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Co-Design Workshops with NSW Filipino Australians: Outreach and communications to recruit participants to the OurDNA Program

March - May 2023

8 May 2023

With the collaboration and support of the Philippine Community Council of NSW

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Introduction

OurDNA is the flagship program of the Centre for Population Genomics (CPG), an initiative of the Garvan Institute for Medical Research in Sydney and the Murdoch Children's Research Institute in Melbourne. Through OurDNA, CPG is aiming to address the underrepresentation of Filipino Australians and other groups from genomics research. More information about CPG and the OurDNA program can be found in the presentation slides in Appendix 1. The Philippine Community Council of NSW (PCC-NSW) supports the OurDNA program and has been collaborating with CPG to co-design OurDNA recruitment strategies and communication materials.

These co-design workshops took place in late March and early April 2023. Prior to these workshops, there have been two previous information sessions about the OurDNA program with Filipino community members organised by PCC-NSW, one online with the PCC-NSW board and one in-person event with PCC-NSW affiliates at the Blacktown Club. PCC-NSW also helped CPG to organise a focus group with community members at Max Webber Library in Blacktown in February 2023 to gather feedback about the translation of generic genomic research information materials into Tagalog for a different project. That focus group has informed the development of the OurDNA consent portal content materials discussed in this document.

This document reports on two codesign events with Filipino community members, one held in-person and one online. This co-design work has been carried out with two lead collaborators from the Filipino community.

Names of people present at co-design workshops

In this section, we name the facilitators and the participants who indicated on their consent form that they would like to be named in documents resulting from the workshop.

Both workshops were facilitated:

1) by the members of CPG's Inclusive Genomics Team:
   Maia Ambegaokar, Team Lead
   Samantha Croy, Senior Communities Specialist
   Shenei Penaia, Community Engagement Organiser
   Rafal Shouly, Community Engagement Organiser
   With the support of Caitlin Morrison, CPG Project Officer

2) by the Lead Collaborators from the Filipino community:
   Lee Maureen Santiago
   Maria Grace Liston

Workshop 1 participants
Twenty-one community members took part in the first co-design workshop, held in person. Six (6) participants asked to remain anonymous. The participants who wish to be acknowledged were:

Evelyn Beed
Gloria M. Bonifacio
Judith Del Prado
Rod Dingle
Jaime R Lopez
Elizabeth C. Opilas
Redempta “Demi” Robinson
Willy Sampang
Merly Bandayrel
Teresita Williams
Fe Hayward
Mayumi Bartolome
Cesar Bartolome
Emelita Howlett
Vera Howlett
Mercedes Jones

Workshop 2 participants

Twelve community members took part in Workshop 2, held on Zoom. Three participants asked to remain anonymous. The participants who wish to be acknowledged were:

Evelyn Beed
Judith Del Prado
Willy Sampang
Rod Dingle
Merly Bandayrel
Mayumi Bartolome
Emelita Howlett
Vera Howlett
Aaron A.

WORKSHOP 1

Overview

From 6 pm to 9 pm on Wednesday 29 March, twenty-three Filipino Australians gathered in the Max Webber Library Function Room in Blacktown, NSW for the first OurDNA Program co-design workshop.

The purpose of this workshop was to gather the opinions and ideas of participants about outreach and communication to improve the recruitment of Filipino Australians in NSW into the OurDNA research program.

Agenda of the workshop

1. *Refreshments & signing consent forms*

The event got underway at 6:30 pm and began with finger food from Mama Lor restaurant and informal conversations around the room.

Participants signed a consent form acknowledging that they understood the purpose of the codesign project and that they voluntarily consented to participate. In addition to consenting to participate, they were asked if they would like to be acknowledged by name in reports and presentations about the project and whether they would like to be contacted in about 6-months' time to participate in an evaluation of this co-design process.

2. *Introductions and project overview*

Everyone in the room introduced themselves. Maia Ambegaokar then gave a short presentation. While some in the room had attended one or more of the previous events, others had not. The presentation explained CPG, the diversity problem in genomic medicine, the OurDNA project and the purpose of the co-design process in designing appropriate outreach, communication and recruitment strategies for the Filipino community in NSW. The presentation slides can be found in Appendix 1.

3. *Part 1: Participant journey*

The first exercise involved the participants considering the first four steps in an OurDNA participant's journey:

1-Learning about the project
2-Reading explanatory materials and consent form
3-Giving consent
4-Giving a blood sample (30ml)

Simplified drawings of each of these stages were placed around the room. Participants took Post-it notes and wrote their questions or suggestions about each of these. Afterwards, the facilitators walked around the room stopping at each of the four steps and discussed with the whole group each point raised. Some questions had straightforward known answers (how many blood samples will be needed?) and were answered on the spot. Others required further thought and lent themselves either to more discussion, or later co-design solutions.

