



UNIVERSITY OF  
LEICESTER



Centre for BME Health



# The 100,000 Genomes Project

Tackling inequalities in access to genomic medicine

A genome is one whole set of genes plus all the DNA between your genes.  
There are 3 billion DNA letters in your genome and every one counts!

The 100,000 genome project aims to sequence whole genomes of NHS patients with certain types of cancer & rare disease. These genomes will be linked to an individual's medical condition. By adding key information from medical records and putting all the data in one secure place, scientists can compare the data from tens, hundreds or even thousands of people with the same condition. By comparing all this data scientists will gain new insights into causes of disease and how to treat it for future generations

The Centre for BME Health in partnership with Genomics England, ProstaId, the National Hereditary Breast Cancer Helpline were asked to increase awareness in the community through media, schools, sports clubs, road shows, leaflets, conferences. This work is vital as cancer rates throughout our community, particularly in ethnic minorities, continue to rise (especially bowel, breast, endometrial, liver and prostate

Awareness of the rise in cancer rates in BME groups amongst communities and clinicians is often poor resulting in lower screening uptake rates and later diagnoses.

Awareness of cancer having an inherited link is limited in BME populations and some health professionals. And a lack of proactive family history taking can accentuate this.

Complicated patient pathways, family history questionnaires and referral/testing criteria for genetics compounds access inequalities.

There is poor access to, or take up of, research studies amongst BME populations.

The Centre for BME Health aimed to achieve the following in the African Caribbean community of Leicester City:

- Identify the benefits of getting involved in the 100,000 Genomes Project.
- Describe the purpose of the 100,000 Genomes Project
- Discuss the role that family history can play in long term conditions such as cancer, and rare conditions

#### Impact & Outcomes

Four community events were organised in venues in Leicester city, including Highfield Rangers Football club – Annual Family Fun Day, Cultural Market which took place at the Peepul Centre which the local African Caribbean Community attended.

At these events contact was made with approximately 1,200 people across a wide age range and both males and females. As a result of these event the need continue to carry out more awareness and to offer support targeting predominately African Caribbean men was identified

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**“We are delighted to have developed links with the BME Centre for East Midlands This has involved spending time reaching out into the community and attending events and giving talks as well as using local community champions to improve access, build trust, provide cultural understanding within the African Caribbean community. We are keen to continue to work even more closely with the Centre for BME Health in the very near future to continue to make a difference.”**

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**J Barwell, 100,000 Genome Project, July 2017**

Professor Julian Barwell, UHL presented with the support Community Project Officer Pamela Campbell-Morris with issues raised and a number of questions and discussion generated by the members of the community.

Hard copies of the genomics England leaflet have been available for people to take away at stalls hosted by the Centre for BME Health at numerous events.

Promotion of the genomics information has been extensive, particularly online and through social media.

More information can be found about the 100,000 genome project by visiting the Genomics England website [www.genomicsengland.co.uk](http://www.genomicsengland.co.uk)

#### Next Steps

Recruitment to the 100,000 Genome project is ongoing and the Centre for BME Health continue to be on the steering committee.

The Community based work led to the design and development of an Initiative 'Play Domino, talk Prostate' in conjunction with ProstaId and Prostate UK

Please get in touch and find out more about what we can do to support you. Visit the contact us page: [www.ourhealthhourway.org.uk/contact/](http://www.ourhealthhourway.org.uk/contact/)

- Email us at: [bmehealth-em@leicester.ac.uk](mailto:bmehealth-em@leicester.ac.uk)
- Follow us on twitter: [@BMEhealthEM](https://twitter.com/BMEhealthEM)

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