

# ABOUT



# STUDY

**YOU ARE INVITED TO TAKE PART IN LIFE STUDY.**

**BEFORE YOU DECIDE WHETHER OR NOT TO TAKE PART IT IS IMPORTANT FOR YOU TO UNDERSTAND WHAT LIFE STUDY IS AND WHAT TAKING PART IN THE STUDY WILL MEAN FOR YOU.**

**PLEASE TAKE TIME TO READ THE FOLLOWING INFORMATION CAREFULLY AND DISCUSS IT WITH OTHERS IF YOU WISH.**

**ASK US IF THERE IS ANYTHING THAT IS NOT CLEAR OR YOU HAVE ANY QUESTIONS.**

**IT IS YOUR CHOICE WHETHER OR NOT YOU PARTICIPATE IN LIFE STUDY.**

### Contact details

**Phone:** 0800 953 6655

**Email:** [midwife@lifestudy.ac.uk](mailto:midwife@lifestudy.ac.uk)

**Website:** [www.lifestudy.ac.uk](http://www.lifestudy.ac.uk)

## ABOUT LIFE STUDY

**Life Study is a new and very important research study that will involve more than 80,000 babies born between 2014 and 2018 – and their families – from across the UK.**

Life Study will collect information about these babies over their early lives and childhoods and into adult life. This will help us understand how early life experiences shape health and wellbeing later on.

Life Study will support a wide range of research designed to understand how to give every child the best possible start in life.

In the UK, there have been several major research studies similar to Life Study beginning in 1946 and most recently in 2000. Between them these studies have recorded the childhoods and adult lives of different generations growing up in Britain. Babies in the earliest study are now well into their sixties and they continue to help researchers understand the importance of childhood experiences and how making a difference to children's lives today makes a difference to their future lives as adults.

Life Study will focus on the lives of a new generation. It is also different to previous studies in some important ways. Unlike most other studies, Life Study will start in pregnancy, creating an exciting new opportunity to understand how babies grow and develop from as early as possible. It is also the largest study of its kind so far, which means that we will be able to answer some research questions we haven't been able to before now using smaller studies.

From the information, measures and samples we collect from Life Study babies and their families, researchers may be able to understand:

- why some babies develop asthma, eczema and food allergies while others do not
- how children get ready for learning at school during their preschool years
- how fathers influence their children's development
- the impact of air and chemical pollutants in early life
- which parental leave policies are best for parents with young children.

### Birth cohort studies

Life Study is a special type of research study known as a birth cohort study – it starts with babies born over a certain period and then continues to study the same babies throughout their lives. The babies in the first UK birth cohort study have been seen more than 17 times and are now over 60 years old!



### Pollutants

A pollutant is a substance put into the environment that may have bad effects either very soon or after a longer time. The metal lead is an example of a pollutant that can have a bad effect on children's development. It was taken out of petrol in the 1990s in the UK to protect children's health.



These are just a few of the many areas of research Life Study will support.

The time is right for a new study. Life in the UK is changing all the time and babies born today will have very different lives to ours and will live longer than their parents – one in five will live to be at least 100 years old! By making sure we involve all different families, from different communities, cultures and backgrounds, whether in good health or not, Life Study will not only reflect the rich social and cultural mix of the UK today but also help us understand how to give all children the best possible start in life.

By taking part in Life Study you could make a difference to the lives of your children, your children's children and many generations to come.

## WHY HAVE I BEEN ASKED TO TAKE PART?

We are inviting you to take part because you are at least 16 years old, are pregnant and are coming to Barking, Havering and Redbridge University Hospitals NHS Trust (BHRUT) for your antenatal care. You may have been having your appointments at Queen's Hospital, King George Hospital or Fanshawe Clinic. Midwives in these clinics are telling pregnant women, like you, about Life Study and giving you this invitation to take part.



## DO I HAVE TO TAKE PART?

No, you do not have to take part. You can choose whether you take part or not. Even if you agree now, you can choose to stop at any time. If you decide not to take part, your healthcare will not be affected.