4. Short break

There was a short break of 10 minutes at about 7:45.

5. Part 2: Locations/events & communication channels

The second set of activities involved two exercises. The group was divided in two. One group answered the questions "Where do people gather? Or see each other?". The purpose of this activity was to identify locations and events where Filipino Australians could be reached for the purposes of sharing information about OurDNA. The second group answered the question "What do people read, look at, and listen to?" The purpose of this was to identify communication channels that are frequently used by the Filipino community in NSW.

Once each group had completed a list, they read it out and asked if there was anything further to add.

6. Next steps and distribute "thank you" vouchers

At the end, participants were thanked for their time and provided with $100 vouchers as a token of appreciation. Volunteers were sought from amongst the group to take part in a review of the content to be included on the OurDNA participant information and consent portal. Fourteen people signed up for this.

Summary of findings: Participant Journey exercise

Step 1: Learning about the project

Workshop participants immediately offered many suggestions of where Filipino Australians might hear about the project (See Appendix 2). These suggestions have been consolidated with the findings from the exercises on locations and communication channels.

Other things that participants considered were:

- Whether there would be information sessions and forums where community members could hear about the project.
- How the OurDNA project could make sure the project was accessible to a broad range of community members.

- If OurDNA could involve Filipino Australian doctors who could tell their patients about the project.
- How frequently they would hear about the project.

Step 2: Reading explanatory materials and consent form

The two main questions participants raised when thinking about this step were:

- Whether materials would be available in hard copy

  Participants thought that providing other options apart from reading about the project materials online would be good (e.g. reading a brochure). This would be suitable for older community members who do not use computers as much as younger people.
  There was a suggestion to let the whole family attend the information meetings so the younger family members can assist the older ones when reading or completing the online forms.

- Whether they would be available in Filipino languages

  There were differing opinions about whether materials needed to be available in Tagalog. Some people thought that it would be good to cater to other Filipino dialects as well as Tagalog. Others noted that Filipino Australians are highly proficient in English and providing materials in Tagalog might not be necessary.

Participants' other suggestions and questions for this step included:

- Having a QR code on materials that community members could scan and be taken to the OurDNA website/portal.
- Having explanatory videos and presentations on social media.
- Being able to contact someone with questions about the consent process. (We confirmed that this would be possible.)
- Producing simple explanatory materials.

One Post-It note said hopefully: “The outcome will be very interesting”!

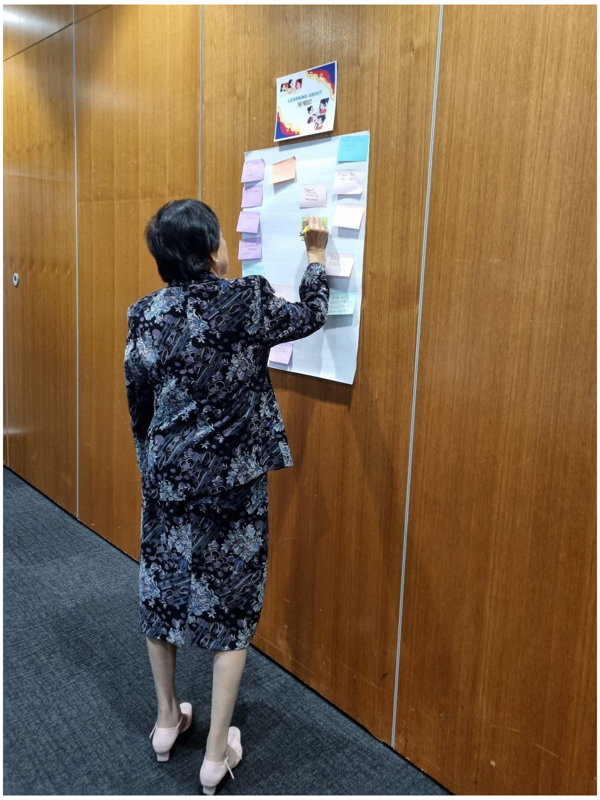
Step 3: Giving consent

Participants had a number of questions about the age of participants and their capacity to consent. We clarified that:

- Anyone over the age of 18 could take part in the project
- 18 is considered the age in Australia that individuals are considered legally to be able to consent to participate in medical research
- Anyone who had the capacity to consent would be able to take part in OurDNA even if they needed support to fill in the consent form

Participants had questions about the kind of information they would be provided with when they took part, including:

- Whether they would be able to get results from participating
- Whether they would receive information about the health of their family
- Whether findings about the community's health would be disseminated



They also asked who would benefit from the research. We explained that the individual results would only be provided to a very small percentage of OurDNA participants who have a change in their DNA that would be useful for them to know about. Some OurDNA participants will be able to request raw (uninterpreted) data about their genome.

