

## We are asking if you want to participate in *"Norwegian CF Register"*

### **Background information**

We would like you to register your health information in the register for patients with cystic fibrosis (CF). As a person living with cystic fibrosis (CF), we want your permission to enter your health information in the Register. The purpose of using the data is to improve future research – nationally and internationally – to provide us with better information on how the treatment of cystic fibrosis can be as best as it possibly can be. The results can also be used to improve the services provided to CF patients. The register is run by the National Center for Cystic Fibrosis (NSCF) and it is Oslo University Hospital (OUS) that is responsible for processing data in the register (data controller). There is also a European CF register, so the data may be shared with several European countries.

### **What happens if I agree to join?**

The data registered in the Register will be taken from routine health checks you receive as a patient at a hospital. This will largely involve information from your patient records like various samples (blood tests, urine samples, mucus samples, tissue samples, stool samples and other bodily fluids) and x-ray results.

Additional biological material may be taken during routine sampling, which is stored in a separate database, called the CF Research Biobank. More information about the Biobank is available below (storage frozen material).

### **Will the research project be useful to me?**

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

### **Everything is secret**

Because you have been receiving treatment at a hospital, the hospital has information about you. That is, the hospital knows a lot of things about you and your disease. We want to use what they know about you in this project. Everything we know about you is kept secret. The CF Register stores your name and personal identity number, but when researching data in the register is used, 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 the project is published in magazines or newspapers, no one will be able to identify you.

### **Participation is voluntary!**

Only you can decide whether you want to be included in the Norwegian CF Register. 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 Register 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, 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 about you when the Register is completed in 2028, but it may be extended. We will then ask you to consent again.

**Will you become 16 years old while your data is in the Norwegian CF Register?**

If you turn 16 while in the Register, 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 consent, once you turn 16.