centre for population genomics

murdoch children's research institute

Garvan Institute of Medical Research



Melbourne's workshop



Sydney's workshop

Co-Designing OurDNA with the Australian Lebanese Community

May-July 2025

Acknowledgements

We acknowledge the First Australian peoples on whose traditional lands we live and work across the country and pay our respects to their elders, past and present. We gratefully accept the invitation in the Uluru Statement from the Heart "to walk with us in a movement of the Australian people for a better future".

Broadmeadows, the site of the Melbourne co-design workshop, is located on the traditional lands of the Wurundjeri Woi-wurrung people. Carramar, the site of the co-design workshop, is located on the traditional lands of the Cabrogal people, who are a sub-group of the Gandangara nation.

At CPG, we celebrate and respect diversity in our team and our work. We believe that including all human diversity in genomic research will empower medical care that benefits everyone.

The OurDNA Lebanese community co-design team extends its sincere appreciation to all members of the Melbourne and Sydney Lebanese Australian communities who contributed their time, perspectives, and feedback during the OurDNA co-design workshop. The Melbourne workshop was held on 13 May 2025 in Broadmeadows, the Sydney workshop on 17 May 2025 in Carramar, and the youth workshop on 20 July 2025 online.

In Melbourne, we extend our appreciation to **Lina Hassan, Leila Alloush** and the team at **Victorian Arab Social Services (VASS)** for generously hosting the session and providing a trusted, community-based venue for discussion. We also thank **Will Abdo** for his valuable advice in the early stages of the team's community outreach. In Sydney, we also extend our acknowledgement to **Kamal Hadid, Wafa Jeha, and Amira Issa** for their guidance and support leading to the planning and facilitating of the Sydney workshop. We also like to extend our thanks to **NSW Service for the Treatment and Rehabilitation of Torture and Trauma Survivors (STARTTS)** for generously hosting the session.

We would also like to thank our youth co-leads collaborators, **Abdul Aziz Khoder** and **Georgette Mouawad** for their contribution in initiating, leading, and facilitating the online youth co-design session.

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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 aims to increase the representation of Australians of Lebanese background and other multicultural communities in genomics research and datasets.

Genomic medicine, which uses the information in genes, is a field that is rapidly growing and delivering better prediction, prevention, diagnosis, and treatment of disease. Improving representation will ensure that all Australians, including the Lebanese community, can benefit from advances in genomic medicine. More information about CPG and the OurDNA program can be found in the presentation slides in Appendix 1.

Melbourne and Sydney Lebanese Communities

According to the 2021 Census, 248,430 Australians reported Lebanese ancestry, and 87,343 were born in Lebanon. In New South Wales, 63,293[1] people were born in Lebanon, with 49,200 people of Lebanese ancestry. Of this figure, 61,620 people live in Greater Sydney and Inner South West, including Canterbury-Bankstown and surrounding areas.

Victoria is home to around 49,100[2] people of Lebanese ancestry, including 18,689 born in Lebanon. Most live in Melbourne's north-west and inner northern suburbs, particularly in the Cities of Hume, Merri-bek, and Whittlesea. Local population focuses include Broadmeadows, Campbellfield, Lalor, Glenroy, Hadfield, Meadow Heights, and Dallas.

[1] https://www.abs.gov.au/census/find-census-data/quickstats/2021/4208_1
[2] https://www.vic.gov.au/lebanese-community-profile#lebanon-born-population

OurDNA’s approach to engaging communities in genomics research

OurDNA follows a community-based participatory approach, building partnerships and working closely with community members to build genomics resources that are more representative of Australian communities. Co-design is a key part of OurDNA’s work, meaning that community members guide CPG to develop an approach to engagement and recruitment that meets the needs of community members and facilitates their participation in the program.

The OurDNA Community Engagement team started by familiarising themselves with the Lebanese community in Melbourne, including active community organisations, leaders, health professionals, and community networks. Engagement with the Australian Lebanese community began in mid 2024, when the team reached out to active community-based organisations.

Outreach and Early Engagement

Melbourne

Based on guidance from Will Abdo at the Australian Arabic Council, the team reached out to Leila Alloush and Lina Hassan at the Victoria Arab Social Services (VASS). After an initial meeting with VASS, the OurDNA team was invited to present an information session to a VASS Lebanese women's group on 24th September 2024 attended by 30 women. The presentation was delivered in English by Chris Richards, the OurDNA program lead, and in Arabic by Rafal Shouly, the OurDNA Community Engagement Organiser.



Through an OurDNA team member, Lebanese community member Bereha Khodr, who has a background in medical science and strong community links, was engaged to collaborate on the co-design with the Melbourne Lebanese community. Working with the OurDNA team, Bereha led the planning and organisation of the co-design workshop with Lina Hassan from VASS.

Sydney

In 2023, the community engagement team (former Inclusive Genomics Team) held an Arabic focus group to get Arabic-speaking community members' feedback about the translation of culturally aligned participant information and education materials. Community member Kamal Hadid attended the session and expressed interest in supporting the program when it was launched with the Lebanese community.

Later on, OurDNA Community Engagement Organiser Rafal met Amira Issa at The Grand Community Session of Trauma Informed Community Development Initiative (TICDI) on the 24th January 2025, and Amira expressed interest in hearing more about the program. And after a couple of meetings, Amira suggested that we could have an in-language information session on 6 February 2025 for her women's group, inviting women from the Arabic-speaking communities (Jordanians, Palestinians, and Syrians). Amira also suggested bringing Wafa Jeha on board; the information session was delivered by team members Rafal and Luke.

The community engagement team then followed up with Kamal, Amira, Wafa's expressions of interest and engaged them as lead collaborators, holding the co-design workshop in Sydney in parallel with the planned co-design workshop Melbourne.



Workshop Attendees

Melbourne

Presenters and facilitators:

- Bereha Khodr, Co-design Co-Lead
- Lina Hassan, Victorian Arabic Social Services
- Samantha Croy, CPG
- Rafal Shouly, CPG
- Saad Khalid, CPG
- Rachel Thorpe, Australian Red Cross Lifeblood

Workshop participants:

29 participants attended the workshop, seventeen participants wished to remain anonymous.

1. Diela Najjar
2. Rabi
3. Leila Alloush
4. Inaam Barakat
5. Nouhad Barakat
6. Nahia Mawal
7. May Chahal
8. Yasmin
9. Elizabeth Salameh
10. Mohamad Alman
11. Mouna Fouda
12. Mirna Bayat

Sydney

Presenters and facilitators:

- Kamal Hadid, Co-design Co-Lead
- Amira Issa, Co-design Co-Lead
- Wafa Jeha, Co-design Co-Lead
- Samantha Croy CPG
- Rafal Shouly CPG
- Saad Khalid CPG

CPG staff attended the workshop:

- Luke Seesink
- Bronwyn Terrill

Workshop participants:

29 participants attended the workshop, eighteen participants wished to remain anonymous.

1. Rowauda Elfata
2. Zeinab Rababi
3. Mouhammad Tanana
4. Zeinab Farhat
5. Adla El Hassan
6. Fida Mahfouz
7. Iman Awada
8. Kilda Eid
9. Lina Ashkar
10. Hassna Dirani
11. Sarah Mourad

Youth workshop

Presenters and facilitators:

- Abdul Aziz Khoder, Co-design Co-Lead
- Georgette Mouawad, Co-design Co-Lead
- Henry Tamasese, CPG
- Samantha Croy, CPG
- Saad Khalid, CPG

Melbourne and Sydney Workshops Overview

- **Date & Venue:**
  Melbourne - 13 May 2025, Victorian Arab Social Services (VASS), Broadmeadows
  Sydney - 17 May 2025, the NSW Service for the Treatment and Rehabilitation of Torture and Trauma Survivors. STARTTS Carramar

The purpose of the workshops was to gather feedback about the OurDNA participant journey and community members' ideas for OurDNA engagement and recruitment with the Lebanese community in Melbourne and Sydney. Participants signed a consent form in either English or Arabic acknowledging that they understood the purpose of the codesign project and voluntarily consented to participate. We also informed participants that we would be taking photos for use in our reports and other materials and they were able to indicate if they preferred not to be photographed. The session was bilingual and was presented in both English and Arabic, with Rafal Shouly from the CPG team presenting in-language and providing interpreting support throughout the workshop.