The immediate benefit of community members' participation would be a freely available resource (OurDNA Browser) that clinicians would be able to use to help their patients of Filipino background. Once the other OurDNA resources have been established (OurDNA Samples and OurDNA Data), these would allow researchers to conduct research on topics relevant to the Filipino community.

A number of participants wanted to know why we did not approach health services for samples and data. We explained that this is because our aim is to recruit healthy people. The genetic information of healthy people will be used as a reference by clinicians to identify the genetic changes in their patients that are causing their illnesses.

An important finding for CPG relating to our participant portal relates to the concerns that participants had over requiring OurDNA participants to register and consent online. Participants noted that:

- Some people would be more comfortable signing hard copies.
- Older people may be uncomfortable with digital consenting.

Step 3: Giving a blood sample

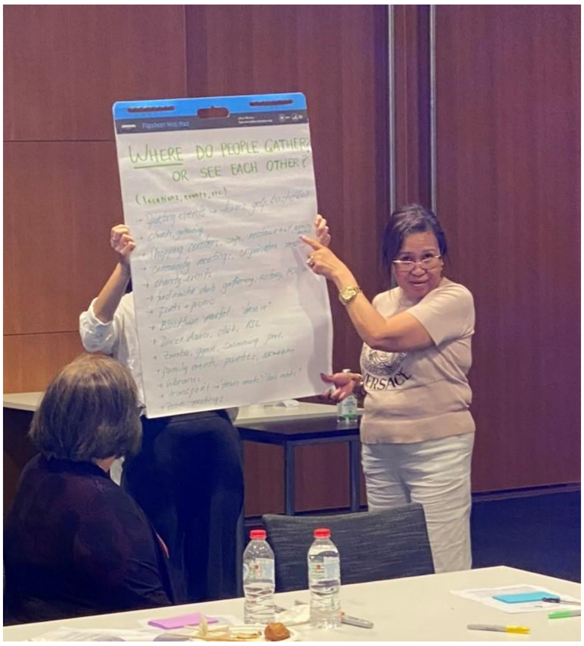
Participants had a number of questions about donating a blood sample such as frequency, security, process, and outputs. We were able to confirm and clarify that:

- OurDNA participants would only need to give a one-off 30ml donation.
- These samples would be securely collected and transported by Sonic Healthcare
- They will be stored securely by Biobanking Victoria.
- OurDNA participants could choose whether or not they wanted to consent to the creation of stem cells with their sample.
- That people would be able to donate their sample at one of many branches of our partners Sonic Healthcare.
- OurDNA participants would not need to fast to give a blood sample.

Participants expressed concerns about privacy and noted they would need to be assured of the confidentiality of the results. We explained that:

- The personal details of OurDNA participants will be stored separately from their data and samples.
- Researchers will not have access to personal details as they will only see a code.
- Access to personal details will only be for defined purposes by authorised personnel (e.g. for blood sample collection, to send reminders to participants)

Encouragingly, one participant’s response to thinking about giving a blood sample was; “No dramas: good for the next generation to come”!



Summary of findings: Locations & Events exercise

In response to the question “Where do people gather? Or see each other?”, participants listed:

- Sporting events and activities (e.g. tennis, golf, basketball, bowling)
- Sporting venues (e.g. pools and gyms)
- Fitness classes such as Zumba
- Filipino line dancing
- Filipino language classes
- Church gatherings, especially after church
- Filipino cafes and restaurants

- Shopping centres
- Beauty salons
- Events such as charity events, Filipino Independence Day celebrations, Fiesta
- Community group and organisations' meetings e.g. Toastmasters Club, Rotary, Illawarra Filipino & Multicultural Women's Group, PCC-NSW and affiliates (including on Zoom)
- Gathering with family and friends (e.g. picnics, parties, excursions)
- Blacktown market "drive-in"
- Blacktown showground
- Social events such as a dinner dance
- Clubs such as RSL
- Libraries, community halls, and other community venues
- On public transport

Summary of findings: Communication Channels exercise
In response to the question "What do people read, look at, and listen to?", key ideas participants raised included:

- Social media such as Facebook, Instagram, YouTube, TikTok, and LinkedIn
- Newspapers including Filipino community newspapers
- Filipino Fiesta
- Radio (e.g. Kiss FM, SBS)
- Word of mouth
- Filipino community leaders
- Religious organisations e.g. churches
- News e.g. CNN
- Filipino doctors, GPs
- Bulletin boards at schools and medical centres
- Educational flyers

WORKSHOP 2

Overview

From 6 pm to 7.30 pm on Monday 3 April, fourteen Filipino Australians gathered on Zoom with members of CPG for the second OurDNA Program co-design workshop. All but two participants had also attended the in-person workshop.

The purpose of this workshop was to gain feedback from community members about the OurDNA portal and consent materials and to gather ideas for OurDNA communication materials. Participants were sent materials to review ahead of the workshop. These included screenshots of the OurDNA portal, the content of the participant consent portal, as well as proposed promotional and communication materials.