## WHAT WILL HAPPEN IF I TAKE PART?

If you agree to take part, we will ask you to:

### 1 Visit our Life Study Centre at King George Hospital

We will ask you to visit us three times: once during the last four months of your pregnancy and then two more times during your baby's first year. The visits may last up to two hours each.

At each visit you will be asked to answer some questions, have your weight and height measured and eyes tested, and give a small amount of blood and urine. Your baby will have similar measurements and will also be given some tasks and games to play – some of them with you. We will watch while they do these and film them. We would like to collect a small amount of their urine, saliva and poo. We will not take any blood from your baby or carry out any tests that are painful or uncomfortable for them.

### 2 Give some biological samples

We will ask you to give some samples around the time of birth. Some of these might otherwise be thrown away. These include:

- placenta (afterbirth) and some blood left in the umbilical cord
- blood samples left over from routine blood tests at your antenatal clinic visits
- blood samples left over from your baby's newborn screening bloodspot (heel prick test).

We would also ask you and your baby to give a sample of stool (poo) and urine and would like you to give a vaginal swab.

### 3 Agree to be contacted again by Life Study in future – we may wish to contact you and your baby again at some time in the future to answer other questions or attend for more visits. It is your choice whether to take part in these when you are contacted.

### 4 Agree Life Study can request information that the NHS and other organisations already hold about you to allow us to understand about your and your baby's future health and wellbeing.

This will help researchers get a more complete picture of how the information Life Study collects directly from you may be related to other events in your and your baby's life. This would only be done with your permission.

If you take part in Life Study you will be agreeing to have the anonymised samples and information you and your baby have provided stored by Life Study and used by researchers for many years to come.

*This booklet is about the first visit to the Life Study Centre before your baby is born, the samples we would like to collect during the visits and at birth, and information we would like to request from your records. There are separate booklets for your partner and the visits after your baby is born.*

## Did you know...

We can measure how much iodine is in urine. This tells us how much iodine is coming from food in the average UK diet today. In Life Study we can link the information on different levels of iodine in pregnancy to children's development and see what levels matter for children's health and development.



## Find out more

Find out more about the samples on pages 14 – 17.

Find out more about information linkage on pages 18 – 22.

You can also visit our website [www.lifestudy.ac.uk](http://www.lifestudy.ac.uk) for more information.



## Did you know...

Previous research based on studies like Life Study has improved children's health and lives. For example, studies like this led to changes to make it easier for parents who want to stay in hospital with their sick child.



## Anonymised

This means that we will remove personal details such as your name and address so any other information you give us, like your answers to questionnaires and your samples, cannot be linked back to you.



## DO I HAVE TO AGREE TO EVERYTHING?

No. If you feel uncomfortable about answering some questions then you do not need to answer them. If you are unable to have some measurements or do not want to have them, you can still take part without doing these.

We do need you to agree to us getting some information from your health records, and to using birth and health records to know when your baby is born. If you do not wish to agree to this, then you will not be able to join Life Study.

Ideally, we would like a blood sample from you and a saliva sample from your baby. If you are worried about giving these samples, then please talk to the Life Study staff or midwife about this.

## ARE THERE ANY BENEFITS FOR ME OR MY BABY IF I TAKE PART?

There are no direct benefits to you or your baby. However, the research supported by the information that Life Study collects from all those who take part will make a difference to the lives of your children, your children's children and to future generations to come.

## ARE THERE ANY RISKS FOR ME IF I TAKE PART?

Taking part in Life Study will not put you or your baby at any risk of harm. The measurements and samples collected have been used with pregnant women before and are not known to have any risks. Many of the questions you will be asked have been asked in other similar studies. They should not make you feel uncomfortable and you can choose whether to answer them or not.

## WHAT IF THERE IS A PROBLEM?

As with all research studies, Life Study is insured against any negligent harm in the unlikely event this occurs.

## HOW WILL MY INFORMATION BE USED?

Results from any questionnaires, measurements or from tests carried out on samples will be used by approved researchers. These researchers will use the information collected on all Life Study participants to understand how early life circumstances influence children's lives as they grow up. They include researchers who are working in the UK or other countries, in universities or for commercial companies looking at new treatments or diagnostic tests.