Overview of the OurDNA program

After the Lebanese community co-leads (Bereha Khodr in Melbourne and Amira Issa in Sydney) welcomed participants to the workshop, the CPG team introduced the OurDNA Program, explaining the problem of the underrepresentation of many multicultural communities in genomic data and the importance of addressing this problem. The presentation slides for both workshops can be found in Appendix 1. The presentation included an example from the Lebanese community of a young Lebanese community member called Rhonda, who has a genetic heart condition. The story illustrated how having more data from the community could lead to faster diagnosis for community members like Rhonda.

In the first part of the workshop, the team described what would be involved in taking part. This included:

OurDNA eligibility criteria

- Having Lebanese ancestry
- Being 18 years old and older
- Being eligible for Medicare
- Not having a severe genetic condition (e.g. muscular dystrophy or cystic fibrosis)

Participant pathways

- Finding out about OurDNA (e.g. encountering promotional materials online or attending a community information session)
- Signing up and consenting through the OurDNA web or phone app
- Donating a 30 ml blood sample
- Receiving a $100 voucher
- Being able to opt in to receiving results related to their genetics and health
- Requesting updates about the study



Blood sample donation options

- The walk-in pathway where participants consent independently and then visit a Melbourne pathology lab to donate
- Our ‘one-stop shop’ pathway: a community event where participants can learn about the program, receive assistance to consent, and donate, all in one go

Participants were able to ask questions about the program.

Part 1: How we can improve the participant pathway for the Lebanese community

In the first part of the workshop, CPG team members Rafal and Saad presented a scenario of OurDNA being at a community event, and we asked participants the following questions:

- How can we make our events welcoming for community members?
- What would help community members to take part in OurDNA? (e.g. at events or through our walk-in pathway)



Following the advice of the community facilitators, the participants were divided into three groups of 10 for group discussion. Participants were given Post-It notes to write down their suggestions, writing in both Arabic and English. The community facilitators, along with Rafal, Sam and Saad, were dispersed across the groups and noted down additional comments made by the groups as needed to ensure that we had an accurate record of participants' contributions to the discussion. After a short break for refreshments, the team moved on to the second part of the workshop.

Part 2: How we can engage the Lebanese community

Part two followed a similar format to part 1. The team presented a scenario of a Community-led Campaign with Lebanese Australians and gave examples of what the Campaign Activities & Outreach could include. Then we asked the following questions:

- What are the best ways to make the Lebanese community aware about the OurDNA program?
- Who should the information come from?

In the Sydney workshop, Parts 1 and 2 were combined to allow more time for questions and answers. At the end of the session, the facilitators read the Post-it notes back to the whole group and noted down additional suggestions and feedback.

Lifeblood discussion (Melbourne workshop only)



In the third part of the Melbourne workshop, Rachel Thorpe from Lifeblood presented three slides with some information about the importance of blood donation from different ancestry groups (See Appendix 1), and discussed perspectives about blood donation with the group. Lifeblood is a partner on the OurDNA program and is similarly working with multicultural communities to increase the diversity of blood donors.

At the end of the afternoon, the team thanked participants for their time and contributions and each participant was given a $100 Visa gift card as reimbursement.

Overview of online Youth co-design workshop

The team then conducted a follow-up online co-design workshop with youth Lebanese-Australians on the 20th of July 2025.

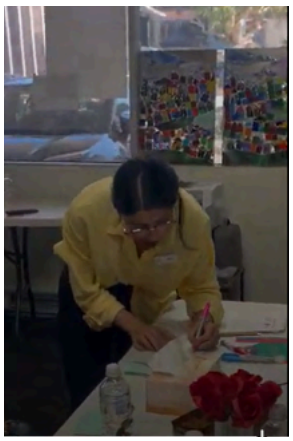
The session was co-lead by Abdul Aziz Khoder and Georgette Mouawad

The participants were broken into two small groups called ‘The Cedars’ and ‘The Dabke Collective’ and each group had a theme and an objective, using Miro board to record their feedback and answers.

Participants were asked to identify sources of health (including genetics) information within the Lebanese-Australian community. They were asked to identify the people, platforms, and places where they sought information about health and where they might see information about genetics. The group discussed why they trusted these sources: what made a source trustworthy, and what were considered red flags. Participants also identified the spaces, events, platforms, champions, groups and organisations where OurDNA should show up.

Summary of findings: Community perspectives on how to engage the Lebanese community in the OurDNA program

Building trust in the OurDNA program



Participants in both Melbourne and Sydney raised the importance of building trust through partnership with **respected community organisations and leaders**. Melbourne participants noted that VASS (Victorian Arabic Social Services) is a very well-known organisation with great insight into the community, and that using the logos and names of trusted organisations could give credibility to the program.

Healthcare professionals were identified as credible sources, with participants emphasising that hearing about the program through ‘community health professionals, trusted leaders, and anyone with credibility’ would be key to getting the Lebanese community on board.

Religious leaders were also considered trusted messengers. A Melbourne participant noted that ‘priests, Sheik[s], have everyone's phone numbers,’ suggesting their reach within community communication networks. A Sydney participant said that who the invitation came from was also important, and that an invitation from a ‘priest, sheikh, or family doctor’ would be influential. Participants in the youth co-design workshop corroborated the importance of who promotes the program, advising OurDNA to avoid ‘blindly advertis[ing]’ as ‘it’s about who posts it as well’.

There was some disagreement about whether politicians should be included. Participants in the youth co-design suggested people tended to trust local government over state or federal government, though one participant suggested that endorsement from independent senator

Fatima Payman would be helpful. However, a participant in the Sydney workshop advised ‘keeping politicians away from this project’.

Participants emphasised the importance of trusted ‘**ambassadors**’ and prominent ‘ **first volunteers/donors**’ who would encourage people to take part. One participant who was in a position to promote the program within the community noted that they would be willing to support the program but that they needed to be ‘convinced first before [they] advocate for this program.’



Several participants in the Melbourne workshop noted the importance of **family and social networks** in supporting community members to take part. Community members themselves would be able to promote the program with their networks by ‘explaining to friends and relatives in a detailed and useful way’, noting that family gatherings could be a way of spreading the word about the program. One participant wrote, ‘by talking about the program, I convince my family to participate. ’

Youth co-design workshop: What builds trust in the Lebanese community

Institutional credibility vs. personal trust: The young people in the online co-design workshop responded to the question of why people trust things from a range of angles. They noted that reputation and credibility mattered (‘BIG NAME!’) and that professional titles could lend a sense of credibility. But they emphasised the importance of relationships. People did not trust ‘ambiguous corporations and institutions’ but ‘people they have personally interacted with’. Participants noted that community members trusted their GPs, especially ones they had known for a long time, that the ‘whole family’ trusted.

Community-based trust networks: They noted that Lebanese people were community- rather than individual-focused, ‘so we trust people we know and those we already trust who have vouched for particular medical opinions’. They emphasised relationship-building and noted that it was ‘hard to separate love of food (as [a] way of bonding)’. They felt trust-building would be more readily achieved by someone who shared a Lebanese background.

Generational dynamics and informational differences: With several medical students in the group, the participants noted that they trusted research and evidence. They emphasised, though, that ‘respect for elders’ was an important value in the Lebanese community, including respecting the opinions of older community members. They thought that the older generation was less inclined to trust medical science and accessed sources of information that the participants thought might be less reliable. For example, they said that language was a barrier and older community members were less likely to access ‘online medical sources’. The young people suggested that the mode of delivery matters too, noting that ‘we are an oral-based tradition, which emphasises local community'.

Health perspectives and recent experiences: The participants suggested that ideas of health were tied to agricultural traditions and the natural world, and that ‘people see labels like 'natural' and 'organic' as reliable’. They thought that older community members might be more sceptical of pharmaceuticals, especially of the idea of the profit motive. One participant linked this scepticism to the way things were mismanaged during the COVID pandemic, where there was ‘not enough targeted information towards MENA communities’ that appropriately and accessibly explained the vaccine e.g. 'what is it', 'why you should trust it', 'why you should do it'?



Information, communication, and language needs

Participants emphasised the importance of having properly compensated **bilingual and bicultural staff** who could provide language support. There was a specific preference that interpreters be of Lebanese background and able to converse in the **Lebanese dialect**. In Melbourne, a participant recommended ‘clear Lebanese [interpreters] like Elizabeth Salama, precise and clear recitation, like Inaam Barakat’.

Simple explanations of genomics were appreciated, and having materials in **Arabic** was essential. Participants also recommended the use of multimedia (e.g. ‘Story telling: use media + storytelling, short videos’ and ‘Explain the definition of genomics (illustration, mapping, pictures)’.