Inclusive Genomics team members Rafal and Shenei took notes during the discussion. These notes were sent around to participants after the workshop, and a number of participants provided additional comments.

Agenda of the workshop

1. *Introduction*

   As most participants had previously attended the in-person workshop, Maia gave a brief introduction to the materials and outlined the aims of the workshop.

2. *Discussion of OurDNA web portal screenshots*

   Maia shared her screen so that everyone could see the OurDNA portal screenshots, previously shared by email with the participants. These included the OurDNA landing page, the 'Contact us' pop-up, screening question pages, as well as information and consent pages. Sam led a discussion about what community members thought about the portal and any suggestions they had for how the portal could be improved.

3. *Discussion of OurDNA web portal content*

   Next, the group discussed the content of the OurDNA portal. This included the participant information and consent questions, all previously shared by email. Maia took the group through the portal content section by section, asking for feedback on the appropriateness of the content and the process for the Filipino Australian community. From this exercise, participants were able to get a clearer sense of the steps involved in participating and in registering and consenting to take part.

4. Discussion of OurDNA participant-facing materials

   Finally, we discussed community members' ideas for the OurDNA participant-facing materials. Participants were shown in advance and on-screen during the session possible flyers, reminder emails, and a range of social media messages that community members might receive. We asked participants about their ideas for how we could make the materials more appealing to members of the Filipino Australian community.

Summary of findings: OurDNA web portal screenshots

Community members responded positively to the appearance of the portal. Participants' feedback was that the landing page would grab people's attention without being distracting. One participant added later that it would be good if the fact that participants receive a $100 voucher was clear when participants visited the OurDNA website. Another suggestion was to provide potential participants with an estimation upfront of the time it would likely take them to go through the OurDNA portal to consent to the project.

OurDNA is working to improve healthcare for all Australians

Welcome to **OurDNA.**

OurDNA is **building resources** to improve health research and health care for all Australians - for you, your family and your community.

OurDNA is **working to include ethnic minority communities** who are mostly missing from the health databases that doctors and researchers use to study illness.

Participants raised the question of accessibility, noting that some people would need help to register online. They liked that the 'contact us' pop-up would provide contact details so that participants could speak to someone about questions they had or difficulties they were experiencing with registering. To restrict registration to people in Australia, one participant suggested also requiring participants to provide an Australian phone number to register as well as an email.

While participants noted that the text on the screenshots they received was readable and understandable, they also pointed out that having different accessibility options such as larger font options would be helpful. Participants were pleased to hear that the portal would be mobile-friendly as they thought that many people would access the portal on their phones.

Summary of findings: OurDNA web portal Content


BENEFITS

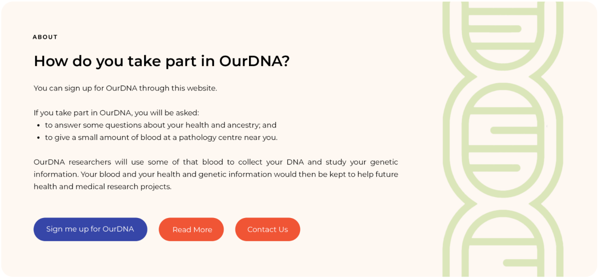
Why would you want to take part in OurDNA?

If you belong to one of these ancestry groups and you enrol in OurDNA, you will help researchers:

In the short term
- to identify health conditions faster; and
- to understand and predict illness in the community;

In the long term
- to improve healthcare in the community of people who have the same ancestry as you; and
- to develop future medicines and treatments for all communities in Australia.

OurDNA is **including people in a national research project** that will help researchers and doctors to identify, predict and treat disease.


ABOUT

How do you take part in OurDNA?

You can sign up for OurDNA through this website.

If you take part in OurDNA, you will be asked:
- to answer some questions about your health and ancestry; and
- to give a small amount of blood at a pathology centre near you.

OurDNA researchers will use some of that blood to collect your DNA and study your genetic information. Your blood and your health and genetic information would then be kept to help future health and medical research projects.

Going through the content of the OurDNA portal, participants had a number of questions and comments about the process of taking part in the OurDNA program, as well as the process of signing up. One participant suggested after the workshop that a video summarising the things people needed to know to take part would be helpful for people who do not have time to read through all the materials. Community members also recommended that prospective participants be able to save their progress and continue at another time. They thought that it would also be good if community members were able to review and edit their answers at a later time. Participants appreciated the fact that people would be able to change their minds and withdraw if they wanted to.

The content of the portal included a number of screening questions to confirm participants' eligibility. One of the criteria for participating in the OurDNA program is that participants do not have a known serious genetic condition or a close family member with a serious genetic condition. While some examples were provided of what would count as a serious genetic condition, one participant noted that a longer list might be needed as people might not know the condition their relative had was genetic.

