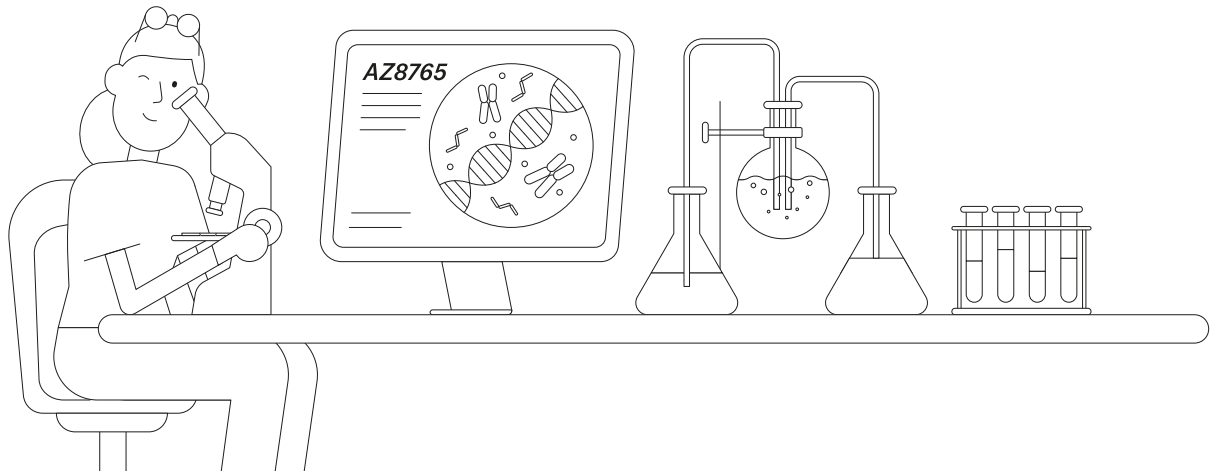


# Taking part in research

How might your medical data and samples be useful for researchers?



What you need to know about general consent to keeping and using samples and data for research purposes

## CHUV is a research centre as well as a hospital

Its mission is to care for patients but also to carry out research and teach. In this leaflet, you can find out about how CHUV carries out research to learn more about diseases and how to treat them. It will help you decide if you want to take part in research.

## What does “carry out research” mean?

There are still lots of things about how the human body functions and what causes diseases that we do not yet understand. Researchers are like detectives who try to solve puzzles. They therefore study tiny amounts of substances (such as blood, urine (wee) and saliva), which are called samples, taken from people who are ill. Sometimes, once the puzzle is solved, it can help to develop medicines or tests to discover diseases more quickly and therefore help cure them.

All different kinds of research can be carried out on how the human body works, organs (such as the heart, lungs, etc.), the cells that make up your body and genes.

Your samples and data may be sent for research purposes to laboratories, hospitals and universities but also to businesses that make medicines and tests to diagnose diseases.

## What are genes?

You could think of your body as a house with lots of rooms: those are your cells. Each room has a bookcase with 46 books: your chromosomes. And each book has chapters: your genes.

Half of the books come from your dad and half from your mum. Genes are like an instruction manual or a dictionary that allow all the parts of your body to work.

Sometimes, the writing in the books is different, which is why certain diseases occur, and it is these differences that researchers study. When several people in the same family have the same “sick” gene, they can develop the same diseases.

## How can you take part in research?

If you wish, you can take part in research by agreeing that your medical data and samples (blood, wee and saliva), which are collected when you are being cared for in hospital, are kept to be passed on to researchers. This is called consent.

**Taking part is voluntary** and your decisions are entirely up to you, but **it is important that you tell us what you decide. You and your parents can complete and sign the consent form attached.** The form covers the data and samples collected in the past, but also any that might be collected at CHUV in the future.

Your and your parents' decision will remain valid until you are 18 years old, unless you and your parents change your mind.

**If you do not sign the consent form**, the hospital still has the right to ask the Research Ethics Committee for a special authorisation to use your samples and data without your consent **as an exception**. A special authorisation is requested when it is very difficult or impossible to contact the patients concerned. It is therefore important for you to make your wishes clear.

**If you decide not to take part in research by ticking "NO" to statement A**, your data and samples cannot be used by researchers under any circumstances.