Following the short introduction to OurDNA, participants noted several practical areas that they wanted **more information** on, including:

- How long the research would take
- How participants' confidentiality would be maintained
- What the risks of the research were and how the benefits outweighed the risks
- How community members with low literacy in English and Arabic could consent to taking part
- Assurances of confidentiality, which were seen as essential for building trust and encouraging participation
- How the benefits outweigh the risks
- How participants could obtain information about their genes

Sydney Workshop: Specific trust concerns and transparency needs

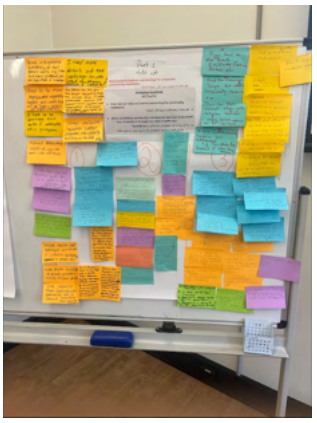
The Sydney workshop involved a robust discussion about trust in medical research within the community. Participants located likely community concerns within the context of a lack of transparency around the COVID-19 vaccine and in Australian leaders' response to the Israel-Palestine conflict, which participants described as having broken trust in Western institutions.

Research governance and ethics: Participants identified concerns about misuse of the results and unethical research, security of the blood collection process, and whether the research aligns with religious beliefs. They also raised questions about why certain institutes or companies are involved, such as why Douglas Hanly Moir was chosen as a pathology provider.

Institutional trust: Participants raised potential concerns about organisational affiliations. They identified that the Murdoch Children's Research Institute might be perceived to be affiliated with the Murdoch press, leading to the fear that information might be misused.

Need for transparency: Participants wanted greater transparency about funders, partners, and users of the data, as well as more information about research governance, data security and confidentiality, and protocols to prevent unethical use of blood samples. Participants requested 'clarity of objectives' and transparency about agendas. They noted that the program could build trust by addressing community concerns directly.

Participants in both Melbourne and Sydney workshops appreciated the story about Rhonda presented in the introduction. They emphasised the importance of sharing **real-life stories** like Rhonda's to demonstrate how the research could lead to better medical care for the community. More examples to 'show people evidence on how this DNA testing will benefit and has worked' would raise awareness and build confidence in the program.



A Sydney participant wrote: 'Stories like Rhonda's would help show that participation in these programs has amazing results & can help decrease mistrust. Perhaps interviews with these families could help as well.'

Participants were interested to learn more about:

- Particular health conditions and genetic diseases
- More detailed information on how the research would benefit the community
- How future research could prevent people from getting sick in the future

Youth perspectives on Lebanese Australians' health information seeking

Individual sources of information

- Local, long-time, trusted GPs with whom they have a good rapport
- Family members, friends, and others with a medical background
- Religious leaders/sheikhs with backgrounds in health and wellbeing
- Online dieticians
- People who have had experiences/symptoms
- Parents and other family members
- Reporters
- Talk show hosts (e.g. Dr Oz, Dr Phil, Oprah)

Places where community members feel comfortable talking about health

- Doctor's clinic
- Hospitals, to some extent
    - (participant comment: 'Many people I know don't trust hospitals')
- Religious places
- With friends

Online platforms where they look for information

- Medical websites like WebMD and the Mayo Clinic website
- RACGP guidelines
- Google and Google search AI mode
- AI chatbots like ChatGPT and Grok
- Social media (e.g. WhatsApp, Facebook, Instagram, TikTok)
- Channel 7 and 9 (parents)

Outreach Channels and Community Venues



Workshop participants recommended the dissemination of information about OurDNA via radio, social media, newspapers, organisations, community venues and events. They noted that multiple approaches were needed to reach different segments of the community effectively.

Age-based differences were highlighted in the Melbourne and Youth co-design workshops. Participants noted that 'young people don't listen to radio or read newspapers' while suggesting that 'youth groups depend on social media.' For older community members, participants recommended reaching out 'through radio, centers, health centers'. One suggestion was to distribute flyers in Arabic through healthcare facilities with a participant writing: 'Don't like website + links not good in technology'.

Youth participants provided detailed platform breakdowns: older community members primarily use Facebook, WhatsApp, and get their health information from news on TV (Channel 7/9), while younger people use Instagram, TikTok, and Snapchat.

Melbourne Workshop: Understanding diversity within the community

Tailoring to sub-cultural groups: Participants noted that the Lebanese community was diverse and OurDNA would need to 'tailor [the approach] for subcultural groups'. The program should design activities that take into consideration 'age, subcultural [group] and background'. Participants emphasised understanding 'religious differences, political differences, village differences.'

Lebanese villages and suburb settlement: It was also noted that the suburbs where the Lebanese community has settled in Melbourne correspond to their villages of origin in Lebanon.

Participants identified multiple venues and channels for reaching different segments of the Lebanese community. **Media channels** included:

- SBS radio
- Middle Eastern radio stations
- Local newspapers
- YouTube commercials (e.g. via the No Garlic, No Onions channel)
- Arabic TV

Outreach could include social media pages of important **community organisations**, as well as community pages such as those linked to particular Lebanese villages such as Mish Mish (a village located in Akkar, Lebanon). Community organisations, services, charitable and religious associations provided established networks for outreach. Some specific examples participants provided included:

- Victorian Arabic Social Services (VASS)
- United Lebanese Council
- Arab Council Australia
- Australian Lebanese Chamber of Commerce
- Lebanese Australian Association
- Whittlesea and Epping Community Connection
- HAYA (Hyderabadi Australian Youth Association).
- SSI (Settlement Services International)
- Village associations (e.g. Imar Hall and Dar Al Awda)
- Sport clubs (e.g. Glenroy Football Club)



Potential community champions and influencers

- Athletes: Bachar Houli, Adam Saad
- Religious leaders: Bilal Assad, Mohammed Hoblos, Abdul Abu Hamsa
- Samira from Masterchef

Healthcare facilities represented trusted venues for information dissemination. Participants suggested connecting with ‘clinics, hospitals where there are doctors of Lebanese background’ and providing Arabic-language flyers. One participant also suggested reaching out to aged care service providers. Specific facilities mentioned included:

- St. Vincent Hospital (Participant comment: ‘has a list of Arabic-speaking doctors’)
- Resolve Medical Centre in Coburg

A participant in the youth co-design workshop warned that active recruitment in hospitals could feel 'exploitative' of vulnerable patients.

Religious venues and religious organisations were also frequently mentioned, with suggestions to approach ‘religious places, churches on Sunday/Mosques on Friday.’ Specific venues identified included:

- Preston Mosque
- Alawi Social Centre
- St. George Orthodox Church, Thornbury,
- Meadow Heights Mosque
- Thornbury Maronite Church
- HIYC (Hume Islamic Youth Centre), Roxburgh Park.

Participants noted that **educational institutions** were also considered to be pathways for reaching community members. They noted that in some suburbs, 80% of students in some schools were of Lebanese background, and this would be a good way to reach their parents. Participants also suggested engaging college students, including those at:

- Kangan TAFE
- Holmesglen
- Other RTOs and TAFEs
- Victoria University
- Lebanese societies at universities
- Young Australian Lebanese Association (YALA) at UNSW, University of Sydney, and UTS

Other community venues
Lebanese cafes and restaurants (e.g. Al Alamy, A1 Bakery, EL Jannah, Mount Lewis Pizzeria, Tibbas, Acai shops) Gyms

Events

- Human Appeal events sponsorships
- BBQs
- Community festivals (e.g. Eid, Easter)
- Community markets (e.g. Ramadan night markets)
- Village Eid
- Music events
- Open day at mosques and churches

Event design and practical support

Participants requested more **information sessions** in language to tell people about the project in a simplified way; they emphasised avenues for conveying accurate information. The inclusion of knowledgeable professionals of Lebanese background would help make the case that OurDNA was an impactful initiative for the future Australian Lebanese community. A Sydney participant suggested 'holding awareness sessions by specialists to explain the importance of this project', suggesting that this would prevent 'misleading information' from circulating. These sessions could promote the benefit of the program, drawing on 'examples from the Lebanese community'.

A participant in the Melbourne workshop noted that having team members equipped to answer questions who could 'explain the content perfectly' and provide 'new and valuable info' would be helpful. Further, it was seen to be important to have people available during the consenting process to answer any questions that OurDNA prospective participants might have.