Participants also gave us feedback on the process of participation. We asked specifically about the process of donating a blood sample and whether printing out a pathology slip would be a barrier. Community members said that not everyone would be willing or able to print out a slip.

A final comment about the process of registering and consenting to take part was a suggestion from one participant to make some of the questions compulsory so that people filled in the form correctly.

Summary of findings: OurDNA participant-facing materials

Workshop participants had many suggestions for how we could make the OurDNA materials more appealing to members of the Filipino Australian community. A participant noted that keywords and phrases on materials could be in bold e.g. ‘identify as Filipino’. Participants also suggested that using Tagalog words in headings would get community members’ attention. These included words like:

- Genetika (genetics)
- Salina (join now)
- Pinoy/Filo (Filipino)

Participants noted that use of these terms would be eye-catching and relatable to community members.

The materials provided to participants included graphics depicting people of diverse backgrounds. Participants suggested that the characters used in materials for the Filipino community could be made more clearly identifiable as Filipino. Characters could be dressed in traditional Filipino clothing such as baro't saya or barong tagalog. Participants also suggested that images of Filipino things would also attract attention such as pictures of jeepneys, traditional Filipino houses, the Philippine flag, or the use of Philippine flag colours.

Community members also offered recommendations for the content of the recruitment communication materials. One participant noted that recruitment materials should be specific about who can take part (e.g. NSW-based only for the first round of OurDNA, Australian citizen or permanent resident). Another suggestion was that it would be good to state upfront why the Filipino community has been prioritised.

The content materials included draft emails to participants with reminders of blood donation appointments. The materials referred to ‘Douglass Hanly Moir Pathology’ which a participant noted is the Sydney name for the Sonic Healthcare pathology laboratory. This participant noted that the email would need to be adapted depending on where in New South Wales participants were located.

Conclusion

This report will inform the decisions about OurDNA recruitment strategies and the design of communications materials for the Filipino community in New South Wales. The draft report is being sent to everyone who participated in the co-design workshop so that participants are able to suggest amendments to it.

CPG will work closely with our lead collaborators Maureen and Grace, and PCC-NSW, to implement the recommendations of Filipino community members in New South Wales. CPG is working towards beginning recruitment for the OurDNA project by mid-2023. The aim is to start initially with the recruitment of 100 community members in NSW, and eventually roll out the program to other states.

Acknowledgements

The Inclusive Genomics team at CPG would like to thank all the co-design workshop participants who generously gave their time to share their ideas and give us feedback on the OurDNA processes and materials.

We especially thank our lead collaborators Lee Maureen Santiago and Maria Grace Liston for all the work they put into helping to organise, facilitate, and write up the co-design workshops.

We thank Caitlin Morrison from the CPG Project Management team who organised the venue, catering, and much more besides!

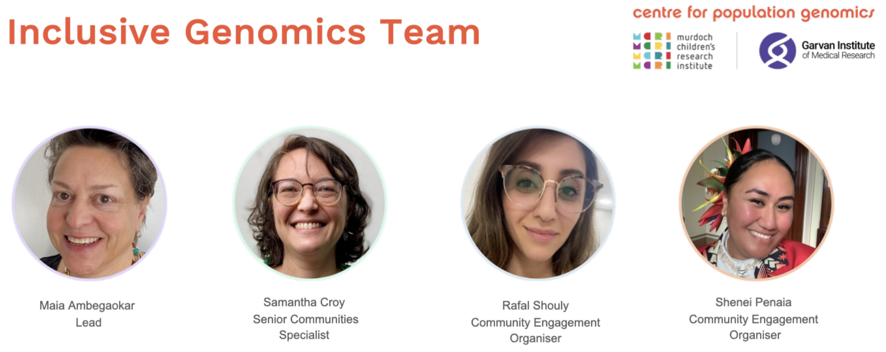
Finally, we would like to express our deep gratitude to PCC-NSW, especially Cesar Bartolome, for supporting the OurDNA project and helping us to address the underrepresentation of Filipino Australians in genomics research.

