

Taking control of our care, together

Everything you need to know about the
co-creation project in **Breast Cancer Care**
for **South Asian** community members



Imperial College
London

What is it about?

We will explore how we could improve **access to breast cancer care pathways** for **South Asian people** living with and beyond breast cancer and their families/carers.

We want to invite you as '**experts by experience**' and create a safe space to share experiences and make decisions together.

1

We will explore the **challenges** of breast cancer care pathways.

2

Create and **design solutions** together, led by you and fellow participants.

Why am I invited?

You are invited because you are either:

- A person (aged 18 to 65) who is **South Asian living with or beyond breast cancer**
- **Family members and carers** (aged 18 to 65) of South Asian person, caring for someone living with or beyond breast cancer
- **Community leader / Health and social care practitioner**

And also:

- Have experience of using NHS cancer care support and/or other support (e.g. community, personal); and
- Live in London (United Kingdom)

What will I be doing?



INTERVIEW (1 HOUR) - OCT TO NOV 2021

An individual interview session where we will talk about your own, or the person you care for, **experiences of cancer diagnosis and any positives and negatives** of your experiences.



DESIGN WORKSHOP (2 HOURS) - JAN TO FEB 2022

This session is to **generate design questions and ideas** for possible solutions alone with the researcher.



GROUP WORKSHOP (3 HOURS) - FEB TO MARCH 2022

This session is to **generate design questions and ideas for possible solutions as a group**, with other participants.



FEEDBACK SESSIONS (1-2 HOURS) - MARCH TO APRIL 2022

This session is to **provide feedback and make decisions** together on the best solution.



All meetings will be **online**, using Zoom.



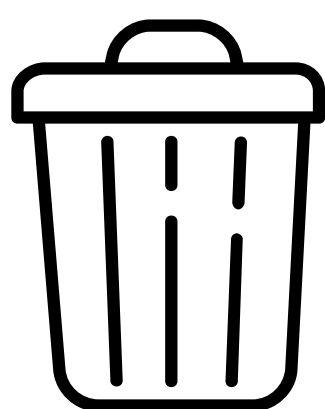
You can indicate **if you prefer an in-person meeting**. We will abide by the most updated COVID guidance for any optional in-person meetings.



All the sessions will be **recorded** to help with note-taking after each session, but tell us if you do not wish to be recorded.




All the recordings will be **fully anonymised**.



After all the recordings are transcribed, they will be **permanently deleted**.


What will I gain?




£25 per hour of
your time
(work from home
fee included)



Learn about
Co-design



Build your network
with community
members, researchers,
and healthcare
professionals



Contribute to current
research and future
research

Common Questions

1

Can I withdraw from the study?

Yes. It is up to you to decide whether or not to take part.

We understand that circumstances change, and even if you decide to take part in the project, you are free and welcome to change your mind and withdraw from the project without giving a reason.

Withdrawing from the project, at any stage, will not affect the current care you receive or your relationship with the researcher.

All the data will be deleted, except the results that have already been analysed or published.

2

What support will I receive?

If anyone is concerned about the impact of receiving a monetary reward for their involvement on benefits, you can get in touch with us, and we will signpost you to confidential and free advice.

If the project raises any difficult emotions, participants can request to be put in touch with a Mental Health First Aider from Imperial College for support. We can also key contact/support from the cancer information specialists.

You will receive continuous support from the researcher, Ms Soh- Yon Park, for further information and resources.

3

What will happen to the result of this research?

The interview data collected will be anonymised to remove all identifiable information, including your name.

The ideas, drawings, notes from the sessions, will be used to develop prototypes of design solutions for this project. Any data will be fully anonymised.

You will not be personally named alongside any quotes from the session; however, if you wish to be personally listed under the acknowledgements section of the researcher's publications, you can indicate this on the consent form.

The results of this project will be included in future publications (articles/blogs) and peer-reviewed literature academic papers for the researcher's fellowship.

For those who wish to get a copy of the results, please contact the researcher.

4

What if something goes wrong?

The study has been carefully designed to minimise any risk to you. You may decide to share some personal information when answering some of the questions. You may also feel uncomfortable answering questions about some of the topics.

You do not have to answer any questions if you don't wish to do so. However, we do not want this to happen; you do not have to give us any reason for not responding to any question.

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, you may have grounds for legal action.

If you wish to complain or have any concerns about any aspect of the way you have been treated during the course of this study then you should immediately inform the researcher.

If you are still not satisfied with the response, you may contact the Imperial College Research Governance and Integrity Team (rgitcoordinator@imperial.ac.uk).

5

Who is organising and funding this project?

This study is funded by the National Institute for Health Research (NIHR) through the RM Partners Pan-London Cancer Research Fellowship 2020/21

6

Who has reviewed this study?

This study was given approval by the Head of the Department of Surgery and Cancer and Research Governance Integrity Team (RGIT).

For any further information you can contact by email any of the researchers of this study:

Name: Ms Soh-Yon Park

E-mail: soh.park18@imperial.ac.uk

Contact Telephone: +44 (0) 7444 457022

NEXT STEPS

01

Read Participant Information Sheet

02

Sign the Consent Form for Phase 1
and send to the researcher

03

Schedule a call for Phase 1

04

Sign the Consent Form for
Phase 2, if participating

05

Schedule Individual and
Group Workshops

Transparency Notice

How will we use this information about you?

Research Study Title: Equity to Cancer Care 21IC7139

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 properly. 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.

We will need to use information from you for this research project. People will use this information to do the research or to check your records to make sure that the research is being done properly. 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.



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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. 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

International Transfers

There may be a requirement to transfer information to countries outside the European Economic Area (for example, to a research partner). 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 European Commission (EC) adequacy decision in respect of its data protection standards, Imperial College London will enter into a data sharing agreement with the recipient organisation that incorporates EC approved standard contractual clauses that safeguard how your personal data is processed.

Sharing your information with others

For the purposes referred to in this privacy notice and relying on the bases for processing as set out above, we will share your personal data with certain third parties.

- Other College employees, 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.

- the following Research Collaborators/Partners in the study: Royal Marsden Partners (RMP) Cancer Alliance - only disseminated and fully anonymised final findings will be shared with our RM Partners.

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.

If you agree to take part in this study, you will have the option to take part in future research using your data saved from this study.

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 one of the research team
- by sending an email to soh.park18@imperial.ac.uk, or
- by ringing us on +44 (0) 7444 457022.

Complaint

If you wish to raise a complaint on how we have handled your personal data, 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 are not satisfied 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). The ICO does recommend that you seek to resolve matters with the data controller (us) first before involving the regulator.