Your name and address are kept separately and Life Study will never

pass on information with these personal details to researchers. Information that is given to researchers will be anonymised so they will not be able to identify you or your baby. Researchers using the Life Study information will not know it was you who gave us that information or those samples.

Life Study will not sell your information to anyone.

Life Study will not pass on your personal information or results to insurance companies or employers. Life Study will not allow access to personal information or results by the police, security services, relatives or lawyers, unless legally forced to do so by the courts.

## HOW WILL LIFE STUDY KEEP MY INFORMATION CONFIDENTIAL AND SECURE?

We're very careful to keep all of your information confidential and secure as this is very important to us.

Information or samples will be stored separately from your personal details (such as name and address) to protect your identity. Only the Life Study staff who need to contact you will know your name and contact details.

We will store your information securely. We use a number of methods, such as encryption and secure computer systems, to prevent unauthorised access to your personal information. All possible precautions will be taken to prevent

unauthorised access and we do not expect this to ever happen. However, in the extremely unlikely event of unauthorised access you could not be identified. This is because when we collect your information or obtain further information from records we remove your personal details and replace them with a unique identification number (code).

## WHAT WILL HAPPEN TO THE RESULTS OF LIFE STUDY RESEARCH?

Researchers will be expected to make the results of research based on Life Study publicly available so that other researchers and the public can obtain full benefit from it.

## WHERE CAN I FIND OUT THE RESULTS OF LIFE STUDY RESEARCH?

Summaries of the results of Life Study research will be put on the Life Study website at [www.lifestudy.ac.uk](http://www.lifestudy.ac.uk). For further information about the study, please contact us using the details in this booklet.

## WILL I BE ABLE TO CLAIM MY TRAVEL COSTS TO VISIT THE LIFE STUDY CENTRES?

Yes, you will be able to claim reasonable travel costs at the end of the visit - for example bus fares or parking costs - by completing a simple claim form (it would be helpful to keep any receipts).

## WHAT SHOULD I DO IF I WANT TO TAKE PART?

If you would like to take part in Life Study, you should speak to your Life Study midwife or phone the study centre reception on 0800 953 6655 to make your appointment for a visit. The first visit will be in the last four months of your pregnancy. You can make this appointment at a time convenient for you, such as when you are visiting to have blood tests. When you come to the visit, someone will discuss the study with you and check you still wish to take part. You can also ask any questions.

## WHO DO I CONTACT IF I HAVE ANY CONCERNS?

If you have any concerns or complaints about anything to do with Life Study you can telephone us free of charge on 0800 953 6655 or email [midwife@lifestudy.ac.uk](mailto:midwife@lifestudy.ac.uk).

You can also talk to Patient Advice and Liaison Service (PALS) at BHRUT if you have more general enquiries or concerns about involvement in this research at the local hospital trust: phone 020 8970 8234 or email [pals@bhrhospitals.nhs.uk](mailto:pals@bhrhospitals.nhs.uk).

If you would like to write to the Director of Life Study, Professor Carol Dezateux, then please send your letter to her at:

Life Study  
UCL Institute of Child Health  
30 Guilford Street  
London WC1N 1EH

# THE LIFE STUDY JOURNEY



## At the 20 week scan

At your scan appointment, our Life Study midwife will give you some more information and ask you if you would like to take part in the study.

You will be able to ask questions and discuss anything you need to know or are unsure about.

You don't have to decide straightaway. You can think about it and contact us later.



## After 20 weeks

Your first Life Study appointment at your local study centre:

King George Hospital

It should be about two hours long.

With your permission, we will ask you some questions, take some measurements and collect a small amount of your blood and urine.

We would like to see dads or partners at the pregnancy visit and you can come along together or at different times.



## Birth

With your permission, we will collect some samples from you and your baby around the time you give birth. Some samples would normally be thrown away after birth, such as placenta (afterbirth). We will not take any blood from your baby.

The samples include:

- placenta, umbilical cord and cord blood
- blood leftover from routine blood tests
- vaginal swab
- stool (poo)
- urine
- saliva
- throat swab



## Baby 6 months

Your second Life Study appointment at your local centre:

King George Hospital

It should be about two hours long.

