What will it be like?

We hope you will find it interesting! Children usually enjoy doing the survey. The interviewer will explain everything to you clearly so it is easy for you to understand what you have to do. You don't need to do anything before hand.

### Who is being asked to be in the survey?

You, your parent(s) (that you live with) and your teacher. We won't ask your teacher if you don't want us to.

Ipsos MORI



## Answer some questions about my life. 30 minutes

The interviewer will give you a booklet of questions to fill in on your own. You can ask the interviewer to help you if you find it difficult to do it on your own.

The questions are about lots of different things. These things include your family and friends, school, the things you do outside school, the area you live in, how you feel, what you think about things and growing up.

## What if I have questions?

The interviewer will explain everything to you when they come to see you. They will ask you if you have any questions and make sure you understand everything before you start.

## What will I have to do?

The interviewer will ask you to do four things:

## Do some activities to find out how I think. 30 minutes

We'd like you to do some activities to find out how you think. The interviewer will ask you to explain some words to them and time you making patterns with some blocks. They will also ask you to do some activities on a computer.

## Be measured to find out how I am growing. 15 minutes

The interviewer will find out how tall you are using a ruler, how much you weigh and what your body fat percentage is using special scales, and the size of your waist using a tape measure. The interviewer will give you a copy of your measurements if you want.

## Give a saliva sample so they can learn more about how I grow and think.

Saliva is the watery stuff you have in your mouth. To collect your saliva, the interviewer will ask you to spit into a small plastic tube. Saliva contains something called 'genes'. Genes are part of you and are like recipes for what people are like. The way children grow and think is decided in part by their genes.



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