Can our DNA be used to test if family members will develop a disease later in life (such as breast cancer or Alzheimer's disease)?

No. Gemini DNA samples will not be analysed for any individual person. The DNA will be used by Gemini scientists to compare groups of people. For example, we will compare the DNA of all the children with a big appetite versus those with a small appetite, or all those who have experienced slow growth versus those who have not. The research will not yield any useful test result for an individual. We will not use your twins' DNA to test for genes whose risk is already known, such as the breast cancer gene. The goal of our research is to search for possible new genes, but these would have to be confirmed by other studies before it is known if they are medically useful. If there is a gene that is already used medically to test an individual's risk for a disease, you can ask your GP about testing them for it.

Can my GP contact you to find out the results of our DNA?

No. The Gemini DNA bank will always be kept completely confidential, without exception. The Gemini DNA bank will be used only for research purposes. If your GP ever wishes to conduct a DNA test for your twins, the GP can easily take a DNA sample from your twins' saliva or blood so there is no need for GP's to contact Gemini.

If someone asks if I or my twins have had genetic screening, what should I say?

You should say your twins have not had genetic screening, as we are not conducting screening tests on the DNA.

For further information please contact us:
Phone: 0207679 1732
Email: Gemini@public-health.ucl.ac.uk
Post (no stamp required): Gemini, Health Behaviour Research Centre, UCL, 1-19 Torrington Place, London, WC1E 6BT, FREEPOST SE64 15.

Professor Jane Wardle, Principal Investigator
Dr Ellen van Jaarsveld, Study Co-ordinator
Dr Laura Johnson, Researcher
Dr Abigail Fisher, Researcher
Ms Clare Llewellyn, Researcher
Miss Alison Fildes, Researcher

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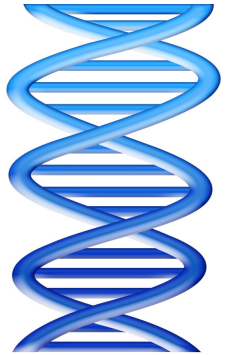
Information about DNA collection



What is DNA?

Almost all cells in your body have DNA in them, and cheek cells are very easy to get. You can collect these cheek cells by rubbing a cotton-bud inside your twins' mouth. Knowing this, we have developed a very easy way of collecting DNA, where we can send you special "DNA packs" by mail. You can collect cheek cells, put them in the tubes with special liquid and just send them back to us in the prepaid envelope provided. The packs do not last forever - but they are surprisingly robust.

What are genes?

Genes are like recipes written in tiny strands of DNA, and they provide information to help make us who we are. We all have thousands of genes, and each of us has our own complex set of genes. It is well known that identical twins actually share the same genes - non-identical twins and other siblings share a lot of genes too, but not all. Genes have a major influence on what we look like, such as the colour of our eyes and our hair, how tall we are, and so on. Genes also have a partial influence on many other aspects of development. Genes certainly don't explain everything - but they are important to look at, alongside the environment, when trying to understand how people develop differences.

What is a Zygosity test?

The purpose of zygosity testing is to determine whether or not twins are truly identical; that is, derived from a single fertilised egg (monozygous, **MZ**), or non-identical (fraternal twins), being derived from two independently fertilised eggs (dizygous, **DZ**). Whereas MZ twins are genetically identical, DZ twins share on average only half of their genes, inherited from their parents. There are two ways of testing the zygosity of twins: (i) check the DNA of each twin to see if it is the same or different; (ii) use a questionnaire. The Gemini team will use these methods to find out which twins are identical and which twins are non-identical. If you would like to know the results you can indicate this on the consent form that you will receive with the DNA packs; we will be able to tell you the results of the zygosity testing in June 2010.

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How do you do a Zygosity test using DNA?

The zygosity test using DNA is based on analysis of a series of sites at different points along the DNA molecules which carry the genetic information. These sites are chosen because they usually differ a lot between people and are referred to as **DNA markers**. Because DNA is passed from parents to their children in a very specific and well understood way, analysis of these DNA markers can give very accurate information about whether twins are MZ or DZ. A parent will generally have two different versions of each DNA marker, but can only give a single version to each child. Therefore, the child will also have two versions of the DNA marker, one from each parent. For any single DNA marker, brothers and sisters may by chance inherit the same one from their parents, but on average only half of the marker types will be shared by siblings, including DZ twins. Whereas MZ twins will have identical versions of DNA markers passed on from their parents.

With this in mind, we use automated technology to examine twelve such DNA markers simultaneously. We compare the results for all the twin pairs that we examine. If a pair of twins has all twelve marker types in common, we can be fairly sure (with only a very tiny chance of being wrong) that they are MZ. If one or more pairs of markers are different between the twins, we can be sure that they are DZ. These DNA based tests are extremely reliable and to our knowledge have not resulted in a false labelling of MZ or DZ twins for any twin pairs examined so far.

How do you do a Zygosity test using the questionnaire?

It is also possible, and much simpler, to find out if twins are identical or non-identical using a special questionnaire that focuses on the physical likeness between a set of twins; you may remember completing a questionnaire like this at the beginning of the Gemini study. The questionnaire identifies differences in physical characteristics that are determined by our genes, such as eye and hair colour, and blood type. In another study with older children, this questionnaire was found to be correct about 95% of the time when checked against DNA, but we would like to check it works with babies as well. To do this in Gemini we will use DNA from a small number of twins to check that the zygosity results from both the DNA test and the questionnaire test are the same.

Who is funding us?

The study is funded and regulated by a research grant from Cancer Research UK, independent of any commercial interest and is concerned with research only. You can be assured that nothing will be passed to the private sector and that all DNA collected will be destroyed at the end of the study. As a research study we are not allowed to pass on individual results to participants apart from our "Zygosity test", which determines whether any twins of the same sex are identical or not. We will however tell you about our research progress through our newsletters.

What will be done with our DNA?

DNA samples will be deep frozen, in a special locked freezer that belongs to the Gemini study. No names will be on the test tubes we freeze, only identification numbers. Before any scientists can use the DNA for research, their research must be approved in writing by the Gemini director, Professor Jane Wardle.

Could our DNA be used for cloning?

Absolutely not.

Can our DNA ever be used in police investigation?

No. The Gemini DNA bank will always be kept completely confidential, without exception. In addition, if a criminal court ever wishes to conduct a DNA test, they can easily take their own DNA sample from saliva, so there would be no need for them to contact Gemini. The Gemini DNA bank will be used only for research purposes.

Can my twins' DNA ever be used to test for who is their father?

No. The Gemini DNA bank will always be kept completely confidential, without exception. In addition, if a family court ever wishes to conduct a paternity test, they can easily take their own DNA sample from the alleged father's saliva, so there is no need for them to contact Gemini. The Gemini DNA bank will be used only for research purposes.

Can our DNA be used to predict if we will have future children with health problems (such as Down's syndrome or spina bifida)?

No. DNA is not used by doctors to test for genetic risk to unborn babies. The health of unborn babies is tested in a different way. Families who are concerned about their babies' risk can ask their GP about pregnancy testing and genetic counselling.