THE JEWISH HEREDITARY CANCER REVIEW: A QUALITATIVE STUDY OF *BRCA* AWARENESS AND TESTING EXPERIENCE IN THE UK JEWISH COMMUNITY

PARTICIPANT INFORMATION SHEET

Please read the following information and discuss it with others (your family and friends) if you wish. If you have any questions or you would like more information, please do let us know.

What is The Jewish Hereditary Cancer Review (JHCR)?

JHCR is a research study evaluating *BRCA* awareness and access to genetic testing in the UK Jewish community. *BRCA* stands for '*BR*east *CA*ncer gene'. It will explore sources of *BRCA* awareness, and key factors influencing access to and experiences with *BRCA* testing in the UK Jewish population. Qualitative interviews with Jewish *BRCA* carriers will form a significant part of the study.

Outcomes of the research will be published in a community report and as scientific publications. The report will be shared with key stakeholders and outcomes will be presented at community and scientific meetings. Findings will help inform improvements in promoting *BRCA* awareness and testing provision for the UK Jewish community and include recommendations for the same. The JHCR will support awareness raising and promote positive action to improve hereditary cancer management and prevention for Jewish people in the UK.

Background information

Genes are basic units of inheritance. They contain the blueprint of all hereditary information. Genes are made up of building blocks called DNA. Each gene is a short sequence of DNA, which corresponds to a unique set of instructions. Some individuals may have an alteration in their DNA sequence or genetic code. This is called a mutation.

Those who carry an alteration in certain specific genes are at a greater risk of developing cancer. Two such genes are known as the *BRCA*1 and *BRCA*2 genes (pronounced 'brakka-1' and 'brakka-2'), where *BRCA* stands for '*BR*east *CA*ncer gene'. Established early detection and preventive strategies such as screening and surgery are available to minimise the cancer risk of these 'at risk' individuals.

One in 40 Ashkenazi Jewish people have an alteration (or mutation) in their *BRCA*1 or *BRCA*2 genes. This compares to 1 in 200-300 in the wider general population. Carrying a *BRCA* gene mutation puts an individual at increased risk of certain types of cancers. These include breast (female and male), ovarian, prostate, pancreatic cancer, and melanoma. *BRCA* carriers, whether male or female, have a 50% chance of passing on their *BRCA* mutation to each of their children.

Genetic testing can identify if a person is a *BRCA* carrier. This enables them to consider the various options available to manage their cancer risk and improve their health outcomes. The NHS offers *BRCA* testing to individuals that reach a certain 'high risk' threshold based on their family history of cancer. However, research[i] has shown that, using this NHS approach, over 50% of *BRCA* carriers will not be considered sufficiently 'high risk' to access genetic testing. Thus, this family-history based approach misses 50-60% of people who carry a *BRCA* alteration.

Many more lives could be saved if the service were made available to all Jewish adults and not just those assessed as 'high risk'. A UK study[i] (GCaPPS study) showed that this was feasible, acceptable and had high satisfaction. It was not detrimental to psychological well-being, and reduced anxiety in Jewish men and women. Many private services now offer an alternative to the NHS genetic testing. However, these services are often unaffordable and lack essential genetic counselling.

A cost-effectiveness analysis[ii] evaluating offering *BRCA* screening to everyone in the Jewish population concluded that this would save hundreds more lives as well as millions of pounds of NHS funds. Yet even the current restricted service is not being fully utilised by the Jewish community. Many individuals eligible for NHS testing today do not access this vital service. Given its huge life-saving potential, there is a critical need to further understand and address the barriers to *BRCA* awareness and testing for the 'at increased risk' UK Jewish population.

What are the aims of the project?

This study aims to

- Evaluate sources of *BRCA* awareness, attitudes towards and factors influencing *BRCA* testing in the UK Jewish population
- Evaluate experiences and satisfaction with *BRCA* testing in the UK Jewish population

Outcomes from the study will help inform priority needs and practical recommendations to improve *BRCA* awareness in, and access to *BRCA* testing for the UK Jewish community.

Am I eligible to take part?

You may take part if you:

- Are over the age of 18 years **and**
- Have a *BRCA*1 and/or *BRCA*2 mutation identified through UK based genetic testing, **and**
- Have Jewish ancestry – at least 1 Jewish grandparent

When does it begin and how long will it last?

It is anticipated the study will begin around October 2021 will finish by the end of 2022.

How do I take part in the project?

If you are eligible and interested in taking part in the *BRCA* carrier interviews, please complete and return the participant consent form. You can return it by email to jhcr@qmul.ac.uk or by post to '*Freepost JHC-Review, Room 131, Wolfson Institute of Population Health, Queen Mary University of London, Charterhouse Square, London, EC1M 6BQ'*.

Do I have to take part in the project?

No, you do not have to participate in this study. Participation is completely voluntary. You are also free to withdraw from the study at any time without giving any reason for this. This does affect any future care in any way.

What will my participation involve?