With your permission, we will ask you some questions, take some measurements and collect some samples from your baby: urine, saliva and stool (poo).

We would also like to watch or record your baby doing some tasks and games together with you.



## Baby 12 months

Your third Life Study appointment at your local centre:

King George Hospital

It should be about two hours long.

With your permission, we will ask you some questions, take some measurements, and collect some samples from both you and your baby.

You: blood and urine

Baby: urine, saliva, stool (poo)

We would also like to watch or record your baby doing some tasks and games together with you.

# THE PREGNANCY VISIT

## Find out more

Find out more about the measurements on page 13.



### WHAT HAPPENS BEFORE THE VISIT?

Before you come, we will confirm your appointment in a letter that will include a checklist of the things you need to bring along with you.

For example, we will ask you to bring your pregnancy notes (records) with you so we can look at information about this and past pregnancies. We will also ask you to make a note of medicines you are taking and to bring some information with you that you might not otherwise remember (for example your own birth weight).

### WHAT HAPPENS DURING THE VISIT?

When you arrive, staff will tell you more about Life Study. You can ask any questions before deciding whether to join in. If you decide to join Life Study you will be asked to sign a consent form.

During the visit, we will ask you to:

- answer questions – some using a computer and some with an interviewer -about your health, pregnancy, lifestyle and diet, education and work, support from family and friends, and your neighbourhood
- have your height, weight and body fat measured (by standing on special scales) and a special eye test
- give a small amount of blood and urine.

### WILL I GET ANY RESULTS AT THE VISIT?

The visit is not a health check and blood, urine and other samples will not be analysed immediately so we cannot give you or your GP any results. We will give you some readings of measurements (for example of your baby's size). If any measurements are outside of expected limits you would be advised to take them to discuss with your GP but we would not contact your GP directly. Life Study staff are trained to collect and record research information.



### WILL MY GENERAL PRACTITIONER (GP) KNOW I AM TAKING PART?

If you agree, we will send a letter to your GP to say that you are taking part in Life Study.

We will NOT tell your GP anything about the information that you provide or the results of measurements or tests carried out during the visit. You may tell your GP about these if you wish.

If during the visit Life Study staff become concerned about keeping your unborn baby safe from serious harm, they will follow child protection guidance. They may consider it necessary to contact your midwife, obstetrician or GP.

### WHAT IF I DON'T WANT TO CARRY ON WITH LIFE STUDY?

You can withdraw from Life Study at any point.

During the visit, you can withdraw by telling one of the staff.

After the visit, you can withdraw by telephoning 0800 953 6655 or by emailing [midwife@lifestudy.ac.uk](mailto:midwife@lifestudy.ac.uk).

### WHAT HAPPENS ONCE I HAVE STOPPED BEING PART OF LIFE STUDY?

This depends on what you have told us you want to happen. There are three options open to you. You can ask Life Study for: "no further contact" or "no further access" or "no further use". These are explained below and more details are also on the Life Study website.

**'No further contact'**: This means that Life Study would not contact you again, but would have your permission to keep and use information and samples that you have already given and to request further information from your health and other records in the future.

**'No further access'**: This means that Life Study would not contact you again and would not request information from your health and other records in the future. Life Study would still have your permission to keep and use the information and samples you have already given us.

**'No further use'**: This means that Life Study would no longer contact you and would not request information from your health and other records in the future AND any information and samples already collected would no longer be given to researchers.

Under all of these options Life Study would keep some of your information: for example, the consent form and withdrawal form would be kept as a record of your wishes and some information would be retained to ensure you are not contacted again. Your information would not be used for new research, but it would not be possible to remove your information from research already completed. Depending on your preference, Life Study would destroy your samples that are still in storage. Your samples would not be given out for new research but it may not be possible to trace and destroy the remains of any anonymised samples that have already been given out.

Details of how to withdraw are on the Life Study website [www.lifestudy.ac.uk](http://www.lifestudy.ac.uk).



# CHOOSING TO WITHDRAW FROM LIFE STUDY

## OPTION 1 NO FURTHER CONTACT

- ! Life Study will not contact you again.
- ➔ Life Study can request further information from your health and other records in the future.
- ➔ Life Study has your permission to keep and use information and samples that you have already given.

