

We are asking if you want to participate in "CF Research Biobank"

Background information

We are asking all patients with cystic fibrosis (CF) to participate by providing biological samples to the biobank (frozen biological material). As a person living with cystic fibrosis (CF), we want your permission to use your biological samples in the Biobank. The material will be collected during treatment at the hospital or through separate cystic fibrosis research projects. The Oslo University Hospital is the Data Controller for the study. The National Center for Cystic Fibrosis (NSCF) at Oslo University Hospital (OUS) Ullevål aims to further develop a register for cystic fibrosis in Norwegian (the Norwegian CF Register) which is closely related to this biobank. The biological material stored in the biobank will only be used to better understand CF or CF-like conditions.

What happens if I agree to join?

Various samples are often taken for routine health checks and treatment or research projects (blood tests, urine samples, mucus samples, tissue samples, stool samples and other bodily fluids). If you agree to participate in the CF Research Biobank, some of the samples you have taken will be stored in a freezer at OUS. As part of future research projects, upon application to the Regional Committee for Medical Research Ethics and the Norwegian Data Protection Authority, the samples may be sent for analysis to other laboratories inside and outside of Norway. The biobank is scheduled to exist until 2043. After this, the material (samples) will be destroyed according to internal guidelines. If the project is to be extended, new consent will be obtained from you. If your samples are already stored at OUS, they will also be stored in the same biobank.

Will the research project be useful to me?

Participation may not be directly useful to you. The project may be useful to other patients who have the same disease as you.

Everything is secret

We want to use what they know about you in this biobank. Everything we know about you is kept secret. Instead of using your name, your data is hidden behind a code so the people who read the information cannot see your name. The information is stored in a secure area on our computer network. If data from the biobank is published in magazines or newspapers, no one will be able to identify you.

Participation is voluntary!

Participating in the CF Research Biobank is voluntary. If you do not feel like it, that's fine; no one will be angry about it. You will still get the same treatment from your doctor. You do not have to tell anyone why you do not want to participate.

You are allowed to change your mind

Even if you want to join the CF Research Biobank now, you can change your mind if you want. If you or your parents later wish to withdraw your consent, you simply contact the head of section at the NSCF or his deputy in medical questions. Telephone: 23 01 55 90 (09-15), Monday-Friday – and tell them you do not want to participate anymore. If you change your mind, you can ask us to delete all the information we have on you. You do not have to tell anyone why you do not want to participate. You will still get the same treatment from your doctor.

If you agree to participate in the CF Research Biobank, you are allowed to know what information we have about you. If you think some of the information is wrong, ask us to correct it. We will delete all the information we have on you in the year 2043. If the CF Research Biobank project is extended, we will ask you to consent again.

Will you become 16 years old while your data is in the CF Research Biobank? If you turn 16 while in the Biobank, you will receive a new letter by mail after you have reached the age of 16. In that letter, we will ask if you still want to participate. That is because you are allowed to decide for yourself, without your parents, once you turn 16.