Participants had many practical suggestions for how OurDNA could organise events that would be welcoming for the community. Community members could learn about the program when visiting **trusted community organisations**, which could also host OurDNA events with appropriate funding. Participants suggested multiple event options to cater to a range of preferences. In-person gatherings were valued with someone on hand to 'answer your questions', while one participant suggested online information sessions could also be useful.



Participants also suggested 'piggybacking on **existing events**', and suggested that OurDNA should be present at key community events. There was a suggestion to have 'mobile caravans or booths'. The team should be 'familiar with community activities taking place, such as Eid al-Adha', and the 'timing needs to suit the community'.

Awareness of cultural practices would be key, and including Lebanese cultural elements such as "**good music, Dabke group and free food**' would make events welcoming to community members. One participant recommended making the events lively: 'The happy noise that attracts the crowd to the event, shows that it is the event/practice, not to miss out'. Providing food was considered to be important; for example, a 'light lunch' would be appreciated.

Participants noted some people might 'feel more comfortable' in 'smaller groups'. Events held on the weekend would be accessible to more people. To further **increase accessibility**, particularly for those unable to attend festivals, one participant suggested the option of 'in-home collection'.

Participants noted that **reimbursement** for time and travel would be helpful, as well as providing 'transport options'. While one participant noted that mentioning the incentive provided would capture people's attention in outreach materials, on the other hand, some noted that the $100 voucher might also be seen as a bribe. A participant in the youth workshop said they had mixed feelings about the incentive, wondering whether it might be

coercive. One participant recommended that the team 'clarify that the $100 incentive is not a bribe, it is only a small token of appreciation'. Participants also suggested other tangible benefits, with one person suggesting a card that could help with DNA testing when accessing healthcare.

A full list of the Post-It notes written in English and Arabic with translations can be found in Appendix 2 here.

Conclusion

Community members' feedback and their ideas summarised in this report will inform the OurDNA Program's community engagement and recruitment approaches with the Lebanese community in Melbourne and Sydney. The team is dedicated to increasing awareness about genomic medicine and advocating for underrepresented communities to be involved and take leadership in this effort. The team will actively seek further opportunities to plan information sessions, raise awareness and understanding. Based on the above findings, the Community Engagement Team has initiated the following steps and will continue to incorporate community feedback into future planning with the Melbourne Lebanese community.

Next steps

Following the co-design workshop, the OurDNA Community Engagement team incorporated community feedback and undertook some further steps including:

- **Establishment of Community Liaison Officer roles:** Based on community feedback regarding the need for a trusted individual with a health and research background, the team established this new position. *(On-going)*
- **OurDNA Lebanese Community Leaders Dinner in Melbourne:** The team hosted a dinner attended by approximately 16 people, including community leaders, representatives, health professionals, faith leaders, and community-based media representatives. Attendees showed interest in the program, expressed support, and were keen to share information with their networks. *(Completed)*
- **Connect and partner with well-established and trusted community organisations:** OurDNA partners including Victorian Arabic Social Service VASS in Melbourne and the Arab Council Australia ACA in Sydney initiated a couple of 'one-stop-shop' events. The events introduced community members to the OurDNA program. Interested community members engaged with a team member to learn about the program, provided consent with support from bicultural workers, and enjoyed Lebanese catering. *(On-going)*
- **On-going consultation sessions:** are being planned with various groups to gather their on-going insights for the program improvement. *(On-going)*
- **Sharing lessons learnt and best practices with the wider community**: publishing reports and connecting with relevant mainstream and grass-roots media platforms and community partner networks. *(On-going)*

Appendices

Appendix 1: presentation slides

Melbourne's slides



centre for population genomics

murdoch children's research institute

Garvan Institute of Medical Research

Co-Designing OurDNA outreach & communication with the Melbourne Lebanese Community

Samantha Croy (CPG)
Rafal Shouly (CPG)
Saad Khalid (CPG)
Bereha Khodr (Lebanese Community co-lead)
Rachel Thorpe (Life Blood)

المشاركة في تصميم طرق التواصل والتوعية الخاصة بـ OurDNA مع المجتمع اللبناني في ملبورن



Acknowledgement of Country

بيان الاعتراف بالسكان الأصليين للبلد



Agenda – co-design session

centre for population genomics

murdoch children's research institute | Garvan Institute of Medical Research

- Introductions and project overview
- **Part 1: How we can improve the participant pathway for the Lebanese community**
- Short break
- **Part 2: How we can engage the Lebanese community**
- Lifeblood discussion



جدول الأعمال – جلسة التصميم المشترك

مقدمة ونظرة عامة على المشروع

الجزء الأول: كيف يمكننا تحسين خطوات المشاركة للمجتمع اللبناني

استراحة قصيرة

الجزء الثاني: كيف يمكننا إشراك المجتمع اللبناني

مناقشة: Lifeblood

Centre for Population Genomics

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murdoch children's research institute

Garvan Institute of Medical Research

- Jointly based at the **Garvan Institute of Medical Research** in Sydney and the **Murdoch Children's Research Institute** in Melbourne
- **50+ team** members in Australia and New Zealand
- **Not-for-profit research initiative** Funded through institutional support, government grants, and philanthropic donations

Centre for Population Genomics مركز

مقر المركز المشترك في معهد **Garvan** للأبحاث الطبية في سيدني

ومعهد **Murdoch Children's** لأبحاث في ملبورن

50 عضوًا في الفريق في أستراليا ونيوزيلندا

مبادرة بحثية غير ربحية ممولة من خلال الدعم المؤسسي والمنح الحكومية والتبرعات الخيرية

Our Mission

We believe **everyone** should benefit from advances in genomic medicine

مهمتنا

نحن نؤمن أن الجميع يجب أن يستفيدوا من التقدم في الطب الجينومي



What is genomic medicine?

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- It is a field that is **rapidly advancing** and becoming **routine healthcare**
- Relies on understanding the **genetic variation in healthy populations**
- Clinicians and researchers need to understand healthy variation from **people of all ancestries**



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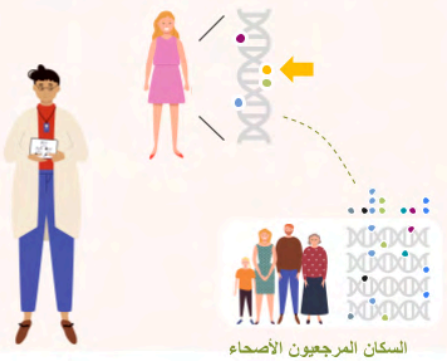
ما هو الطب الجينومي؟

إنه مجال **يتطور بسرعة** ويصبح من ضمن روتين **الرعاية الصحية**

يعتمد على فهم **التباين الجيني (المتغيرات الجينية) في السكان الأصحاء**

يحتاج الأطباء والباحثون إلى فهم التباين الصحي بين **الأشخاص من جميع الأصول**

لتشخيص مرض وراثي، نبحث عن المتغيرات الجينية في المريض والتي تكون نادرة أو غائبة في الأشخاص الأصحاء



السكان المرجعيون الأصحاء

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What are the benefits of genomic medicine?

ما هي فوائد الطب الجينومي؟

- Improve medical **diagnosis** — تحسين **التشخيص** الطبي
- Improve **prediction and prevention** of illness — تحسين **التنبؤ والوقاية** من المرض
- Improve disease **treatment** — تحسين **علاج** المرض

So...what's the issue?

إذن ما هي المشكلة؟

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Millions of Australians are not represented in genomic resources

- Existing global genetic databases **don't represent dozens of Australian multicultural communities**
- These communities will be **less likely to access and benefit** from genomic medicine

Global availability of genetic data by ancestry group of origin



Underrepresented regions: East Africa, Middle-East & North Africa, Oceania, South-East Asia

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ملايين الأستراليين غير ممثلين في الموارد الجينية

التوافر العالمي للبيانات الجينية حسب مجموعة الأصول الأصلية



لا تمثل قواعد البيانات الجينية العالمية الحالية **عشرات المجتمعات الأسترالية متعددة الثقافات**

ستكون هذه المجتمعات **أقل قدرة على الوصول إلى الطب الجيني والاستفادة منه**

المناطق غير الممثلة: شرق أفريقيا، والشرق الأوسط وشمال أفريقيا، وأوقيانوسيا، وجنوب شرق آسيا

When someone from an underrepresented group has a serious genetic disease, it is often difficult to identify the genetic change that is causing their disease.

