



Space for local NHS Trust logo if required.
Delete this box if not needed.

CONSENT FORM (Parent/Guardian)

Project Title: CF Registry

		Please Initial
1	I confirm that I have read and understand the information sheet dated 22 January 2024 (version 4) for the above project. I have had the opportunity to consider the information and ask questions and I have had these answered satisfactorily.	
2	I understand that my child's participation is voluntary and that he/she is free to withdraw at any time, without giving any reason, without his/her medical care or legal rights being affected. If I or my child withdraws consent, his/her personal data will be removed from the Registry.	
3	I understand that relevant sections of any of my child's medical notes and data collected during the study may be looked at by a small number of responsible individuals from the NHS Trust (chiefly those involved directly with my child's clinical care), Regulatory authorities, and the authorised individuals at the Cystic Fibrosis Trust (but only authorised individuals who are involved in analysing and maintaining the data contained in the CF Registry).	
4.	I understand that information that can identify my child will only be given to others for the purposes for which I have consented. I understand that the CF Registry may hold my child's data in pseudonymised form meaning it can be viewed without identifying my child (e.g. for research purposes), but my child can only be identified by a small number of authorised individuals mentioned above. I also understand that anonymised data that cannot identify my child may be shared with researchers both in the UK and in other countries.	
5.	I understand that commercial organisations and pharmaceutical companies will never receive individual-level information about me, and that only fully anonymised, aggregate information (combined with information from others in the Registry) will be shared.	
6.	I understand that information held by the NHS and records maintained by the Office of National Statistics may be used to follow my child's health status, and that to obtain linked information, some of my child's personal identifiable data will be shared with authorised individuals.	
7.	I agree for my child to take part in the above study	

Name of Parent/Guardian	Signature	Date
Name of Person Taking Consent	Signature	Date

When completed: 1 for parent/Guardian; 1 for researcher site file; 1 (original) to be kept in medical notes.