Once your completed participant consent form is received, you will be contacted by the study researcher to schedule an interview. Given current Covid-19 restrictions, the interview will take place remotely. This may be via telephone or a virtual platform like zoom.

The interview will last approximately sixty minutes and will be recorded. This will allow the researcher to capture all the information discussed during the interview. This is important for them to analyse later.

Interviews will explore your how you became aware of *BRCA* and your testing experience. This will include awareness of, attitudes towards, and factors influencing *BRCA* testing. We are interested in understanding your experience of accessing testing, your testing process, information and support provided and your satisfaction with it. You can refuse to talk about something or answer any question(s) if it makes you feel uncomfortable. You can also stop the interview at any time.

How will the information I provide be processed and stored?

Your personal details and all study data will be entered on a password protected study database. This will be based on a secure central server at Wolfson Institute of Population Health, Barts Cancer Centre, Queen Mary University of London. Only members of the research team will be able to access this information through a username/password protected computer. Unauthorised persons will not have access to this data. There is a special dedicated team of IT specialists to ensure and monitor data security for this study.

The recording of your structured interview will be transcribed. This may be undertaken by a commercial company. Your responses will be analysed along with those from other *BRCA* carrier interviews to identify key information and themes that will contribute to the evaluation of *BRCA* awareness and testing in the UK Jewish community.

How confidential will my participation be?

Your participation in the study and the information you supply will be completely confidential. Any information you provide will be stored on a secure username/password protected database. This will not be released to anyone outside the study. Data collected will comply with guidance provided in Queen Mary Data Protection Policy.

You will not personally be identified from any of the research outputs of the study. Responses will be summarised and reported in a way that maintains the anonymity of individual participants. Any individual responses or quotes will be anonymised unless the participant has formally agreed for their name to be used.

What are the potential benefits of joining the project?

This UK study will contribute to a better understanding of *BRCA* awareness and testing in the Jewish population. It will help raise awareness among key stakeholders. It will inform development of a better approach to how the community educates itself about *BRCA* risks and facilitates access to genetic testing. Your participation will contribute to research efforts to improve the prevention and early diagnosis of future *BRCA* associated cancers. You will not personally benefit from this research.

What are the disadvantages or drawbacks of taking part?

Some people may feel sad or emotionally upset about talking about their *BRCA* testing experience and test result. Some study participants may have had cancer. Speaking about this may also cause distress or make them emotionally upset.

Who is involved in delivering this research project?

This project is being carried out by the research team based at Wolfson Institute of Preventive Medicine, Queen Mary University of London. The team includes,

- Chief Investigator (JHCR partner) - Professor Ranjit Manchanda
- Project director - Katrina Sarig
- Expert advisors - Professor Ros Eeles, Professor Gareth Evans, Dr Michelle Ferris
- Researcher fellows at Wolfson Institute of Population Health: Monika Sobocan, Samuel Oxley, Ashwin Kalra, Michail Sideris

Further details about the project team and expert advisors can be found at www.jhc-review.uk

Who has reviewed the study?

The study has been reviewed by the Queen Mary Research Ethics Committee. It has also been reviewed by the team of scientists, researchers and doctors involved.

Who is funding and supporting the project?

The project is being carried out with funding support from Charitable Trusts, private donors, The Eve Appeal charity, all of whom have an interest in improving the management of *BRCA*-associated cancers in the Jewish community. This work is also supported by the NHS Innovation Accelerator.

What will happen to the results of the study?

The results of this study will not be known for some time. These will be made available using scientific and medical publications and a community report. Results will also be presented at scientific conferences and meetings, and be shared with community stakeholders and charities. These can be accessed by anyone. You will not be personally identified in any such publications.

What if something goes wrong?

If you have any concerns or questions, you should initially contact the research team. The team will do their best to answer your questions. Team contact details are provided at the end of this information booklet. If there is something that you are unhappy with and wish to complain formally, you can do this through the Research Governance Sponsor of this study. Please write to: Joint QMUL/Bartshealth Biomedical Research Unit, R&D Directorate, Lower Ground Floor, 5 Walden Street, London, E1 2EF quoting reference JHC Review. All communication will be treated in strict confidence.

Every care will be taken to ensure your safety during the study. However, QMUL has special (no-fault) insurance arrangements in place in the unlikely event that something unforeseen goes wrong and you are harmed as a result of taking part in the study. If you are harmed due to someone's negligence, then you may have grounds for a legal action. But you may have to pay for it.

Where can I get further information about the project?

You can email jhcr@qmul.ac.uk or call: 020 8058 3730
An overview of the Jewish Hereditary Cancer Review project can be found at www.jhc-review.uk

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[i] R. Manchanda et al (2020). Randomised trial of population based *BRCA* testing in Ashkenazi Jews: long-term outcomes, *BJOG An International J of Obstetrics and Gynaecology*

[ii] R. Manchanda et al (2015) Cost-effectiveness of Population Screening for *BRCA* Mutations in Ashkenazi Jewish Women Compared with Family History–Based Testing, JNCI J Natl Cancer Inst