**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.

***Continued overleaf***

***Consent to the following items is optional;***

1. 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.
2. 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.

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**Name of participant Date Signature**

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**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.