

UNITED KINGDOM CYSTIC FIBROSIS DATABASE

The UK Cystic Fibrosis Database was started 1995 by the Cystic Fibrosis Trust to record the number and location, the state of health and the treatment of the people in the UK who have cystic fibrosis. The information recorded is similar to that usually recorded at the CF clinic e.g. weights, height, respiratory cultures, lung function tests, x-ray results and a few other investigations.

All the information stored in the national UK Database is anonymous and confidential, as no patient names are recorded. Each patient is issued with a code number under which information is sent to the UK CF Database. The patients' names are only known to their local clinic as the data is entered locally. Sometimes, a trusted third party may also perform this data entry (e.g. should clinic resources be unavailable).

The database will have many uses, some of which are as follows -

- To follow your progress and ensure you are receiving the best treatment. The data will be available for the staff in your local clinic and the staff will have your results available in an easily accessible form in tables and graphs
- To measure the performance of your particular CF clinic when compared with the results of the UK as a whole
- To measure the performance of all clinics to obtain a national or regional picture and compare with other countries or regions
- To provide information for national planning of future services required for people with CF
- To ensure that the NHS puts a fair share of resources into your clinic
- To help judge which types of treatment are of greater benefit, and how overall care is improving.
- To conduct research on the data to identify new trends e.g. an increase in a particular complication or new infection
- To co-operate with CF databases in other countries with a view to gaining a better understanding of the condition and its treatment
- To identify particular patient groups who may be suitable and could be approached to take part in particular research studies. Contact in this respect would only come through your local CF clinic.

The use of any information from the UK Database will require the approval of a Database Steering Committee made up of representatives from the CF Trust, CF Clinic Directors, UKCF Database staff and a patient representative.

Your participation in the database is entirely voluntary, and you have the right to withdraw at any time without stating a reason.

The Data Controller is The Cystic Fibrosis Trust. Our nominated representative to deal with data privacy issues is the Chairman of the Database Steering Committee, should you have any queries about how your information is being used or should you wish your information to be removed from our records. The Chairman of the Database Steering Committee can be contacted at the CF Trust, 11 London Road, Bromley, Kent, BR1 1BY.