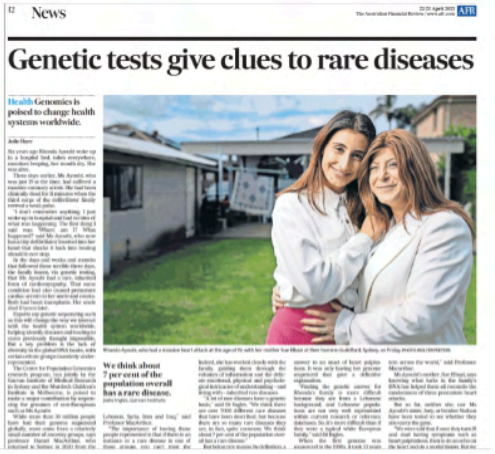
As an example;

- Rhonda, a young Lebanese-Australian community member, suffered from a sudden serious heart attack
- Luckily, she was able to be revived and survived
- Later, her family discovered through genetic testing that Rhonda had a rare, inherited heart condition
- It took longer for Rhonda to be diagnosed due to a lack of genetic data for Middle Eastern communities
- Experts say “a key problem is the lack of diversity in the global DNA banks, with certain ethnic groups massively unrepresented."

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News

Genetic tests give clues to rare diseases

Health Genomics is poised to change health systems worldwide.

We think about 7 per cent of the population overall has a rare disease.

على سبيل المثال، عندما يعاني شخص من مجموعة غير ممثلة من مرض وراثي خطير، فغالبًا ما يكون من الصعب تحديد التغيير الجيني الذي يسبب مرضه

على سبيل المثال؛

- رواندا، شابة لبنانية أسترالية، أصيبت بأزمة قلبية خطيرة مفاجئة
- ولحسن الحظ، تمكنت من إحيائها والبقاء على قيد الحياة
- لاحقًا، اكتشفت عائلتها من خلال الاختبارات الجينية أن رواندا تعاني من حالة وراثية نادرة في القلب
- استغرق تشخيص مرض رواندا وقتًا أطول بسبب نقص البيانات الوراثية لمجتمعات الشرق الأوسط
- يقول الخبراء: "إن المشكلة الرئيسية تكمن في نقص التنوع في بنوك الحمض النووي العالمية، مع وجود مجموعات عرقية معينة غير ممثلة بشكل كبير".

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News

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OUR DNA
AUSTRALIAN GENETIC DIVERSITY DATABASE

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The OurDNA program is an Australian health research program. It will build resources to ensure multicultural communities benefit from genomic medicine.

برنامج OurDNA هو برنامج بحث صحي استرالي . يهدف هذا البرنامج إلى بناء الموارد اللازمة لضمان استفادة المجتمعات المتعددة الثقافات من الطب الجيني



The OurDNA Program

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Our plan:

- to **engage underrepresented multicultural communities** to understand their needs and views with regard to communications, outreach and recruitment.
- to **recruit thousands of individuals from these communities,** collect a blood sample and information
- Store **DNA and cells** to create a new, more representative resource
- to **make resources available in a way that improves diagnosis** of patients from these communities while respecting individual privacy.

Starting with seven Australian communities

- Filipino, Vietnamese, Samoan, Fijian, Tongan, Lebanese, and Sudanese and South Sudanese
- We need **1000 people** from each community

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برنامج OurDNA

خطة عملنا:

إشراك المجتمعات المتعددة الثقافات غير الممثلة لفهم احتياجاتها ووجهات نظرها فيما يتعلق بالاتصالات والتوعية والتسجيل

تسجيل الآلاف من الأفراد من هذه المجتمعات، وجمع عينة دم ومعلومات

تخزين الحمض النووي والخلايا لإنشاء مورد جديد أكثر تمثيلاً

توفير الموارد بطريقة تعمل على تحسين تشخيص المرضى من هذه المجتمعات مع احترام الخصوصية الفردية

بدءًا من سبع مجتمعات أسترالية

- Filipino, Vietnamese. Samoan, Fijian, Tongan, Lebanese, and Sudanese & South Sudanese
- نحتاج إلى 1000 شخص من كل مجتمع

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

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Provide an **immediate improvement** in the diagnosis of families affected by rare disease



Provide a foundation for **future, larger projects** that will **improve the prediction of risk** for common diseases such as heart disease or diabetes

Will be used to **identify genes** that might be important for the **development of new therapies**

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ماذا يعني المشاركة في برنامج OurDNA بالنسبة للمجتمع اللبناني؟

توفير **تحسن فوري** في تشخيص الأسر المتضررة من الأمراض الوراثية النادرة



توفير الأساس **لمشاريع بحث مستقبلية أكبر** من شأنها **تحسين التوقع بمخاطر** الأمراض الشائعة مثل أمراض القلب أو مرض السكري

سيتم استخدامها **لتحديد الجينات** التي قد تكون مهمة **لتطوير علاجات جديدة**

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Building representative resources for doctors and researchers

بناء الموارد التمثيلية للأطباء والباحثين



amples عينات

- **DNA** الحمض النووي
- **Plasma** البلازما, مصل الدم
- **Blood cells** خلايا الدم

Data المعلومات

- **Database of individual level genetic information** قاعدة بيانات المعلومات الوراثية على المستوى الفردي
- **Basic demographic information** معلومات ديموغرافية أساسية
- **Health questionnaire, self-identified ancestry** استبيان الصحة، أصل محدد ذاتيا

Browser المتصفح

- **Summary genetic information from many healthy people** ملخص المعلومات الوراثية من العديد من الأشخاص الأصحاء
- **Grouped by age, sex, ancestry** تم تجميعها حسب العمر والجنس والأصل
- **Publicly accessible** متاح للعامة

Making data and samples available for scientists and doctors

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- We take data privacy seriously
  - Personal details and genetic information are **kept in seperate places**
  - Only **essential OurDNA staff** will have access to your personal information
  - Scientists and doctors **do not see** your personal information
  - **Approved and secure** systems

توفير البيانات والعينات للعلماء والأطباء

نحن نأخذ خصوصية البيانات على محمل الجد

يتم الاحتفاظ بالتفاصيل الشخصية والمعلومات الجينية **في أماكن منفصلة**

لن يتمكن من الوصول إلى معلوماتك الشخصية سوى **الموظفين الأساسيين في OurDNA**

لا يرى العلماء والأطباء معلوماتك الشخصية

أنظمة **معتمدة وآمنة**

Labelling the data from your community
تسمية او تصنيف البيانات من مجتمعك

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- We want to make sure that we use the correct words to describe the data from your community
- نريد التأكد من أننا نستخدم الكلمات الصحيحة لوصف البيانات من مجتمعك
- In the past, labels have been applied to data that did not reflect how communities understood their own identity
- في الماضي، تم تطبيق تسميات على البيانات التي لا تعكس كيفية فهم المجتمعات لهويتها الخاصة
- OurDNA wants to do things differently to make sure that the way we describe the data respects the way community members see themselves
- يريد برنامج OurDNA القيام بالأشياء بشكل مختلف للتأكد من أن الطريقة التي نصف بها البيانات تحترم الطريقة التي يرى بها أعضاء المجتمع أنفسهم
- When participants join OurDNA, they can tell us how they understand their own ancestry
- عندما ينضم المشاركون إلى OurDNA، يمكنهم إخبارنا بكيفية فهمهم لأصولهم او أسلافهم



OurDNA Community Engagement

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Co-design with community members

- To ensure multicultural communities can participate in our research
  - Working with community organisations and other community collaborators to plan engagement and recruitment

Multicultural sector consultation and oversight

- To ensure multicultural communities' interests are central to OurDNA
  - Partnership with the Federation of Ethnic Communities Council of Australia (FECCA)
  - OurDNA Multicultural Consultation Group advising on program policies





المشاركة المجتمعية لـ OurDNA

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التصميم المشترك مع أعضاء المجتمع

لضمان قدرة المجتمعات متعددة الثقافات على المشاركة في بحثنا
العمل مع المنظمات المجتمعية والمتعاونين المجتمعيين الآخرين لتخطيط المشاركة والتوظيف

التشاور والإشراف على القطاع المتعدد الثقافات

التأكد من أن مصالح المجتمعات المتعددة الثقافات هي أمر أساسي في OurDNA
الشراكة مع اتحاد مجلس المجتمعات العرقية في أستراليا (FECCA)
مجموعة OurDNA الاستشارية متعددة الثقافات تقدم المشورة بشأن سياسات البرنامج





OUR DNA

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Q&A

فقرة الأسئلة والأجوبة



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Part 1: How we can improve the participant pathway for the Lebanese community

