

A community champion led breast cancer screening intervention for underserved groups

Participant information sheet – Focus group of community champions

Principal Investigator: Dr Gaby Judah

Invitation:

We would like to invite you to take part in a focus group to understand your experience of being a community champion in the breast cancer screening campaign. The campaign was designed by Imperial College London, and Hounslow Local Authority.

Before you decide whether or not to part, it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish.

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

Part 2 gives you more detailed information about the data protection and privacy aspect of the study.

Please ask us if there is anything that is not clear or if you would like more information.

Thank you for reading this.

PART 1

Do I have to take part?

Taking part in this study is voluntary. The information that you give will be anonymised, stored securely, and analysed confidentially. In any publication of our research findings, the information that you provide will not be identifiable. You are free to leave the study at any time giving an explanation, but any information you have already given will be anonymised and used in the analysis.

A copy of this written information and signed Informed Consent form will be given to you to keep.

What is the purpose of the study?

The NHS invites women aged 50 to 70 years old to a mammogram (breast cancer screening) every three years. This helps to detect cancers earlier when they are more treatable. Breast screening saves around 1300 lives per year. However, many people don't go to their breast screening appointment when invited. This is why we created the community champions campaign, to try to give people more information about breast cancer screening, to help them to attend.

The purpose of this study is to hear the experiences of people who were community champions. We want to know anything that made it easy or difficult to share the materials. We also want to understand people's reactions to the materials, and how this affected how people feel about breast cancer screening.

Why have I been invited?

You have been invited to participate as you have been involved as a community champion in this project.

What do I have to do?

This is a focus group, which will be done with a small group of people, lasting between 1 and 2 hours. During this focus group we will explore with you and other group members topics related to sharing the breast cancer screening materials and the community engagement campaign.

If you have concerns about any aspect of this study, please contact Ada Humphrey (a.humphrey@imperial.ac.uk). You can leave the focus group at any time, without giving a reason.

The focus group will be held at XXXXXXXXX

What are the possible disadvantages and risks of taking part?

The main disadvantage for taking part is that this will take approximately 1-2 hours (focus groups). Given the low-risk nature of our study, we do not perceive there to be any other disadvantages or risks associated with taking part.

What are the possible benefits of taking part?

You will be given £50 to thank you for your time (£25 per hour) You may learn things during the focus group which will help you to make informed choices about your health. You will also be helping us improve breast screening materials that may benefit others in the future.

What if something goes wrong?

If you are harmed by taking part in this research project, there are no special compensation arrangements. If you are harmed due to someone's negligence, then you may have grounds

for a legal action. Regardless of this, if you wish to complain, or have any concerns about any aspect of the way you have been treated during this study then you should immediately inform the Investigator (Gaby Judah, g.judah@imperial.ac.uk). The normal National Health Service complaints mechanisms are also available to you.

What will happen to the results of the study?

Your answers will be used as part of our evaluation process. This evaluation may be published in an openly accessible peer-reviewed medical journal. Any comments provided during the focus group that are published as quotes will shown anonymously so they cannot be traced back to any individual.

Who is organising and funding the research?

The study sponsor is Imperial College London. This research is being conducted under the direction and supervision of Dr Gaby Judah, the Principal Investigator. This research is funded by the National Institute of Health Research (NIHR).

Who has reviewed the study?

This study was reviewed and given an ethical opinion from [REC NAME]. It has also been given ethical approval by the Head of Department and Research Governance and Integrity Team at Imperial College London.

Contact us

If you would like to contact us further, please email Dr Ada Humphrey (a.humphrey@imperial.ac.uk).

This is the end of Part 1.

If you are interested in taking part from the information above, please read Part 2 before you make your decision.

Part 2:

PRIVACY NOTICE

HOW WILL WE USE INFORMATION ABOUT YOU?

Research Study Title: A community champion led breast cancer screening intervention for underserved groups

Imperial College London is the sponsor for this study and will act as the Data Controller for this study. Being a Data Controller means that we are responsible for looking after your information and using it appropriately plus are responsible for explaining this to you. 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 June 2028.

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 from you for this research project.

This information will include your name/ and contact details.

People within the College and 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 research is being done properly and the information held (such as contact) details is accurate. People who do not need to know who you are will not be able to see your name or contact details. Your data will have a code number instead. Imperial College London is the sponsor of this research and is responsible for looking after your information. 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 work out that you took part in the study.

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 i.e. finger prints or facial recognition and genetic data, racial and ethnic data etc.), Imperial College London rely on “scientific or historical research purposes or statistical purposes.

INTERNATIONAL TRANSFERS

We may share data about you outside the UK for research related purposes to:

If this happens, we will only share the data that is needed. We will also make sure you can’t be identified from the data that is shared where possible. This may not be possible under certain circumstances – for instance, if you have a rare illness, it may still be possible to identify you. If your data is shared outside the UK, it will be with the following sorts of organisations:

- To a research partner, either within the European Economic Area (EEA) or to other countries outside the EEA

We will make sure your data is protected. Anyone who accesses your data outside the UK must do what we tell them so that your data has a similar level of protection as it does under UK law. We will make sure your data is safe outside the UK by doing the following:

- We use specific contracts which stipulates that personal data must maintain the same level of protection when outside the UK as it has within the UK. For further details visit the Information Commissioner’s Office (ICO) website - www.ico.org.uk

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.

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. You have the right to ask us to remove, change or delete data we hold about you for the purposes of the study. We might not always be able to do this if it means we cannot use your data to do the research. If so, we will tell you why we cannot do this

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

You can find out more about how we use your information, including the specific mechanism used by us when transferring your personal data out of the UK.

- at www.hra.nhs.uk/information-about-patients/
- by asking one of the research team
- by sending an email to a.humphrey@imperial.ac.uk, or
- by ringing us on 020 7594 6246

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 a.humphrey@imperial.ac.uk, or by ringing us on 020 7594 6246.

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.

What will happen to the results of the research study?

The results of this study will help to inform the development of interventions to improve uptake of breast cancer screening. Results are likely to be published in 2028. You will not be identifiable in any report or publication.

Who is organising and funding the research?

The research is funded by the National Institute for Health Research (NIHR), Population Health Research (PHR) Grant. The research team are based in The Institute of Global Health Innovation at Imperial college London.

Who has reviewed the study?

This study was given a favourable ethical opinion for conduct in the NHS by **xxxx** REC.

Contact for Further Information

Please contact a.humphrey@imperial.ac.uk for further information. Thank you.