**This decision does not have any impact on how you will be treated at CHUV.**

## What happens if you change your mind?

You can change your mind and withdraw your agreement at any time. You will not have to explain why you have made your decision. You will simply need to phone the Research Consent Unit or write to the address shown on the back of this document.

If you decide to withdraw your agreement, researchers will no longer be able to use your data and samples from that point on. **Withdrawing your consent will not have any effect on the care you receive.**

## How are your data and samples protected?

Your name is not shown on your data or samples as it is replaced by a code (for example: AZ8765). All the information remains secret so that the researchers cannot know who the samples and data they are working with belong to.

The key to the code is kept by a doctor who is caring for you or someone who is not involved in the research project. If a research project discovers any results that are important for your health and you need to be informed, the group of experts and the hospital can then give the key to the code to the researchers.

More rarely, data and samples are anonymised. In this case, the key to the code is destroyed and no-one can know who the data or samples belong to.

## Will you and your parents be informed of the results of the research?

In principle, no. In rare cases, it may be that the researchers find a result that is important for your health, and they can offer you a medicine or medical follow-up. In this case, you and your parents would be informed, as long as your data and samples had not been anonymised.

## Will you receive any money if you decide to take part?

Taking part is a voluntary contribution to research. You will not be paid for agreeing to take part, even if products are developed following the research carried out using your data or samples, for example, new medicines or new tests.

## What is CHUV's Genomics Biobank?

CHUV's Genomic Biobank (BGC) organises the collection and storage of blood samples donated by patients at the hospital. It makes these available to researchers at CHUV, in Switzerland and abroad. Samples are kept in the BGC's freezers for a very long time, perhaps even more than 100 years. The biobank was created especially for research on genes.

## What does this mean for you in practical terms?

If you decide to take part in the BGC, a blood sample may be collected **at the same time as another blood sample during your stay at CHUV, if your state of health allows it. This means there will not be any additional needle prick or pain.** The quantity of blood taken will depend on your weight but will not exceed 7.5 ml (the equivalent of a tablespoon). The sample taken will be kept in the BGC and used for research.

**Your decision will not have any effect on your medical treatment or the quality of care you receive.**

If you decide not to participate any longer and you withdraw your consent, the blood sample collected specifically for the BGC will be destroyed.

## Does your consent remain valid once you become an adult?

Once you are 18 years old, we will contact you again to ask for your decision on general consent to research.

If you are under 14 years old when you sign the consent form, your data and samples will no longer be able to be used for research at all unless you give your consent again after your 18th birthday. The same rules apply if your parents and/or your legal representative signed the consent form by themselves when you were a teenager.

If you gave your consent as a teenager when you were between 14 and 17 years old, and you do not respond to our request, your data and samples may still be used for research. However, no genetic analyses can be carried out using samples unless you confirm your consent again.

You can let us know your decision by completing and signing the consent form.

The form is in three sections:

- A** Once you have checked that your last name, first name and date of birth are correct, decide whether or not you agree to researchers using your medical data and samples for their projects.
- B** If you agree to the use of your medical data and samples for research (by answering “YES” to statement A), decide whether or not you are willing to give another small blood sample to CHUV’s Genomic Biobank.
- C** ***If you are less than 14 years old***, we encourage you to sign the consent form below the signature of your parents or the person who looks after you.

***If you are more than 14 years old*** and you have understood this information in full, you can sign the consent form yourself but it is advisable for one of your parents or your legal representative to sign it too. You do not have to make the decision by yourself. If you prefer, your parents can make it for you.

The consent form can be sent to the address shown on the back of this leaflet, using the pre-paid envelope. You can also give it to your doctor on your next visit to the hospital.

Would you like to know more or do you have any questions?

You are welcome to send us an email or phone us.

By post:

CHUV-Département de la formation et recherche  
Unité consentement général  
Boîte aux lettres N°47  
Rue du Bugnon 21  
1011 Lausanne

By email:

[info.cg@chuv.ch](mailto:info.cg@chuv.ch)

By phone:

021 314 18 78

Mon-Fri 07:30-12:00 and 13:00-16:00

You can also visit our website for more information and videos:

[www.chuv.ch/fr/consentement-general/cg-home](http://www.chuv.ch/fr/consentement-general/cg-home).