## OPTION 2 NO FURTHER ACCESS

- ! Life Study will not contact you again.
- ! Life Study will not request information from your health and other records in the future.
- ➔ Life Study has your permission to keep and use information and samples that you have already given.

## OPTION 3 NO FURTHER USE

- ! Life Study will not contact you again.
- ! Life Study will not request information from your health and other records in the future.
- ! Any information and samples already collected by Life Study will no longer be given to researchers.

# MORE ABOUT THE MEASUREMENTS

## WHAT MEASUREMENTS WILL BE DONE AT THE LIFE STUDY CENTRE?

The tests and measurements that you may be asked to do include:

### HEIGHT

Your height will be measured when you are standing up and sitting down.

### WEIGHT AND BODY FAT COMPOSITION

Your weight and body fat composition will be measured by asking you to stand on a special machine. The machine may interfere with a pacemaker or similar electronic implant – you must tell staff if you have one of these and the test will not be done.

You will be asked to take your shoes, tights and outdoor clothes off when your weight and body fat is measured.

### SKINFOLD THICKNESS

Skinfold thickness will be measured on the upper back. A staff member gently holds the skin and fat up (not the muscle) then measures the thickness using measuring equipment called calipers.

You may need to remove or pull back clothing to allow staff to reach your upper back.

The calipers are used often in clinical practice and research. They are safe for use at all ages and are not painful.

### ARM SIZE (MID-UPPER ARM CIRCUMFERENCE)

The circumference of your mid upper-arm will be measured using a flexible measuring tape. You will need to roll your sleeve up or remove your top to do this if you are wearing clothing that covers your upper arm.

### PLUSOPTIX EYE TEST: to look at how your eyes move

The Plusoptix is usually used to screen for squint in children but can be used in adults also. The staff member will ask you to look at a machine they are holding and a reading will be taken.

If the Plusoptix does not give a reading, we will ask to take a photograph of your eyes and an expert scientist will look at this later.

### FRISBY EYE TEST: to test how both eyes work together (stereovision)

The Frisby screening stereotest is used regularly by eye specialists. It can test if both eyes work together – but it doesn't test how good your eyesight is. You will be shown a glass plate with four squares. If you have stereovision, then one square will look different.



# MORE ABOUT THE SAMPLES

## Did you know...

We can analyse cord blood to find out about how the immune system develops in very early life.

From placenta samples, we can test for effects of environmental pollutants such as air pollution or lead. The placenta feeds baby while in the womb so it is a good record of baby's environment. We are interested in finding out how the environment around mums reaches their babies and what effects this might have.

In stool (poo), we can measure the number and type of different microbes (bugs like bacteria). We are interested in the types of microbes that live in different parts of the body. These microbes may have an important role in deciding whether children get asthma or other illnesses.

From saliva, we can test for food allergies.



### WHEN ARE SAMPLES COLLECTED?

Samples will be collected with your permission at each visit to the Life Study Centre and around the time you give birth.

### WHAT SAMPLES ARE COLLECTED AT THE FIRST LIFE STUDY VISIT (DURING PREGNANCY)?

We will ask your permission to collect samples from you when you visit the Life Study Centre. These samples include:

- Blood (40-50ml or around three tablespoons)
- Urine

### WHAT SAMPLES ARE TAKEN AROUND THE TIME OF BIRTH (DELIVERY) IN THE LABOUR WARD?

We will ask your permission to collect samples from you after your baby is born. These samples will be collected in the labour or maternity ward and include:

- umbilical cord
- some blood from the umbilical cord (cord blood)
- placenta (afterbirth)
- any blood samples left over from those taken routinely during your pregnancy or delivery
- stool (poo) sample (or swab)
- vaginal swab
- urine.

We would also like to take the following samples from your baby around the time of birth:

- urine
- saliva – using a soft sponge wiped over the gums
- throat swab
- first infant stool (poo) – probably taken from nappies

- stool collected at home in the first two weeks after birth (either by a visiting midwife/health visitor or taken by a parent or carer and returned by post)
- any blood left over from your baby's routine screening heel prick test (this is usually taken at five days old).

