Imperial College London

Participant Information Sheet

Study title

Promoting Equitable Breast Cancer Screening through Service Redesign: A Study of Women Under Age 55 in Saudi Arabia.

Principal Investigator: Samar Nassar – Healthcare & Design Msc/Postgraduate Student at Department of Surgery and Cancer, Imperial College London.

Co-investigators: Dr. Hutan Ashrafian - BSc (Hons.), MBBS, PhD, MBA Lead for Applied Artificial Intelligence (AI) and Big Data at the Institute of Global Health Innovation at Imperial College London.

Invitation

You are being invited to take part in a research study. Before you decide whether to participate, it is important that you understand the purpose of this research and what it will involve. Please take the time to read the following information carefully and discuss it with others, if you wish.

- Part 1 explains the purpose of this study and what will happen to you if you take part.

- Part 2 provides more detailed information about how the study will be conducted.

If there is anything that is unclear or for which you would like more information, please ask us. Take time to decide whether or not you wish to participate.

Thank you for reading this.

- **What is the purpose of the study?**

This research study is part of my final project to obtain a master of science (Msc) in Healthcare & Design at Imperial Collage London. It will test the hypothesis that redesigning health service delivery can help increase access to care and health equity for women.

Specifically, this study aims to identify ways to increase breast cancer screening adoption among women under age 55. This research will explore the potential new technology together with enhanced services could have on augmenting access and adoption while reducing common barriers to participation, such as fear, lack of knowledge, or the perceived difficulty of screening for certain body types. The goal is to improve women's experience while lowering the cost burden on healthcare systems.

By the end of this research study, I hope to be able to determine definitively the primary barriers to entry and factors contributing to the low rate of breast screening adoption in Saudi Arabia. I will use design frameworks to develop more insights to define the areas of focus as well as the potential gaps that must be bridged.

- **Why have I been invited?**

The study aims to recruit a minimum of 50 women, 25 in each of two age groups, who reside in Saudi Arabia. If you are under the age of 55 and living in Saudi Arabia, you fit the eligibility criteria of the target group. However, all women are welcome to take part if they fall within this age category, regardless of their location.

- Women ages 30-39
- Women ages 40-55

Your Invitation could be received directly, via an online campaign or project webpage.

- **Do I have to take part?**

It is up to you to decide whether or not to take part. If you do decide to take part, you will be given this information sheet to keep and be asked to sign a consent form. Study participants remain free to withdraw at any time and without giving a reason. Withdraw process is through a written request via email or phone call to PI (details in contact information). This is to ensure that your data is no longer processed and is deleted, if your data was already processed and grouped in data sets then it will be impossible to delete so it would be best to notify IP as soon as possible.

- **What will happen to me if I take part?**

Research will take place through 29 September 2023. Results will be published on the project webpage as a way to inform women participants as well as any interested groups, such as product designers.

- **What do I have to do?**

Complete the survey questions on www.breastcancerscreeningsurvey.com survey should take 5 minutes to complete. You can revisit the project website if you are interested in seeing survey results and the feedback of all participants. The project webpage is intended to offer a place for women to share their experiences throughout their breast cancer screening journey.

- **What are the possible disadvantages and risks of taking part?**

There are no risks involved in taking the survey or participating in the study. Your responses will remain anonymous. All data will be saved in PI laptop archives with secure password.

- **What are the possible benefits of taking part?**

We cannot promise the study will help you but the information we get might help improve the experience of women undergoing breast cancer screening.

- **What if something goes wrong?**

This question is not applicable to the study format concidering it's an anonymous survey and will not be included accordingly.

- **What will happen to the results of the research study?**

Results of the insight survey will be published on the project webpage, and published data will be grouped and anonymized.The full study will be published according to the Imperial College of London's (ICL's) publishing policy, if you wish to be notified, please leave your email address when completing the survey. This is entirely optional.

- **Who is organising and funding the research?**

This study is not being funded by the Medical Research Council, or any original equipment manufacturer, charity or academic institution. It is entirely self-funded part of Msc program.

- **Who has reviewed the study?**

This study was approved by Professor Vassilios Papalois Head of specialty for transplantation surgery, consultant transplant and general surgeon at the department of surgery Imperial College London. This study was also given approval by Professor Hutan Ashrafian, BSc (Hons.), MBBS, PhD, MBA Lead for Applied Artificial Intelligence (AI) and Big Data at the Institute of Global Health Innovation at Imperial College London research supervisor and lastly by Research Governance and Integrity Team (RGIT).

Contact for Further Information

For further information or should you have any questions please contact:

Samar Nassar – Principal Investigator of this study:
samar.nassar20@imperial.ac.uk
cellphone: +966 555589464

My sincere thank you for taking part.

Note: A copy of this information sheet and signed Informed Consent form will be given to all participants to keep.

Imperial College London

Transparency Notice

How will we use Information about you?
Research Study Title: Promoting Equitable Breast Cancer Screening through Service Redesign: A Study of Women Under Age 55 in Saudi Arabia

[Study number]

Imperial College London is the sponsor for this study and will act as the Data Controller for this study. This means that we are responsible for looking after your information and using it appropriately. Imperial College London will keep your personal data for:

- 10 years after the study has finished in relation to data subject consent forms.
- 10 years after the study has completed in relation to primary research data.

