



The University Of Sheffield.

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Screening number

Screening number

CFHealthHub ID

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 (if using a 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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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 by the research team 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 by the research team 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.