The samples will only be collected once the midwife has made sure that your baby is safe and healthy. The samples are all easy to collect and won't upset your baby.

### WHAT SAMPLES ARE TAKEN AT THE OTHER LIFE STUDY VISITS (WHEN YOUR BABY IS 6 OR 12 MONTHS OLD)?

At the 6 month visit, we would like to collect:

From mothers

- No samples

From babies

- urine
- saliva
- stool (poo)

At the 12 month visit, we would like to collect:

From mothers

- urine
- blood (40-50ml or around three tablespoons)

From babies

- urine
- saliva
- stool (poo)







### WHAT WILL HAPPEN TO THE SAMPLES THAT I GIVE?

The samples that you give to Life Study, as well as the samples from your baby, are considered as donations or gifts. You can still ask for them to be destroyed if you withdraw from the study.

In general, there will be no tests or analyses done on your samples immediately. They will be stored so they are available for future research studies, some of which may not take place for many years to allow Life Study to benefit future science. Samples will be stored in a facility licensed under the Human Tissue Act 2004 (England and Wales).

Over the coming years, a very wide range of tests may be carried out on Life Study samples. All these tests will be approved by an ethics committee and also be scientifically reviewed to make sure that the research is of high quality.

### WILL I FIND OUT THE RESULTS OF ANY TESTS ON SAMPLES THAT I GIVE?

In general, Life Study will not feedback any results from tests on samples taken as part of Life Study because:

- Tests are not done on all of the samples immediately – so it may be a long time (years) before some of your samples are tested.
- Research studies may use new or experimental tests that are not yet used widely by doctors for their patients. This means that we do not as yet understand what results might be expected in the general population and their meaning in terms of future health.
- Test results on anonymised samples cannot be given back to you, your doctors or anyone else because we won't know who the samples come from.

### WILL ANY GENETIC TESTS BE DONE?

Yes, it is likely that there will be genetic tests on your DNA and your baby's DNA. These tests will be used for research purposes and results will not be given to you, your doctors or anyone else. Personal information from questionnaires will be kept confidential and separate from genetic information.

## Human Tissue Act

The Human Tissue Act is a law to make sure that biological samples are handled properly and ethically and that independent checks are in place to confirm this.



## Did you know...

By looking at genes, researchers and doctors have made important discoveries about how some conditions such as asthma, autism or obesity develop.



# MORE ABOUT INFORMATION LINKAGE

## Did you know...

Information linkage has been used in other birth cohort studies, for example to get more information about the way mothers give birth (such as, normal delivery or Caesarean section) or about the baby's birth weight.



### WHAT IS INFORMATION LINKAGE?

Routine records are kept by organisations like the National Health Service (NHS), education and other government departments. We would like your permission to collect some of the information held in these records about you or your baby so we can understand how health and other life events are related. This is sometimes called 'information linkage' because we link one type of information (for example, Life Study) to another source (for example, routine health records).

### HOW DO INFORMATION REQUESTS WORK?

Routine records are kept by a number of different organisations. We can only request information for Life Study with your permission.

If you take part in Life Study you will be asked to sign a consent form. Part of this consent form sets out the types of routine records from which we would like to request information.

We will never give any information from the answers you have given to questions on Life Study questionnaires, or any other information you provided to Life Study, to organisations that hold these records. We will only give them some essential personal details so we can be sure that they find the correct records to provide the information that has been requested.

### WHY DO YOU NEED THIS INFORMATION?

This is a good way to obtain information that you might not be able to remember easily. For example, GPs record details about the name or dose of medicines such as antibiotics or asthma inhalers that you or your baby may have been prescribed and this will give a better understanding of these important illnesses and treatments.

In Life Study, we are interested in linking to information from records which are related to a child's health and wellbeing and the wider circumstances of their family and community. Examples of these are records from GPs, hospitals, fertility treatment, dentists and opticians, and also education and school records, employment and benefit records and the Census which describes your neighbourhood area.