Appendix 1: presentation slides

Co-Designing the OurDNA program outreach & communication with Filipino Australians in Sydney -

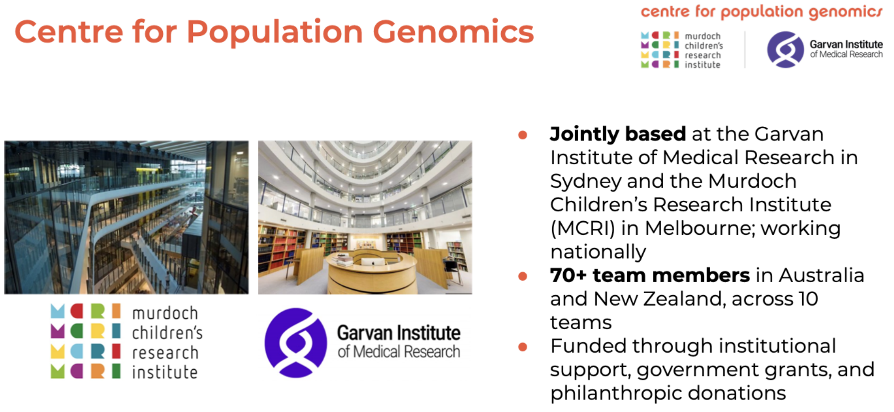
Introduction

29 March 2023
Maia Ambegaokar, Lead - Inclusive Genomics, CPG



Inclusive Genomics Team

Maia Ambegaokar Lead	Samantha Croy Senior Communities Specialist	Rafal Shouly Community Engagement Organiser	Shenei Penaia Community Engagement Organiser



Centre for Population Genomics

- **Jointly based** at the Garvan Institute of Medical Research in Sydney and the Murdoch Children's Research Institute (MCRI) in Melbourne; working nationally
- **70+ team members** in Australia and New Zealand, across 10 teams
- Funded through institutional support, government grants, and philanthropic donations

CPG's Purpose

*To establish **respectful partnerships** with **diverse communities**, collect and analyse genomic data at **transformative scale**, and drive **genomic discovery** and **equitable genomic medicine** in Australia*

The power of genomic medicine

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- Improve medical **diagnosis**
- Improve **prediction and prevention** of illness
- Improve disease **treatment**

*...but for the impact of genomic medicine to be equitable, these tools need to be accessible and useful to everyone **regardless of their ancestry.***

Diagnosing genetic diseases

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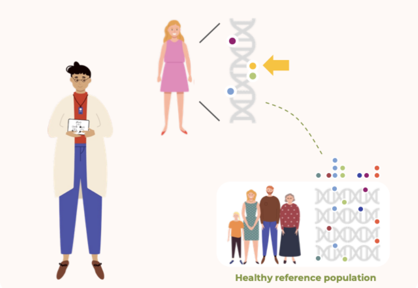
To diagnose a **genetic disease**, we look for genetic variants in the patient that are rare or absent in **healthy people**



- At present, maps of healthy variation are based on only some groups of people, mainly **European** or **American**, and some **East Asian** and **South Asian**.
- This means when someone of an **underrepresented group** has a serious genetic illness, it is often **much harder** to pinpoint which change causes their disease.
- Lack of a diagnosis has **implications for treatment**, access to **clinical trials**, and many other aspects of healthcare
- It also makes it less likely that future treatments for these diseases will benefit patients from under-represented communities

A problem for Australia

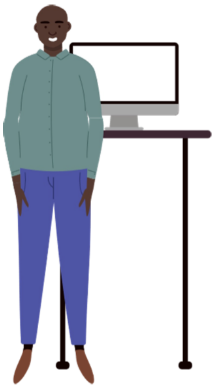
- Existing global resources of genetic variation, mainly built in the US and UK, **don't include many large Australian communities**, spanning several million Australians
- This results in **inequity in access** to accurate diagnosis and future developments in genomic medicine
- If we fail to address this, the impact of genomic medicine will **exacerbate existing health inequities** - leaving many Australians behind

OurDNA: an Australian medical genomics research program

The **OurDNA** program will build genomic resources for ancestry groups currently unable to benefit fully from genomic medicine.

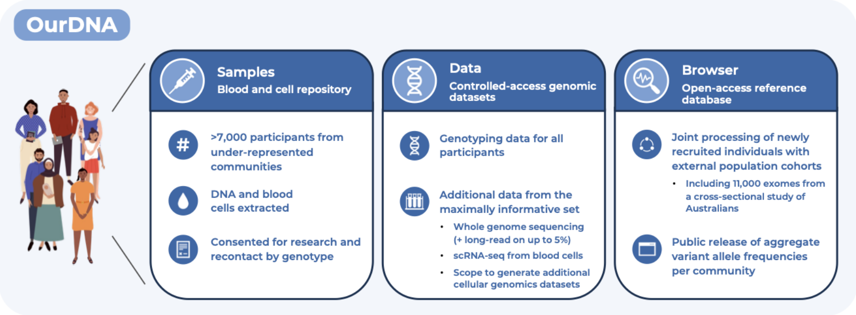
Our plan:

- to **engage underrepresented ethnic communities** to understand their needs and views with regard to communications and outreach
- to **recruit over 7,000 individuals from these communities** and collect DNA and cells to create a new, more representative resource
- to **make data available in a way that improves diagnosis** of patients from these communities while respecting individual privacy



OurDNA: CPG's flagship program

GOAL: work with priority communities, to create co-designed recruitment strategies to build a national resource of genetic variation that better represents the genetic diversity of Australia.



