

*Sample Patient Consent Form:
Please check with your local Data Protection Agency before using to obtain patient consents.*

Cystic Fibrosis Registry Patient Consent Form

Dear Patient or Parent

To ensure that the care of people with cystic fibrosis (CF) continues to improve, it is essential we have detailed information on the state of health and treatment of as many people with the condition as possible. We are setting up such a CF registry for our country and are asking your permission to include your data. There are also plans to create Europe-wide and global registries for CF patients that will share anonymised data from many countries in order to give us even better information on how to improve the treatment for CF.

A short descriptive sheet provides further details about the registry and its uses.

Recent regulations state that to include your data we require your written permission. We do hope you will agree to have your medical details being included on this registry. Your participation is entirely voluntary and any information that would allow you to be identified directly or indirectly will be removed. Also you can withdraw your permission at any time.

If you agree to participate please would you sign below as indicated.

Thank you for your help.

The person with CF whose data is to be entered into the CF Registry:

Name :.....

Name :.....
[If not the patient]

Signature :.....

I am a Patient **Parent** **Guardian** **Other** **(give details)**
[Please tick as appropriate]

Date :.../.../...

The Data Controller is your local hospital and the European Cystic Fibrosis Society (ECFS) for the European Registry. If you have any questions about the use of your data, or if you want your information removed from the registry, please contact your local clinic team.