

PARTICIPANT INFORMATION STATEMENT AND CONSENT FORM

Study Title: Developing and testing a conceptual framework for the utilization of Digital Health, Social Enterprise and Citizen Engagement in the co-creation of Integrated People-Centred Health Services. Chief Investigator: Dr. Siaw-Teng Liaw

1. What is the research study about?

You are invited to take part in this research study. The research study aims to develop and test a conceptual framework that can be used to create and enable sustainable social enterprises that utilise digital health and citizen engagement to deliver integrated, people-centred health services; in order to ultimately:

- improve the health and well-being of citizens;
- strengthen democratic participation and institutional responsiveness;
- strengthen digital literacy for service procurement and social engagement;
- create sustainable employment opportunities and economic growth.

Your contact information was obtained from public records, and you have been invited because we believe that you may be able to provide us with information on how Community Health Alliances deliver integrated, people-centred health services.

2. Who is conducting this research?

The study is being carried out by the following researchers:

- Chief Investigator: Prof. Dr. Siaw-Teng Liaw
- Co-investigators: Dr. Md. Mahfuz Ashraf, Dr. Padmanesan Narasimhan
- Student Investigator: Dr. Myron Anthony Godinho
- School of Public Health & Community Medicine, UNSW Sydney

Research Funder: No funding has been acquired for the conduct of this study.

3. Inclusion/Exclusion Criteria

The research study is looking recruit individuals who are either of the following:

- Involved in the management and/or operations of Community Health Alliances;
- Involved in organisational partners of Community Health Alliances;
- Service providers or representatives of community organisations that work in partnership with Community Health Alliances;
- Civil servants or elected representatives who work in partnership with Community Health Alliances.

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

Participation in this research study is voluntary. If you do not want to take part, you do not have to. If you decide to take part and later change your mind, you are free to withdraw your participation from the study at any stage.

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

- Read the information carefully (ask questions if necessary);
- Sign and return the consent form if you decide to participate in the study;
- Take a copy of this form with you to keep.

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

We do not anticipate there to be any risks that can arise from your participation in this study.

If you decide to take part in the research study, you will be asked to participate in a face-to-face interview with the student investigator. You will be asked questions about the activities/initiatives of the Community Health Alliance that you and/or your organisation are involved with. It should take approximately 45 minutes to one hour to complete.



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To ensure that we collect the responses accurately, we seek your permission to digitally record the interview using an audio recorder. If you would like to participate but do not wish to be recorded, you will need to discuss your options for participation with the research team.

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 also tell a member of the research 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 information we get from this research study to benefit communities, neighbourhoods and networks who would benefit from social enterprises that utilise digital health and citizen engagement to deliver integrated, people-centred health services.

7. What will happen to information about me?

By signing the consent form you consent to the research team collecting and using information about you for the research study. Your data will be kept for 5 years following the completion and publication of the research. We will store information about you in a non-identifiable, electronic format on the UNSW OneDrive (UNSW-supported data storage) at the School of Public Health and Community Medicine, UNSW Sydney. Your information will only be used for this research study and will not be disclosed. Your information will not be made available to any other research projects.

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 <u>UNSW</u> Privacy Management Plan.

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

The research team intend to publish and/ report the results of the research study in a variety of ways. All information published will be done in a way that will not identify you. If you would like to receive a copy of the results you can let the research team know by including your details in the space provided in the consent form.

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 so by completing the 'Withdrawal of Consent Form' which is provided at the end of this document. Alternatively you can ring the research team and tell them you no longer want to participate. Your decision not to participate or to withdraw from the study will not affect your relationship with UNSW Sydney or any of the other individuals or organisations involved in this study.

If you decide to leave the research study, the researchers will not collect additional information from you. Any identifiable information about you will be withdrawn from the research project.

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



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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:

This study has been approved by the South Western Sydney Local Health District Human Research Ethics Committee. Any person with concerns or complaints about the conduct of this study should contact the Ethics and Research Governance Office on 02 8738 8304, email: SWSLHD-Ethics@health.nsw.gov.au and quote *HE #*.

Research Team Contact Details

Name	Dr. Siaw Teng Liaw	
Position	Professor of General Practice	
Telephone	+6196168520	
Email	siaw@unsw.edu.au	

Support Services Contact Details

If at any stage during the study you become distressed or require additional support from someone not involved in the research please call:

Name/Organisation	Dr. Abrar Chugtai	
Position	Lecturer, SPHCM, UNSW Sydney	
Telephone	+61 (2) 93851009	
Email	abrar.chughtai@unsw.edu.au	

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	osition UNSW Human Research Ethics Coordinator	
Telephone	+ 61 2 9385 6222	
Email	humanethics@unsw.edu.au	
HC Reference	[INSERT HC reference number]	
Number		



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Consent Form – Participant providing own consent

Declaration by the participant

- □ I understand I am being asked to provide consent to participate in this research study;
- □ I have read the Participant Information Sheet or someone has read it to me in a language that I understand;
- □ I understand the purposes, study tasks and risks of the research described in the study;
- □ I understand that the research team will audio/video record the interviews; I agree to be recorded for this purpose.
- □ I provide my consent for the information collected about me to be used for the purpose of this research study only.
- □ I have had an opportunity to ask questions and I am satisfied with the answers I have received;
- 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 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;
 Name:

Email Address:	

□ I understand that I will be given a signed copy of this document to keep;

Participant Signature

Name of Participant (please print)	
Signature of Research Participant	
Date	

Declaration by Researcher*

□ I have given a verbal explanation of the research study, its study activities and risks and I believe that the participant has understood that explanation.

Researcher Signature*

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Name of Researcher (please print)	
Signature of Researcher	
Date	

^{*}An appropriately qualified member of the research team must provide the explanation of, and information concerning the research study.

Note: All parties signing the consent section must date their own signature.



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Form for Withdrawal of Participation

I wish to **WITHDRAW** my consent to participate in this research study described above and understand that such withdrawal **WILL NOT** affect my relationship with The University of New South Wales, or other organisation involved in this research. In withdrawing my consent, I would like any information which I have provided for the purpose of this research study withdrawn.

Participant Signature

Name of Participant	
(please print)	
Signature of Research	
Participant	
Date	

The section for Withdrawal of Participation should be forwarded to:

CI Name:	Prof. Dr. Siaw-Teng Liaw
Email:	siaw@unsw.edu.au
Phone:	+6196168520
Postal Address:	Prof. Dr. Siaw-Teng Liaw, School of Public Health and Community Medicine, Samuels Building, F25, Samuel Terry Ave, Kensington NSW 2033