OurDNA

Samples
Blood and cell repository

- >7,000 participants from under-represented communities
- DNA and blood cells extracted
- Consented for research and recontact by genotype

Data
Controlled-access genomic datasets

- Genotyping data for all participants
- Additional data from the maximally informative set
  - Whole genome sequencing (+ long-read on up to 5%)
  - scRNA-seq from blood cells
  - Scope to generate additional cellular genomics datasets

Browser
Open-access reference database

- Joint processing of newly recruited individuals with external population cohorts
  - Including 11,000 exomes from a cross-sectional study of Australians
- Public release of aggregate variant allele frequencies per community

Some Partners

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- We have established a number of **high-impact partnerships** with key local and international stakeholders and organisations
- These partnerships span **academia**, **not-for-profits**, **philanthropic** organisations and **industry**

BROAD INSTITUTE
Google
Sano
illumina
Microsoft
SONIC HEALTHCARE
Australian Red Cross Lifeblood
Australian Genomics
GENV
SaxInstitute
45 and Up Study
INVITAE
FECCA
VCGS leaders in genetic health
Ethnic Communities' Council of NSW Representing All Communities

Prioritising our engagement

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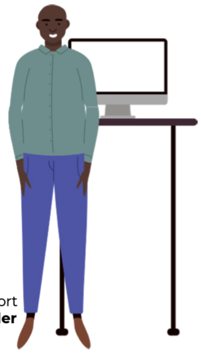
- A careful assessment was made to prioritise Australian communities for the initial OurDNA engagement
- Prioritisation inputs:
  - Under-representation in existing global databases
  - Size of each community from the Australian census
  - Clinical need based on a survey of Australian clinicians
  - Inclusion of groups from all under-represented regions
  - Partnership with Lifeblood
- Top priority regions: **Oceanian, South-East Asian, Middle Eastern,** and **East African**
- Beginning with Australians from these ancestries: **Samoan, Fijian, Tongan, Filipino, Vietnamese, Lebanese,** and **Sudanese**
- We will also work closely with the **CONNECT consortium**, a national Indigenous-led effort focused on improving representation of **Australian Aboriginal and Torres Strait Islander** peoples in genomics



What will participation in the OurDNA program mean for the Filipino community?

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- The **OurDNA Browser** will eventually support improvements in the **diagnosis of Filipino (and other) families affected by rare disease**
- The program will provide a foundation for future, larger projects that will improve the **prediction of risk for common diseases** such as heart disease or diabetes
- The **OurDNA Samples** resource will be used to identify **genes that might be important for the development of new therapies** and help to identify those who will benefit the most from particular treatments

Stage 1: Filipino Australians in NSW

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PCCNSW
WWW.PCCNSW.ORG.AU

- Collaborating with the Philippine Community Council of NSW
- Co-designing communication and outreach approaches:
  - Preferred communication channels
  - Messaging (content and format)
  - Locations and special events where community members can be reached
  - How people react to the information and consent materials
- Goal to recruit first 100 participants in June – July 2023

Agenda – co-design session

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- Refreshments & signing consent forms
- Introductions and project overview
- **Part 1: Participant journey**
- Short break
- **Part 2: Locations/events & communication channels**
- Distribute "thank you" vouchers

Next steps

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- Seeking volunteers!

  Read OurDNA program information & attend online workshop on Monday evening

  (receive $100 voucher)
- Summarise findings and share with you all
- Identify issues for further consultation

Thank you!

Appendix 2: Workshop 1 post-its and comments from Participant Journey exercise

1. Learning about the project

- Social media e.g., Facebook, Instagram
- Church gathering
- Filipino restaurants
- Events: Independence Day celebration, fiesta
- Filipino line dancing
- Filipino language class via zoom
- Venues: local, near public transport, community halls
- Frequency reading info about the project
- Recruit wider, group/demographic, families
- Community groups
- Sporting activities
- Contact Filipino GPs
- Different Filipino community newspapers
- Australian Filipino doctors should be involved in this project
- Info sessions, forum, Fiestas
- Filipino radio like SBS
- School bulletin board, medical centres
- Contacts of PCCNSW
- Different meeting locations to be more accessible to more broader audience
- Contact the Illawarra Filipino multicultural women's group Wollongong
- After church

2. Reading explanatory materials and consent form

- Would a brochure be a good way to start to disseminate necessary information for this project?
- Reading material might be good because not all know how to use computers and by reading, they can read during their spare time anywhere
- Language? Yes – no, translated in different Filipino dialects
- Material Pilipino Tagalog
- Consent form
- Audio, Filipino dialects
- Information materials to be simpler
- Presentation/ slides/ profile in Facebook or YouTube, social media
- Someone available to answer my consent questions
- QR code scanning will direct to the website
- The outcome will be very interesting