The study is expected to finish in September 2023.

For more information / confirmation regarding the end date please contact the study team, see '**WHERE CAN YOU FIND OUT MORE ABOUT HOW YOUR INFORMATION IS USED'** for contact information.

We will need to use information (including personal data and data created as part of the study) from you for this research project. This information will include your contact details if provided with your permission**.** People within Imperial College London and the study team (see section 'Sharing your information with others') will use this information to do the research or to check your records to make sure that the research is being done properly and that the information held (such as contact details) is accurate.

We will keep all information about you safe and secure.
Once we have finished the study, we will keep some of the data so we can check the results. We will write our reports in a way that no one can determine that you took part in the study.

LEGAL BASIS

As a university we use personally-identifiable information to conduct research to improve health, care and services. As a publicly-funded organisation, we have to ensure that it is in the public interest when we use personally-identifiable information from people who have agreed to take part in research. This means that when you agree to take part in a research study, we will use your data in the ways needed to conduct and analyse the research study. Our legal basis for using your information under the General Data Protection Regulation (GDPR) and the Data Protection Act 2018, is as follows:

• Imperial College London - "performance of a task carried out in the public interest"; Health and care research should serve the public interest, which means that we have to demonstrate that our research serves the interests of society as a whole. We do this by following the UK Policy Framework for Health and Social Care Research;

Where special category personal information is involved (most commonly health data,

biometric data and genetic data, racial and ethnic data etc.), Imperial College London relies on “scientific or historical research purposes or statistical purposes.

INTERNATIONAL TRANSFERS

There may be a requirement to transfer information to countries outside the United Kingdom (for example, to a research partner, either within the European Economic Area (EEA) or to other countries outside the EEA. Where this information contains your personal data, Imperial College London will ensure that it is transferred in accordance with data protection legislation. If the data is transferred to a country which is not subject to a UK adequacy decision in respect of its data protection standards, Imperial College London will enter into a data sharing agreement with the recipient research partner that incorporates UK approved standard contractual clauses or utilise another transfer mechanism that safeguards how your personal data is processed.

SHARING YOUR INFORMATION WITH OTHERS

We will only share your personal data with certain third parties for the purposes referred to in this participant information sheet and by relying on the legal basis for processing your data as set out above.

- Other Imperial College London employees (including staff involved directly with the research study or as part of certain secondary activities which may include support functions, internal audits, ensuring accuracy of contact details etc.), Imperial College London agents, contractors and service providers (for example, suppliers of printing and mailing services, email communication services or web services, or suppliers who help us carry out any of the activities described above). Our third party service providers are required to enter into data processing agreements with us. We only permit them to process your personal data for specified purposes and in accordance with our policies.

POTENTIAL USE OF STUDY DATA FOR FUTURE RESEARCH

When you agree to take part in a research study, the information collected either as part of the study or in preparation for the study (such as contact details) may, if you consent, be provided to researchers running other research studies at Imperial College London and in other organisations which may be universities or organisations involved in research in this country or abroad. Your information will only be used to conduct research in accordance with legislation including the GDPR and the UK Policy Framework for Health and Social Care Research.

This information will not identify you and will not be combined with other information in a way that could identify you, used against you or used to make decisions about you.

COMMERCIALISATION

Samples / data from the study may also be provided to organisations not named in this participant information sheet, e.g. commercial organisations or non-commercial organisations for the purposes of undertaking the current study, future research studies or commercial

purposes such as development by a company of a new test, product or treatment. We will ensure your name and any identifying details will NOT be given to these third parties, instead you will be identified by a unique study number with any sample analysis having the potential to generate 'personal data'.

Aggregated (combined) or anonymised data sets (all identifying information is removed) may also be created using your data (in a way which does not identify you individually) and be used for such research or commercial purposes where the purposes align to relevant legislation (including the GDPR) and wider aims of the study. Your data will not be shared with a commercial organisation for marketing purposes.

WHAT ARE YOUR CHOICES ABOUT HOW YOUR INFORMATION IS USED?

You can stop being part of the study at any time, without giving a reason, but we will keep information about you that we already have because some research using your data may have already taken place and this cannot be undone.

- We need to manage your records in specific ways for the research to be reliable. This means that we may not be able to let you see or change the data we hold about you if this could affect the wider study or the accuracy of data collected.

WHERE CAN YOU FIND OUT MORE ABOUT HOW YOUR INFORMATION IS USED

You can find out more about how we use your information:

- by asking a member of the research team
- by sending an email to samar.nassar20@imperial.ac.uk or
- by ringing us on +966 555589464.

COMPLAINT

If you wish to raise a complaint about how we have handled your personal data, please contact the research team first by sending an email to samar.nassar20@imperial.ac.uk or by ringing us on +966 555589464.

Following our response, if you are not satisfied please contact Imperial College London's Data Protection Officer via email at dpo@imperial.ac.uk, via telephone on 020 7594 3502 and/or via post at Imperial College London, Data Protection Officer, Faculty Building Level 4, London SW7 2AZ.

If you remain unsatisfied with our response or believe we are processing your personal data in a way that is not lawful you can complain to the Information Commissioner's Office (ICO)- via www.ico.org.uk. Please note the ICO does recommend that you seek to resolve matters with the data controller (us) first before involving them.