

PHASE 1 - World-class research into the genetic profile of breast cancer among women of colour Mukul Madhav Foundation, Royal Free Charity and Royal Free Hospital

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The urgent need for research into breast cancer among women of colour

Detecting breast cancer early is crucial in helping women to beat the disease. The five-year survival rate for localised cancer – cancer which has not yet spread to other parts of the body – is 99%. Existing screening programmes help clinicians to spot the signs of potential cancer sooner, but genomic research could offer the next major leap forward.

However, there is a worrying risk that global populations of women could be left behind

Breast cancer is the most common cancer in women worldwide – but to date, research has focused predominantly on data from patients of European heritage. Since this data informs treatment, innovations in care have been inevitably Eurocentric in focus, failing to consider the unique risk factors, and way breast cancer presents itself, in women from different ethnic groups.

A pioneering breast cancer research programme with global reach

Thanks to the generous funding through the Mukul Madhav Foundation, we are closer to being able to use genomics to predict the risk of breast cancer among South Asian women.

If clinicians were able to identify an individual's inherited risk of developing breast cancer, they could tailor prevention programmes and care options to a person's genetic make-up, reducing their risk of developing severe disease, and minimising the side-effects of any treatment. This personalised approach would revolutionise care, helping women to access safer and better treatment faster.

We believe that advances in healthcare should be advances for all. With the support of the Mukul Madhav Foundation, we were able to recruit 300 women to international studies making sure that the findings will be useful to all. We are in the process of recruiting the rest of the 700 women currently to assess the accuracy of genomic tests among women of South Asian ethnicity.

Thank you for all your ongoing support. Please see below for our next project which is aiming to impact South Asian women living in the UK (PHASE 2).

PHASE 2 - World-class research into the genetic profile of breast cancer among women of colour Mukul Madhav Foundation, Royal Free Charity and Royal Free Hospital

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RAKSHA Study - Summary

- The risk of developing breast cancer varies for different women. Advances in technology now allow us to evaluate each woman's individual risk of developing breast cancer by calculating a "score". This score comprises of both clinical data and genetic data and as a result we can predict and classify women as either 'higher risk' or 'lower risk' than general population for developing breast cancer. The ability to identify the risk of these women demonstrates the potential for targeted screening. The higher-risk groups would benefit from more frequent screening, chemoprevention advice and other

preventative strategies as recommended through the NICE guidance. This should also allow for earlier detection of breast cancers, thereby improving success of treatments.

- Several international trials of 'Risk-Stratified breast cancer screening' have been set-up to inform future policies. However, most women that have volunteered are educated women, of European ancestry. What is not clear yet, is *how this new strategy will impact women of ethnic minority origins*. South-Asians account for largest ethnic minority groups in the UK and traditionally have the lowest attendance rates for UK breast screening programmes (43% Bangladeshi women; 70% National screening rate). The reasons identified for this poor attendance include low perception of risk, misperceptions of risk-factors, socio-economic deprivation, and knowledge of breast cancer by women.

Aims

The RAKSHA study aims to see if *knowledge of the personalised risk of getting breast cancer will lead to a positive uptake of preventative advice and screening*. We will pay particular attention to assess perception, accessibility to risk prediction tools and appropriateness of communication tools with the help of focused Patient & Public groups.

Study Design

We will invite women of South Asian origins living in London. In this study, half of the women will be randomly allocated to follow the standard NHS breast screening programme and the other half will follow a 'risk-based screening' programme, where imaging frequency will be determined based on the woman's individual risk. We aim to measure screening attendance and lifestyle change uptake over 4 years. The number of cancers detected and the stage at diagnosis will also be compared and the impact on costs will be estimated. Through this study, we will also understand the enablers and barriers to screening access that exist within this community through questionnaires and interviews.

Potential Impact

The first study to focus on Risk-stratification among South-Asians. This study will use the CanRisk tool that has been recently calibrated and developed through CRUK funding. The findings can be combined with larger international studies to ensure representation of South Asian women in international research. The findings will not only influence screening strategies in the UK and EU, but also South Asian countries in the future.

If risk stratified screening is to be evaluated as a clinical tool in cancer risk management, then we must strive to ensure this is acceptable, available, and applicable to all irrespective of race or ethnicity. Otherwise, we stand the risk of widening gaps that already exists.

We believe that advances in healthcare should be advances for all. With the support of the Mukul Madhav Foundation, we will be able to increase the representation of women of South-Asian ancestry in international research.

FUNDS REQUIRED

We are raising funds for a bilingual research assistant speaking Urdu/Bengali to work full time within our breast unit to support recruitment to this study - £48,000/year. This will allow us to recruit faster and more efficiently without having to pay a research nurse per hour.

Kind regards

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