الجزء الأول: كيف يمكننا تحسين خطوات المشاركة للمجتمع اللبناني



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Who can take part in OurDNA?
من يمكنه المشاركة في برنامج OurDNA ؟

- Have Lebanese ancestry من أصول لبنانية
- 18+ فوق السن القانوني الثامنة عشر
- Eligible for Medicare مؤهل للحصول على بطاقة الرعاية الطبية
- Do not have severe genetic condition (e.g. muscular dystrophy or cystic fibrosis). لا يعاني من حالة وراثية شديدة (مثل ضمور العضلات أو التليف الكيسي)



Participant pathways
خطوات المشاركة

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FIND OUT اكتشف → SIGN UP اشترك/التسجيل → CONSENT الموافقة → DONATE التبرع → RECEIVE استلام



Walk-in pathway

- Consent independently on the OurDNA app
- Visit a Melbourne Pathology clinic close to you
- Donate a blood sample any time Mon-Thu from 9am-5pm

خطوات المشاركة (الفردية) بدون حجز

- الموافقة بشكل مستقل على تطبيق OurDNA
- قم بزيارة عيادة Melbourne Pathology clinical القريبة منك
- تبرع بعينة دم في أي وقت من الاثنين إلى الخميس من الساعة 9 صباحًا حتى 5 مساءً

'One-stop shop' pathway



- Attend a community OurDNA event
- Learn more about OurDNA
- Consent on the OurDNA app (with assistance from staff)
- Donate a blood sample on the spot

خطوات "المشاركة الشاملة للاشتراك"



- حضور حدث مجتمعي تابع لـ OurDNA
- معرفة المزيد عن OurDNA
- الموافقة على تطبيق OurDNA (بمساعدة من الموظفين)
- التبرع بعينة دم على الفور

Scenario: OurDNA at a Community Event







Imagine that OurDNA has a stall at a community festival. Or that we we are attending your community group's event. At the stall or event:

- You can learn more about the program and speak with our team
- If you are interested, you can donate a small blood sample on the spot
  - Our team can help you consent through the OurDNA app
  - Trained blood collectors can safely collect your blood
  - Everyone who takes part will receive a $100 voucher

You can tell your friends or family about OurDNA later. They can also sign up with the app and visit a Melbourne Pathology clinic.







سيناريو: OurDNA في فعالية مجتمعية

تخيّل أن لـ OurDNA كشكًا في أحد المهرجانات المجتمعيه، أو أننا نحضر فعاليةً لمجموعة مجتمعك. في الكشك أو الفعالية:

- يمكنك معرفة المزيد عن البرنامج والتحدث مع فريقنا.
- إذا كنت مهتمًا، يمكنك التبرع بعينة دم صغيرة فورًا.
  - يمكن لفريقنا مساعدتك في الموافقة من خلال تطبيق OurDNA
  - يستطيع جامعو الدم المدربون بأخذ عينة دم بأمان
  - سيحصل كل من يشارك على قسيمة بقيمة 100 دولار

يمكنك إخبار أصدقائك أو عائلتك عن OurDNA لاحقًا. يمكنهم أيضًا الاشتراك في التطبيق وزيارة إحدى عيادات Melbourne Pathology clinic.

Scenario: OurDNA at a Community Event

Workshop Questions

- **How can we make participation more comfortable and welcoming for your community?**
- **What would help your family and friends to take part in OurDNA?**
- **What would help your community feel confident about taking part in genetics research?**

سيناريو: برنامج OurDNA في فعالية او حدث مجتمعي

أسئلة ورشة العمل

- كيف يمكننا أن نجعل المشاركة أكثر راحة وترحيباً لمجتمعك؟
- ما الذي قد يساعد عائلتك وأصدقائك على المشاركة في OurDNA؟
- ما الذي قد يساعد مجتمعك على الشعور بالثقة بشأن المشاركة في الأبحاث الوراثية او أبحاث علم الوراثة؟



Part 2: How we can engage the Lebanese community

الجزء الثاني: كيف يمكننا إشراك المجتمع اللبناني



Scenario:
Community-led Campaign with Lebanese Australians



Example:

A three-month community-led campaign, designed together with Lebanese Australians. The campaign reflects community voices, values, and the things that are important to the community.

Delivered through

- trusted Arabic language radio,
- community newspapers,
- Community Facebook groups, and Instagram pages

Containing:

- Stories in Arabic and English
- Showing Lebanese community members speaking openly about health, community, and the importance of representation in medical research.

السيناريو:
حملة يقودها المجتمع الأسترالي اللبناني



مثال:

حملة يقودها المجتمع المحلي لمدة ثلاثة أشهر، تم تصميمها بالتعاون مع أستراليين لبنانيين. تعكس الحملة أصوات المجتمع وقيمه والأمور المهمة له

يتم تقديمها عبر:

- **محطات إذاعية باللغة العربية الموثوق بها من قبل المجتمع،**
- **والصحف المجتمعية،**
- **ومجموعات المجتمع على فيسبوك، وصفحات إنستغرام.**

تحتوي على:

- **قصص باللغتين العربية والإنجليزية.**
- **تُظهر أفراد المجتمع اللبناني يتحدثون بشكل علني وبصورة واضحة عن الصحة والمجتمع وأهمية التمثيل في البحث الطبي.**

Campaign Activities & Outreach

Please help us design an awareness campaign that is relatable to community members. Your campaign could include:



30 second radio ad about OurDNA inviting individuals to visit our website to find out more about the program.



Facebook / Instagram series sharing stories from well-known community members and 'influencers'.



Podcast conversation talking about why medical research should better represent diversity in our Australian community.



A feature **article in a Lebanese Australian newspaper** explaining how joining OurDNA can help improve diagnosis and treatment for future generations.

- **What messages would you include to make OurDNA relatable?**
  - **What would you focus on? (e.g. family, health, culture, or something else?)**
- **Which successful health or community campaign would you use as inspiration?**
- **Which community members would you want to involve in the campaign?**
  - **E.g. where do community members turn to when they need health information or advice?**

أنشطة الحملة والتوعية

ساعدونا في تصميم حملة توعية تناسب أفراد المجتمع. يمكن أن تتضمن حملة التوعية ما يلي:



إعلان إذاعي مدته 30 ثانية عن برنامج OurDNA يدعو الأفراد لزيارة موقعنا الإلكتروني لمعرفة المزيد عن البرنامج.



تشارك سلسلة فيسبوك/انستغرام تُشارك قصصًا من أعضاء المجتمع المعروفين و"المؤثرين".



محادثة بودكاست تتناول لماذا يجب أن يُمثل البحث الطبي التنوع في مجتمعنا الأسترالي بشكل أفضل.



مقالة **مميزة في إحدى الصحف اللبنانية الأسترالية** تشرح كيف يمكن أن يساعد الانضمام إلى OurDNA في تحسين التشخيص والعلاج للأجيال القادمة.

- **ما الرسائل التي ستُدرجها لجعل OurDNA أكثر ارتباطًا بالمجتمع؟**
  - **على ماذا ستُركز؟ (مثلًا: العائلة، الصحة، الثقافة، أو أي شيء آخر؟).**
- **ما هي الحملة الصحية أو المجتمعية الناجحة التي ستستخدمها كمصدر إلهام؟**
- **من هم أعضاء المجتمع الذين ترغب في إشراكهم في الحملة؟**
  - **على سبيل المثال، إلى أين يلجأ أفراد المجتمع عندما يحتاجون إلى معلومات أو مشورة أو نصائح صحية؟**

Blood donation
التبرع بالدم

Australian Red Cross Lifeblood is a collaborator on OurDNA

يتعاون الصليب الأحمر الأسترالي "Lifeblood"
في مشروع OurDNA

Why ethnicity is important in blood donation
لماذا العرق او السلالة مهم في التبرع بالدم

BLOOD TYPES ARE INHERITED

فصائل الدم موروثة

1/2

of Australia's population was born overseas or have a parent born overseas

1/2 من سكان أستراليا ولدوا في الخارج أو ولد أحد والديهم في الخارج

1/5

Of donors were born overseas

1/5 من المتبرعين ولدوا في الخارج

As Australia is becoming more diverse, this leads to an increase in the diversity of patients – and their blood types

مع تزايد التنوع في أستراليا، يؤدي هذا إلى زيادة تنوع المرضى - وفصائل الدم الخاصة بهم

To meet the growing demand for particular blood types for patients we need more blood donors from different communities.

