

ECFSPR European Cystic Fibrosis Society Patient Registry

Confirmation of Legal & Ethical Compliance to export data to the ECFS Patient Registry

I confirm that the legal and ethical requirements of my country have been satisfied for exporting data from our national cystic fibrosis registry to the European CF Registry (please type)

Country	
Name of National CF Registry	
Name of Registry Director	
Name of the person responsible for data export (here called the "Data Administrator or Country Coordinator (CC)" if not the Registry Director)	
Email address Data Administrator	
Telephone No. Data Administrator	
Name of IT support contact	
Email address IT support	
Telephone no. IT support	
Postal Address of National CF Registry	
Signature of Registry Director:	
Signature of Data Administrator (if not Registry Director):	
Date of Signature:	

Please sign and scan and send an electronic copy (pdf) of this form along with the following documents by email to the Executive Coordinator, ecfs-pr@uzleuven.be:

Confirmation that the data you report to the ECFSPR has been collected according to your national data protection laws, and that you are allowed to forward these data anonymously to the ECFSPR:

- 1. Permission from the data protection agency, preferably in English, but if not, then in original with a translation by the person requesting the data transfer
- 2. Ethical approval <u>if required</u> for your country, preferably in English, but if not then in original with a translation by the person requesting the access.