Join the South Asian Genes and Health in Australia (SAGHA) Study Community Advisory Group to increase representation of South Asians in health and genomics research in Australia

Closing date: 9am, Monday 27 March 2023

Namaste नमस्ते | Vannakam வணக்கம் | Kem Cho કેમ છો | Sat Sri Akal ਸਤ ਸ੍ਰੀ ਅਕਾਲ Nomoskar নমস্কার | Al Salamu Aleykum السلام علیک

*Are you from a South Asian background and currently reside in Queensland?*

*Are you interested in how your DNA affects your chances of getting heart disease?*

*Do you want to make a difference in your community and your future generations?*

*You could help by becoming a member of the advisory group!*

**The University of Queensland would like to work with five (5) South Asian community members. You will have the amazing opportunity to be part of a Community Advisory Group for a genomics research study called the South Asian Genes and Health in Australia (SAGHA) Study.**

**What is genomics?**

Genomics is the study of genes and other information in a person’s genome - the complete set of instructions in their DNA. Genomics research helps us to better understand diseases so we can develop better ways of preventing and treating disease.

**What is the *Better Health for Us* *Study* and why is it important?**

Most of genomic research has been done on European people and therefore, doesn’t apply well to people from a multicultural background. To ensure genomic research benefits all Australians equally, we need to increase participation of individuals from diverse backgrounds into genomic studies. In this project we want to work with people from the South Asian background to build more research data and information that can help improve the health of people from South Asian communities.

**The first part of this study** is to have conversations with South Asian community members, and understand what things (e.g. understanding of genomics, language, cultural beliefs) will help you or stop you from participating in genomic research. We will use the information to develop culturally appropriate guidelines for conducting genomic research with South Asian Queenslanders.

**In the second stage of the study**, we will use these guidelines to conduct a trial run or a pilot study. The pilot study will look at heart disease risk in at least 200 South Asian people living in Queensland. Health research is showing that heart disease risk is 2-times higher in South Asians than in the general population. We do not understand why this is, but our DNA may provide more clues. This part of the study will involve collection of health information as well as a DNA sample.

We invite you to be part of Australia’s first ever genomic research study that is focused on health in the Australian South Asian community. The study will be run by researchers at the University of Queensland and is funded by the government’s Medical Research Future Fund.

Purpose of the Community Advisory Group

**The University of Queensland is looking for five (5) South Asian community members. It is a unique opportunity to participate on the Community Advisory Group in cutting edge genomics research never done in Australia.**

The purpose of the Community Advisory Group is to give a community perspective on how best to do genomics research with South Asian Queenslanders. The Group will:

1. Advise the research team on how best to interact with the South Asian Queenslanders
2. Help the research team understand the difficulties that prevent South Asian Queenslanders from participating in genomic research
3. Advise on how best to recruit South Asian Queenslanders into a genomic study
4. Give advice on how best to communicate with South Asian Queenslanders
5. Help develop and review documents such as information sheets, questionnaires and consent forms, to advise on language and accessibility
6. Help the research team distribute information about the study to their network of South Asian Queenslanders
7. Contribute to the development of the final published framework. With your permission, your contributions will be acknowledged in this publication by including your name in the published research paper.

Role of the community member

The role of the successful community member will be to attend all Advisory Group meetings and to actively participate in all meeting activities such as pre-meeting reading, discussions, feedback and advice.

Who is it for?

We are looking for five (5) community representatives **over the age of 18 years who have the following heritages: Indian, Pakistan, Sri Lanka, and Bangladesh**. Though geographically South Asia includes many different countries, there are important genetic differences in the risk of heart disease depending on which South Asian ethnic background you are from. However, our long-term goal is to eventually conduct a much larger, nationwide study that will include all South Asian Australians.

* People who have leadership roles within the South Asian community are encouraged to apply.
* Members will be selected to ensure representation from diverse ethnic, gender and age groups.

Time and location

The consumer advisory group will meet every 3 months (up to 8 meetings over 2 years, starting in early 2023)**.** Each meeting will run for 2 hours and will likely be held on a weekday in the late afternoon/evening, depending on availability and preferences.

For ease of attendance, all meetings will be held virtually using either Zoom or Teams, based on the group’s preference. However, there may be opportunities for in-person meetings if possible.

Remuneration and Support

* Consumer Advisory Group members will be renumerated $50 per hour for each meeting attended.
* Meetings will be chaired by a research team member. The research team will provide support for taking notes and any other administrative support.
* Members will have training to support their participation.
* Members will have a point-of-contact at the University of Queensland who can provide admin support, for example pre meeting and post meeting briefings and additional support throughout the study.

How to apply

**Please complete this application form and return to****consumer@hcq.org.au**by 9am, Monday 27 March 2023

For assistance, please contact Health Consumers Queensland via consumer@hcq.org.au or by phone on 07 3012 9090.

**Application Form to join the South Asian Genes and Health in Australia (SAGHA) Study Community Advisory Group**

Full name:

Preferred phone number:

Email:

Postal address:

Postcode:

* By completing this application, I consent for my details to be added to the Health Consumers Queensland network database [ ]  YES | [ ]  NO
* I would like to receive email updates from Health Consumers Queensland [ ]  YES | [ ]  NO
* Are you happy for Health Consumers Queensland to share this form with University of Queensland as part of the process for this application? [ ]  YES | [ ]  NO

Please highlight any group you identify as being a part of:

[ ]  Living with a disability/chronic condition

[ ]  Caring for someone with a disability/chronic condition

[ ]  Physically isolated or transport disadvantaged

[ ]  Culturally or linguistically diverse

[ ]  From a non-English speaking background

[ ]  LGBTIQ+ (lesbian, gay, bisexual, transgender, intersex, queer) These terms are used to describe a person’s sexual orientation or gender identity

[ ]  Currently reside in Queensland

 Do you consider yourself to be of South Asian ancestry i.e. heritage from India (including people of Indian descent from Fiji, Africa, etc), Pakistan, Sri Lanka, Bangladesh?

[ ]  Yes [ ]  No [ ]  Prefer not to say

If you ticked ‘Yes’ to the above question, what is your country of ancestral origin (e.g. India, Pakistan, Fiji, Sri Lanka etc)?

Do you identify with a specific South Asian ethnic group (e.g Gujarati, Tamil, Punjabi, Pashtun etc)?

[ ]  Yes [ ]  No [ ]  Prefer not to say

If you ticked ‘Yes’ to the above questions, please state which South Asian ethnic group you identify with?

Age range: [ ]  18-24 | [ ]  25-29 | [ ]  30-39 | [ ]  40-49 | [ ]  50-59 | [ ]  60-69 | [ ]  70+

|  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- |
| **Gender:** | [ ]  Male | [ ]  Female | [ ]  Intersex | [ ]  Other | [ ]  Prefer not to state |

How would you like to be addressed during meetings: [ ]  he/him | [ ]  she/her | [ ]  they/them

Please describe any support you need to take part in this activity *(examples include support person, hearing loop, tech support, Teams/Zoom support, English speaking translation)*

*Your responses to the following questions only need to be a brief sentence or two or bullet points*

1. Please describe any connections you have to your community (e.g. networks, groups, community organisations you are associated with).
2. Please describe your experience as a community member or community leader (if any). For example, membership of committees and community organisations, attending focus groups, discussion forums, involvement in organising community events and health-related events.
3. Please share with us why you want to be part of this research project and why is it important to you and your family.

*Selection process*

*Applications will be jointly selected by Health Consumers Queensland and the University of Queensland. Shortlisted applicants will be asked to join a short 20-minute online Interview for this role via Microsoft teams or Zoom.*