لتلبية الطلب المتزايد على فصائل دم معينة للمرضى، نحتاج إلى المزيد من المتبرعين بالدم من مجتمعات مختلفة.



What do you know about blood donation? Is it something you are aware of?

ماذا تعرف عن التبرع بالدم؟ هل هو شيء أنت على علم به؟

Community perspectives on blood donation
وجهات نظر المجتمع حول التبرع بالدم



What do you think members of the Lebanese community know about blood donation?

برأيك، ماذا يعرف أفراد الجالية اللبنانية عن التبرع بالدم؟



What do you think your friends and family/people from the Lebanese community know about Lifeblood?

في رأيك، ما الذي يعرفه أصدقاؤك وعائلتك/أفراد المجتمع اللبناني عن Lifeblood؟



Can you think of any reasons why members of the Lebanese community might not be interested in donating blood?

هل يمكنك التفكير في أي أسباب قد تجعل أفراد المجتمع اللبناني غير مهتمين بالتبرع بالدم؟

Follow us on social media!

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Facebook

Instagram

Thank you for your input!

Please make sure you have signed the consent form and returned it to us so that we can give you the $100 voucher

شكرًا لمساهمتك!

يُرجى التأكد من توقيعك على نموذج الموافقة وإعادته إلينا لنتمكن من إعطائك قسيمة بقيمة 100 دولار.



Sydney's slides

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Co-Designing OurDNA outreach & communication with the Sydney Lebanese Community

المشاركة في تصميم طرق التواصل والتوعية الخاصة ببرنامج OurDNA مع المجتمع اللبناني في سيدني

Samantha Croy (CPG)
Rafal Shouly (CPG)
Saad Khalid (CPG)
Amira Issa
Wafa Jeha
Kamal Hadid



Acknowledgement of Country

بيان الاعتراف بالسكان الأصليين للبلد



Agenda – co-design session

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- Introductions and project overview
- **Part 1: How we can improve the participant pathway for the Lebanese community**
- Short break
- **Part 2: How we can engage the Lebanese community**



جدول الأعمال – جلسة التصميم المشترك

مقدمة ونظرة عامة على المشروع

الجزء الأول: كيف يمكننا تحسين خطوات المشاركة للمجتمع اللبناني

استراحة قصيرة

الجزء الثاني: كيف يمكننا إشراك المجتمع اللبناني

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murdoch children's research institute

Garvan Institute of Medical Research

- Jointly based at the **Garvan Institute of Medical Research** in Sydney and the **Murdoch Children's Research Institute** in Melbourne
- **50+ team** members in Australia and New Zealand
- **Not-for-profit research initiative** Funded through institutional support, government grants, and philanthropic donations

Centre for Population Genomics مركز

مقر المركز المشترك في معهد **Garvan** للأبحاث الطبية في سيدني

ومعهد **Murdoch Children's** لأبحاث في ملبورن

50 عضوًا في الفريق في أستراليا ونيوزيلندا

مبادرة بحثية غير ربحية ممولة من خلال الدعم المؤسسي والمنح الحكومية والتبرعات الخيرية

Our Mission

We believe **everyone** should benefit from advances in genomic medicine

مهمتنا

نحن نؤمن أن الجميع يجب أن يستفيدوا من التقدم في الطب الجينومي



What is genomic medicine?

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- It is a field that is **rapidly advancing** and becoming **routine healthcare**
- Relies on understanding the **genetic variation in healthy populations**
- Clinicians and researchers need to understand healthy variation from **people of all ancestries**



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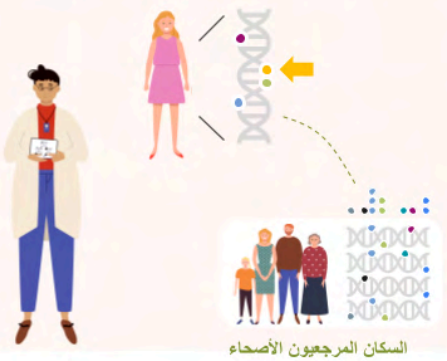
ما هو الطب الجينومي؟

إنه مجال **يتطور بسرعة** ويصبح من ضمن روتين **الرعاية الصحية**

يعتمد على فهم **التباين الجيني (المتغيرات الجينية) في السكان الأصحاء**

يحتاج الأطباء والباحثون إلى فهم التباين الصحي بين **الأشخاص من جميع الأصول**

لتشخيص **مرض وراثي**، نبحث عن المتغيرات الجينية في المريض والتي تكون نادرة أو غائبة في **الأشخاص الأصحاء**



السكان المرجعيون الأصحاء

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What are the benefits of genomic medicine?

ما هي فوائد الطب الجينومي؟

- Improve medical **diagnosis** — تحسين **التشخيص** الطبي
- Improve **prediction and prevention** of illness — تحسين **التنبؤ والوقاية** من المرض
- Improve disease **treatment** — تحسين **علاج** المرض

So...what's the issue?

إذن ما هي المشكلة؟

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Millions of Australians are not represented in genomic resources

- Existing global genetic databases **don't represent dozens of Australian multicultural communities**
- These communities will be **less likely to access and benefit** from genomic medicine

Global availability of genetic data by ancestry group of origin



Underrepresented regions: East Africa, Middle-East & North Africa, Oceania, South-East Asia

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ملايين الأستراليين غير ممثلين في الموارد الجينية

التوافر العالمي للبيانات الجينية حسب مجموعة الأصول الأصلية



لا تمثل قواعد البيانات الجينية العالمية الحالية **عشرات المجتمعات الأسترالية متعددة الثقافات**

ستكون هذه المجتمعات **أقل قدرة على الوصول إلى الطب الجيني والاستفادة منه**

المناطق غير الممثلة: شرق أفريقيا، والشرق الأوسط وشمال أفريقيا، وأوقيانوسيا، وجنوب شرق آسيا

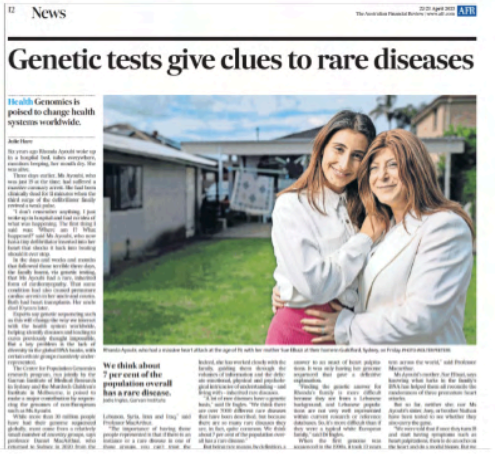
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When someone from an underrepresented group has a serious genetic disease, it is often difficult to identify the genetic change that is causing their disease.

As an example;

- Rhonda, a young Lebanese-Australian community member, suffered from a sudden serious heart attack
- Luckily, she was able to be revived and survived
- Later, her family discovered through genetic testing that Rhonda had a rare, inherited heart condition
- It took longer for Rhonda to be diagnosed due to a lack of genetic data for Middle Eastern communities
- Experts say “a key problem is the lack of diversity in the global DNA banks, with certain ethnic groups massively unrepresented."



News

Genetic tests give clues to rare diseases

Health Genomics is poised to change health systems worldwide.

We think about 7 per cent of the population overall has a rare disease.

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على سبيل المثال، عندما يعاني شخص من مجموعة غير ممثلة من مرض وراثي خطير، فغالبًا ما يكون من الصعب تحديد التغيير الجيني الذي يسبب مرضه

على سبيل المثال؛

- روندا، شابة لبنانية أسترالية، أصيبت بأزمة قلبية خطيرة مفاجئة
- لحسن الحظ، تمكنت من الإنعاش والبقاء على قيد الحياة
- لاحقًا، اكتشفت عائلتها من خلال الاختبارات الجينية أن روندا تعاني من حالة وراثية نادرة في القلب
- استغرق تشخيص مرض روندا وقتًا أطول بسبب نقص البيانات الوراثية لمجتمعات الشرق الأوسط
- يقول الخبراء: "إن المشكلة الرئيسية تكمن في نقص التنوع في بنوك الحمض النووي العالمية، مع وجود مجموعات عرقية معينة غير ممثلة بشكل كبير".



News

Genetic tests give clues to rare diseases

Health Genomics is poised to change health systems worldwide.

We think about 7 per cent of the population overall has a rare disease.