### WHAT ABOUT MY CHILD'S RECORDS?

We will ask for permission to access information from your child's routine records in the same way as we ask for permission to access your information. We can only ask for information from a child's records if we have consent from a parent or legal guardian. Some examples of information from your baby's records that we would like to request are:

- Birth information (including information from any admissions to special or intensive care if your baby has needed this care)
- Child Health Records (which record your baby's development checks and immunisations)
- Screening test results (such as the newborn hearing test)
- School information (once she or he starts attending school)







### WHICH RECORDS WILL LIFE STUDY REQUEST INFORMATION FROM?

Details of the types of records containing information related to your health and wellbeing are in the table over the page. We would like your permission to ask for this information.

This may include information about physical and mental health, progress at school, or any special needs a child may have.

We also provide names of the organisations or departments who currently hold the records which contain this information. Sometimes these organisations or departments change. Where this could happen, we have included a more general statement in the consent form saying that you agree to us asking for information from 'the relevant department holding this information'.

Type of information	Why?	Where from?	What do you want to know about?	What sort of questions could Life Study help to answer?
 <b>Health</b>	We may be able to understand how your health and your child's health is affected by other areas of your lives and has an impact on later health and wellbeing.	Routine medical and other health records: <ul style="list-style-type: none"> <li>• NHS</li> <li>• family doctors or GPs</li> <li>• other healthcare organisations or providers, such as dentists or opticians</li> <li>• NHS registration records (currently held by the NHS Central Register and Personal Demographic Service)</li> <li>• public birth and death registrations (currently held by the National Records for Scotland, Office for National Statistics and General Register Office in Northern Ireland)</li> <li>• health-related records held by the UK Departments of Health</li> <li>• disease or other health-related registers, such as national cancer registers</li> </ul>	<ul style="list-style-type: none"> <li>• visits to your family doctor or other health professional (for example, midwife)</li> <li>• admissions or attendances at hospital</li> <li>• prescriptions and treatment health status, and records of specific conditions such as diabetes</li> </ul>	Does anything in pregnancy or early life make a child more likely to have asthma or food allergies later in life? Can we find a way to prevent that?
 <b>Mobile communication devices (for example, phones)</b>	We are interested in the effects on your health of the electromagnetic and radio waves used by these devices	Your network operator (It is important for Life Study to know when you change to a different network operator or phone number so we can link to records. We would like you to write, email or phone us if this happens.)	<ul style="list-style-type: none"> <li>• how often you use your mobile device</li> <li>• how long you use your mobile device</li> </ul> (This information will not include any details about numbers that you call, people who call you, where you are when you make or receive calls, or the contents of messages.)	How do mobile phones affect children's development? Do we need to put guidelines in place to make sure that our children aren't protected from any problems that might be associated with mobile phone use?

Type of information	Why?	Where from?	What do you want to know about?	What sort of questions could Life Study help to answer?
 <b>Education</b>	Your own experiences at school, college, or university are likely to affect the rest of your life and could have an impact on your child. Your child's experiences at school are also likely to be an important influence on their own lifelong health, development and wellbeing.	Different organisations, such as: <ul style="list-style-type: none"> <li>• school</li> <li>• college</li> <li>• university</li> <li>• work-based training or apprenticeships</li> </ul>	<ul style="list-style-type: none"> <li>• exam results, for example SATS and GCSEs in England, Wales and Northern Ireland and Standard Grades in Scotland</li> <li>• information about disability, special educational needs (SEN), religion, looked after child or children in need status</li> <li>• information from the National Pupil Database</li> <li>• information about the school</li> <li>• courses/training records</li> <li>• higher education records</li> </ul>	Does the age of a child or time of year when they start school make a difference to how well they do overall at school? Should children start school earlier or later than they do now?
 <b>Economic</b>	In Life Study, we can learn about your employment and economic circumstances by asking questions in the questionnaire but it is sometimes easier and more accurate to get some of this information from the government agencies.	For example: <ul style="list-style-type: none"> <li>• the Department for Work and Pensions (DWP) and HM Revenue and Customs (HMRC)</li> </ul>	For example: <ul style="list-style-type: none"> <li>• National insurance contributions</li> <li>• Benefits and tax credits, including Child Benefit and Income Support</li> <li>• Employment and earnings</li> <li>• Savings and Pensions</li> <li>• Participation on schemes such as the New Deal for Young People and the New Deal for Lone Parents</li> </ul> (Taking part in Life Study record linkage is confidential. Your linked information in Life Study will not be shared with your employer or government benefit or tax offices, to work out if you are claiming the correct benefits. It will not affect any current or future claims for benefits)	What are the benefits for children of both parents having paid parent (maternity or paternity) leave?