3. Giving consent

- What age group should we target?
- Why don’t we get the needed data from the hospital system?
- Clear statements – can I get a copy of results.
- Simple explanation in Tagalog/ Filipino
- As a volunteer can I get the result
- What about those unable to give consent

- Who benefits the outcome of the research? e.g., GPs?
- Refer back
- Electronic/ digital paper – copy of results accessibility
- Hard copies only seen by participants (legal docs) some people more comfortable
- Hard copy by post
- To consider: can we do everything electronically
- Why only 18 and over?
- Seniors with computers > older people might freak out with digital consent
- Communal findings for the community
- Can I find out why my father passed away at a younger age

4. Giving blood sample (30ML)

- Is this a one off (30 ml) collection?
- No dramas: good for next generation to come
- Protecting the samples
- Will stem cell be collected of the DNA project
- Target different age groups
- How often do we give blood sample
- How about getting existing blood sample data from GPs or blood labs with consent?
- Collaboration with Filipino GPs
- Safeguarding people's privacy
- How many times do we provide a sample?
- Giving blood sample collection
- When do we go to blood collection
- How many blood test they can make in 30ml
- Do we have to go through a GP
- Is it only one lab that does the testing
- Do we need to fast
- Can we access results or blood samples?
- Reservation of giving blood samples – ensuring that results are completely confidential

Appendix 3: Workshop 1 post-its and comments from Locations & Events exercise

- Sporting events > tennis > golf > basketball >
- Church gathering
- Shopping centres, cafes, restaurants, beauty salons
- Community meetings, organisation meeting
- Charity events
- Toastmaster Club gathering, rotary, PCC all clubs
- Parks > picnic
- Blacktown market “drive in”, Blacktown showground
- Dinner dance, club, RSL
- Zumba, gyms, swimming pools
- Family events, parties, excursion
- Libraries
- Transport > trains > buses
- Zoom meetings

Appendix 4: Workshop 1 post-its and comments from Communication Channels exercise

- Facebook
- Messages
- YouTube
- LinkedIn
- Travel agents
- Asian shops/ Book shops etc.
- Newspaper
- TikTok
- Filipino Fiesta
- Money exchange
- Community Newspaper PCG
- Radio whilst driving
- Word of mouth
- Filipino community leaders
- Religious organisations/Churches
- Kiss FM
- CNN
- SBS
- Filipino doctors, GPs
- Bowling/Tennis
- Education flyer

Appendix 5: Workshop 2 Comments on OurDNA Portal Website Screenshots (Landing page, contact us, and screening questions)

- It grabs people's attention
- It is straightforward
- It is readable and understandable
- There are not a lot of distractions with colours
- Would be good to enlarge the font and provide other accessibility options
- It is good that contact details are provided to participant in the Contact Us pop-up
- It would be good to provide participants with an estimate of how long it will take to fill in
- Regarding screening question about genetic illness in family, what if people don't know that the condition their family member has is genetic? Should a longer list of examples be provided?
- Make it clear on the website that participants will be given a $100 voucher
- Have a video summarising what people need to know to decide to take part.

Appendix 6: Workshop 2 Comments on OurDNA Portal Website Content

- It would be beneficial to have portal registration verification confirmed using mobile phone numbers rather than emails to avoid access from overseas
- Not everyone wishes or will be able to print out a referral form to organise blood sample donation
- Some people may need help to register online
- It is good that people can change their minds and withdraw if they wish
- It would be useful for participants to be able to review and edit their answers later
- It would be good to be able to save and continue later
- Some people will access the website on their phones, so it is good that it will be mobile friendly
- Required questions in portal are helpful for participants to ensure portal completed properly and will prompt participants if this isn’t done

Appendix 7: Workshop 2 Comments on OurDNA participant facing materials

Communications for participants and recruitment materials

- To make it stand out for a Filipino user, have a highlighted headline in Tagalog (e.g. use words like ‘genetika’, ‘salina’, ‘Pinoy’,‘Filo’). This would be eye catching and relatable to people.
- Don’t confuse people if they are not eligible e.g. not NSW resident or an Australian citizen or permanent resident; don’t mislead people into joining
- Mention upfront why we are prioritising or starting with Filipino community

OurDNA flyer/ poster

- Have more clearly identifiable Filipino characters (e.g. characters could wear traditional Filipino dress like baro't saya or barong tagalog)
- Other Filipino images e.g. native Filipino house, jeepney
- Could include the Filipino flag or the colours of the flag
- Make the word “Identify as Filipino” in bold or highlight it

Reminders and follow up communications for participants

- Note that Douglass Hanly Moir Pathology is only in Sydney. The Sonic Healthcare branches in Blue Mountains and Wollongong etc. have different names.
- Reminder provided to participants should state correct name of local pathology laboratory