

ONLINE PARTICIPANT INFORMATION STATEMENT

"EXPLORING THE ACCEPTABILITY OF ORGANOID TECHNOLOGY AMONG HEALTHCARE PROFESSIONALS AND SCIENTIFIC COMMUNITIES"

Dr Laura Fawcett, Clinical Trials Medical Lead, Sydney Children's Hospital, 93821475

Prof A Jaffe, Respiratory medicine, Sydney Children's Hospital, 93821111

Dr Ursula Sansom-Daly, Behavioural Sciences Unit, Kids Cancer Centre, Sydney Children's Hospital, 93823114

A/Prof Natalie Taylor, School of Population Health, UNSW, 93481126

Cherine Marciana, School of Medicine, University of Notre Dame, 8204 4450

Chief Investigator: Dr Shafagh Waters, School of Biomedical Sciences, UNSW, 90652098

1. What is the research study about?

This research study aims to investigate the acceptability of using organoid technology amongst healthcare professionals and the scientific community. Specifically, our objectives are to (1) evaluate the acceptability of the utility of organoids to guide the management of a patient's disease in a sample of healthcare workers and scientists and (2) compare organoid acceptability between healthcare professionals and the scientific community.

The proposed research holds significant value as it explores unexamined perspectives of healthcare professionals and scientists' acceptability in the use of organoids for personalised medicine. By investigating the acceptability of organoid technology and its practical implementation in clinical care, the research establishes a connection between research findings and real-world applications.

2. Who is conducting this research?

The study is being carried out by the researchers listed above. This study is conducted by Molecular and Integrative Cystic Fibrosis Research Group at the School of Biomedical Sciences, UNSW, in collaboration with Sydney Children's Hospital.

3. Inclusion/Exclusion Criteria

The research study is looking recruit people who meet the following criteria:

- Healthcare Professionals (Clinicians [Medical, Nursing, Physiotherapist, Dietitian, Psychology], Social Workers and Pharmacists)

And/or

- Part of a multidisciplinary team caring for patients.

And/or

- Scientists

Exclusion criteria:

- Unable to read and understand English.

4. Do I have to take part in this research study?

Participation in any research study is voluntary. If you do not want to take part, you do not have to.

If you decide you want to take part in the research study, you will be asked to:

- Read and/or watch the information carefully (ask questions if necessary);
- Complete the online questionnaire.

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5. What does participation in this research require, and are there any risks involved?

If you decide to take part in the research study, we will ask you to complete an online questionnaire. The questionnaire will be divided into four domains, which includes (1) knowledge and awareness of personalised medicine using organoids, (2) attitudes and beliefs about personalised medicine using organoids, (3) barriers and challenges to equitable implementation of personalised medicine using organoids, and (4) strategies for addressing the barriers and challenges. The questionnaire should take 15 minutes to complete.

If you experience discomfort or feelings of distress while participating in the research and you require support, you can stop participating at any time. You can contact a member of the research team and they will provide you with assistance or alternatively a list of support services and their contact details are provided below.

6. What are the possible benefits to participation?

We hope to use the information we get from this research study to better understand the acceptability of utilising organoids for personalised clinical decision-making among healthcare professionals and scientists. There is no direct benefit for participants from completing the survey.

7. What will happen to information about me?

Submission of the online questionnaire is an indication of your consent. By clicking the 'I agree to participate' button you are providing your permission for the research team to collect and use information about you for the research study.

The research team will store the data collected from you for this research project for:

- A minimum of 7 years after the completion of the research

The information about you will be stored in a:

- Non-identifiable format where your identity will be unknown.

You will be asked to provide your consent for the research team to share or use the information collected from you in future research that will be specific to the aims of this research study.

Your information will only be shared in a format that will not identify you.

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8. How and when will I find out what the results of the research study are?

The research team intend to publish and/or report the results of the research. All information will be published in a way that will not identify you.

You can access the results by registering your email at the end of the questionnaire. The list of emails is collected by a separate survey in Qualtrics, therefore will not be linked to the questionnaire responses.

9. What if I want to withdraw from the research study?

If you do consent to participate, you may withdraw at any time. You can do this by closing the questionnaire. If you withdraw from the research, we will destroy any information that has already been collected. Once you have submitted the questionnaire however, we will not be able to withdraw your responses as the questionnaire is anonymous.

The information you provide is personal information for the purposes of the Privacy and Personal Information Protection Act 1998 (NSW). You have the right of access to personal information held about you by the University, the right to request correction and amendment of it, and the right to make a complaint about a breach of the Information Protection Principles as contained in the PPIP Act. Further information on how the University protects personal information is available in the [UNSW Privacy Management Plan](#).

10. What should I do if I have further questions about my involvement in the research study?

The person you may need to contact will depend on the nature of your query. If you require further information regarding this study or if you have any problems which may be related to your involvement in the study, you can contact the following member/s of the research team:

Research Team Contact

Name	<i>Dr Shafagh Waters</i>
Position	Principle Investigator and Main Study Contact Person
Telephone	+61 2 90652098
Email	Shafagh.Waters@unsw.edu.au

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What if I have a complaint or any concerns about the research study?

If you have a complaint regarding any aspect of the study or the way it is being conducted, please contact the UNSW Human Ethics Coordinator:

Complaints Contact

Position	Human Research Ethics Coordinator
Telephone	+ 61 2 9385 6222
Email	humanethics@unsw.edu.au
iRECS Project ID	0813

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Consent Form – Participant providing own consent

Declaration by the participant

By checking the I agree/start questionnaire option below:

- I understand I am being asked to provide consent to participate in this research study;
 - I have read the Participant Information Sheet, or it has been provided to me in a language that I understand;
 - I provide my consent for the information collected about me to be used for the purpose of this research study only.
 - I understand that if necessary, I can ask questions and the research team will respond to my questions.
 - I freely agree to participate in this research study as described and understand that I am free to withdraw at any time during the study and withdrawal will not affect my relationship with any of the named organisations and/or research team members;
- I understand that I can download a copy of this consent form from <http://bit.ly/AvatarAccep2>

I agree, start questionnaire

- I would like to receive a copy of the study results via email or post, I have provided my details below and ask that they be used for this purpose only;
-

Email Address: _____