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Screening number

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CFHealthHub ID

CFHealthHub Data Observatory Participant Consent Form

Please initial box

1. I confirm that I have read and understand the participant information sheet dated **DATE (version XXX)** regarding the above study and have had the opportunity to ask questions.
2. I understand CFHealthHub will store my personal details, data related to CF, medication adherence, CFHealthHub usage data and any additional information I provide related to my condition.
3. I understand this data will undergo procedures to remove my personal identifiable information (pseudonymised) to people outside of the research study.
4. I understand my data will be shared with and analysed by the Clinical Trial Unit at the University of Sheffield.
5. I understand and agree that data from my existing nebuliser and medical notes, such as my NHS number and information relevant to CF will be stored securely in CFHealthHub.
6. I consent for the CF team to contact me via mobile phone (calls and texts), emails, and Skype to discuss the study and my adherence.
7. Within CFHealthHub I will be given the option to share my identifiable data with my local CF clinical team for use in my care. I understand that I am in control of this data sharing and that I can choose to turn this on/ off at any time.
8. I consent for my data stored within CFHealthHub to be grouped at centre level and shared with CF centres participating in the study across the UK. I understand I cannot be identified from this data.
9. I understand that my CF Registry data will be added to CFHealthHub.
10. I understand that my CFHealthHub data may be shared with the CF Registry and my GP will be informed of my participation in the study.
11. I understand that I can use CFHealthHub as part of my ongoing CF care and I consent to any existing data within CFHealthHub to be retained as part of this study.
12. I understand that my participation is voluntary and I can consent to any or none of the optional consent items below. I can update or withdraw my consent at any time, without giving any reason, and without consequence.
13. I agree to take part in the above study.



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CFHealthHub ID

Continued overleaf

Consent to the following items is optional;

14. I consent for my pseudonymised data within CFHealthHub to be used for future research related to CF which has been ethically approved. I give permission for my contact details to be stored securely at the University of Sheffield for this purpose.

15. I consent to be included for selection in future research studies which have been ethically approved. I understand when I meet the desired characteristics for the study I may be selected by chance to receive a new treatment. When I am not selected to receive the new treatment I consent to sharing my pseudonymised data without further notification. If I am selected to receive the new treatment I understand that I will be contacted and will have the opportunity to decline participation in the new study. I give permission for my contact details to be stored securely at the University of Sheffield for this purpose.

Name of participant

Date

Signature

Name of consenting researcher

Date

Signature

Three copies; one for participant, one for medical notes, one to be posted to researcher at University of Sheffield.