## I HAVE HAD FERTILITY TREATMENT – WILL LIFE STUDY ASK FOR INFORMATION FROM THESE RECORDS?

Yes, if you agree and with your specific permission only. In Life Study we know a large number of women may have had fertility treatment to help them become pregnant, both in and out of the UK. Life Study is an important opportunity to find out more about the health of babies who are born after this fertility treatment. As well as asking all women in Life Study about their use, we wish to request linkage to information from the records of fertility treatments held by the Human Fertilisation and Embryology Authority (HFEA) about fertility treatments carried out in the UK. Information about your treatment will only be released to Life Study by the fertility clinic on receipt of a signed special HFEA consent form. If you have had fertility treatment in the UK, you will be asked if you wish to sign this form.

## HOW OFTEN WILL LIFE STUDY ASK FOR INFORMATION FROM MY RECORDS?

This will depend on the type of record and how often it changes. We may request some information, for example from medical records, at regular intervals so we can look at any new information and keep up to date with events in your and your baby's lives. Other records such as school records may not change so often, and so we may ask for information from these once or twice. We may want to ask for information about your baby more regularly as this may change more often.



## DO I HAVE TO AGREE TO INFORMATION LINKAGE?

We will ask you to agree to obtaining some information from your routine health records as without this permission we cannot, for example, find out about your baby's birth, or trace you and your baby as you both grow older. *If you do not wish to agree to this linkage, then you will not be able to join Life Study.*

Education, employment or mobile phone (or communication technologies) records are helpful to build a complete picture of the wider environment and life of children in our study but these are optional. We would like to have your permission to request this information but you can still take part in Life Study if you choose not to let us use information from all the records suggested. On the consent form, you will be asked to indicate which records you will allow us to request information from.

## CAN I WITHDRAW OR STOP INFORMATION LINKAGE?

You are free to tell us to stop requesting information from some or all of your records at any time without giving a reason.

We will continue using your information until you tell us that you wish to withdraw your consent or stop taking part.

# OTHER INFORMATION

## UNDERSTANDING WHO DOES AND WHO DOES NOT TAKE PART

All NHS hospitals collect information about the patients who are using them. This is so they can check that they are providing good quality services. The Life Study team will also use some of this information to check that all pregnant women are being given an invitation and the chance to take part in Life Study. We will check that we are not missing out any particular groups of women, such as women who have their baby early or are having twins. If you are concerned about your information being used for these checks, please speak with the Life Study research midwife; phone 0800 953 6655 or email [midwife@lifestudy.ac.uk](mailto:midwife@lifestudy.ac.uk).

## WHO IS ORGANISING AND FUNDING THE STUDY?

Life Study is funded by the Economic and Social Research Council (ESRC), Medical Research Council (MRC), University College London (UCL) and the Wellcome Trust. The Life Study team is based at UCL and collaborates with scientists, researchers and doctors from all over the UK. Doctors and midwives in NHS maternity units in different parts of the UK are also working closely with us to support Life Study and help make it a success.

## WHO HAS REVIEWED THE STUDY?

The plans for Life Study were reviewed by an independent group of international scientists before it was given funding. There has also been a UK-wide consultation with academics and researchers about the types of questions, measurements and samples to be used or collected. Participant representatives and members of the public have been involved in various ways, including focus groups and a study pilot, to give us their feedback on the study.

The study has been approved by the NHS London – City and East Research Ethics Committee (REC reference 12/LO/1492).

**If you or someone you know would like this information provided in a different format or language, please visit our website [www.lifestudy.ac.uk](http://www.lifestudy.ac.uk) for more information.**