OUR DNA
AUSTRALIAN GENETIC DIVERSITY DATABASE

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The OurDNA program is an Australian health research program. It will build resources to ensure multicultural communities benefit from genomic medicine.

برنامج OurDNA هو برنامج بحث صحي استرالي . يهدف هذا البرنامج إلى بناء الموارد اللازمة لضمان استفادة المجتمعات المتعددة الثقافات من الطب الجيني



The OurDNA Program

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Our plan:

- to **engage underrepresented multicultural communities** to understand their needs and views with regard to communications, outreach and recruitment.
- to **invite thousands of individuals from these communities** to donate a blood sample
- Store **DNA and cells** to create a new, more representative resource
- to **make resources available in a way that improves diagnosis** of patients from these communities while respecting individual privacy.

Starting with seven Australian communities

- Filipino, Vietnamese, Samoan, Fijian, Tongan, Lebanese, and Sudanese and South Sudanese
- We hope **1000 people** from each community will take part

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برنامج OurDNA

خطة عملنا:

إشراك المجتمعات المتعددة الثقافات غير الممثلة لفهم احتياجاتها ووجهات نظرها فيما يتعلق بالاتصالات والتوعية والتسجيل

لدعوة الآلاف من الأفراد من هذه المجتمعات للتبرع بعينة دم

تخزين الحمض النووي والخلايا لإنشاء مورد جديد أكثر تمثيلاً

توفير الموارد بطريقة تعمل على تحسين تشخيص المرضى من هذه المجتمعات مع احترام الخصوصية الفردية

بدءًا من سبع مجتمعات أسترالية

- Filipino, Vietnamese. Samoan, Fijian, Tongan, Lebanese, and Sudanese & South Sudanese
- نأمل أن يشارك **1000 شخص** من كل مجتمع

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OurDNA Community Engagement

Multicultural sector consultation and oversight

- To ensure multicultural communities' interests are central to OurDNA
  - Partnership with the Federation of Ethnic Communities Council of Australia (FECCA)
  - OurDNA Multicultural Consultation Group advising on program policies

Partnering and co-designing with community members

- To ensure multicultural communities can participate in our research
  - Working with community organisations and other community collaborators to plan engagement, communication and recruitment

This is why you are invited here today!





المشاركة المجتمعية لـ OurDNA

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التشاور والإشراف من قبل القطاع متعدد الثقافات

- لضمان أن تكون مصالح المجتمعات متعددة الثقافات محور اهتمام OurDNA
  - الشراكة مع مجلس اتحاد المجتمعات العرقية في أستراليا (FECCA)
  - مجموعة الاستشارات متعددة الثقافات في OurDNA تقدم الاستشارات بشأن سياسات البرنامج

الشراكة والتصميم المشترك مع أعضاء المجتمع

- لضمان قدرة المجتمعات متعددة الثقافات على المشاركة في بحثنا
  - العمل مع المنظمات المجتمعية والمتعاونين المجتمعيين الآخرين للتخطيط للمشاركة والتواصل والتوظيف

ولهذا السبب أنتم مدعون هنا اليوم!





Building representative resources for doctors and researchers

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بناء الموارد التمثيلية للأطباء والباحثين



amples عينات

- DNA الحمض النووي
- Plasma البلازما, مصل الدم
- Blood cells خلايا الدم

Data المعلومات

- Database of individual level genetic information قاعدة بيانات المعلومات الوراثية على المستوى الفردي
- Basic demographic information معلومات ديموغرافية أساسية
- Health questionnaire, self-identified ancestry استبيان الصحة، أصل محدد ذاتيًا

Browser المتصفح

- Summary genetic information from many healthy people ملخص المعلومات الوراثية من العديد من الأشخاص الأصحاء
- Grouped by age, sex, ancestry تم تجميعها حسب العمر والجنس والأصل
- Publicly accessible متاح للعامة

Making data and samples available for scientists and doctors

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- We take data privacy seriously
  - Personal details and genetic information are **kept in seperate places**
  - Only **essential OurDNA staff** will have access to your personal information
  - Scientists and doctors **do not see** your personal information
  - **Approved and secure** systems

توفير البيانات والعينات للعلماء والأطباء

نحن نأخذ خصوصية البيانات على محمل الجد

يتم الاحتفاظ بالتفاصيل الشخصية والمعلومات الجينية **في أماكن منفصلة**

لن يتمكن من الوصول إلى معلوماتك الشخصية سوى **الموظفين الأساسيين في OurDNA**

لا يرى العلماء والأطباء معلوماتك الشخصية

أنظمة **معتمدة وآمنة**

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

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Provide an **immediate improvement** in the diagnosis of families affected by rare disease



Provide a foundation for **future, larger projects** that will **improve the prediction of risk** for common diseases such as heart disease or diabetes

Will be used to **identify genes** that might be important for the **development of new therapies**

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ماذا يعني المشاركة في برنامج OurDNA بالنسبة للمجتمع اللبناني؟

توفير **تحسن فوري** في تشخيص الأسر المتضررة من الأمراض الوراثية النادرة



توفير الأساس **لمشاريع بحث مستقبلية أكبر** من شأنها **تحسين التوقع بمخاطر** الأمراض الشائعة مثل أمراض القلب أو مرض السكري

سيتم استخدامها **لتحديد الجينات** التي قد تكون مهمة **لتطوير علاجات جديدة**

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Who can take part in OurDNA?
من يمكنه المشاركة في برنامج OurDNA ؟



- Have Lebanese ancestry من أصول لبنانية
- 18+ فوق السن القانوني الثامنة عشر
- Eligible for Medicare مؤهل للحصول على بطاقة الرعاية الطبية
- Do not have severe genetic condition (e.g. muscular dystrophy or cystic fibrosis). لا يعاني من حالة وراثية شديدة (مثل ضمور العضلات أو التليف الكيسي)

Participant pathways
خطوات المشاركة

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FIND OUT اكتشف → SIGN UP اشترك/التسجيل → CONSENT الموافقة → DONATE التبرع → RECEIVE استلام



Walk-in pathway

- Consent independently on the OurDNA app
- Visit a Douglass Hanly Moir Pathology clinic close to you
- Donate a blood sample any time Mon-Thu from 9am-5pm

خطوات المشاركة (الفردية) بدون حجز

- الموافقة بشكل مستقل على تطبيق OurDNA
- قم بزيارة عيادة Douglass Hanly Moir Pathology القريبة منك
- تبرع بعينة دم في أي وقت من الاثنين إلى الخميس من الساعة 9 صباحًا حتى 5 مساءً

'One-stop shop' pathway



- Attend a community OurDNA event
- Learn more about OurDNA
- Consent on the OurDNA app (with assistance from staff)
- Donate a blood sample on the spot

خطوات "المشاركة الشاملة للاشتراك"



- حضور حدث مجتمعي تابع لـ OurDNA
- معرفة المزيد عن OurDNA
- الموافقة على تطبيق OurDNA (بمساعدة من الموظفين)
- التبرع بعينة دم على الفور

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Q&A

فقرة الأسئلة والأجوبة



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Part 1: How we can improve the participant pathway for the Lebanese community

الجزء الأول: كيف يمكننا تحسين خطوات المشاركة للمجتمع اللبناني



طرق المشاركة في برنامج OurDNA







OurDNA often joins festivals and groups' events in other communities.

At these events:

- You can learn more about the program and speak with our team
- If you are interested, you can donate a small blood sample on the spot
  - Our team can help you consent through the OurDNA app
  - Trained blood collectors can safely collect your blood
  - Everyone who takes part will receive a $100 voucher

You can tell your friends or family about OurDNA later. They can also sign up with the app and visit a Douglass Hanly Moir Pathology clinics.

سيناريو: OurDNA في فعالية مجتمعية







غالبًا ما ينضم OurDNA إلى المهرجانات والفعاليات الجماعية في المجتمعات الأخرى.
في هذه الفعاليات:

- يمكنك معرفة المزيد عن البرنامج والتحدث مع فريقنا.
- إذا كنت مهتمًا، يمكنك التبرع بعينة دم صغيرة فورًا.
  - يمكن لفريقنا مساعدتك في الموافقة من خلال تطبيق OurDNA
  - يستطيع جامعو الدم المدربون بأخذ عينة دم بأمان
  - سيحصل كل من يشارك على قسيمة بقيمة 100 دولار

يمكنك إخبار أصدقائك أو عائلتك عن OurDNA لاحقًا. يمكنهم أيضًا الاشتراك في التطبيق وزيارة إحدى عيادات Douglass Hanly Moir Pathology

Making participation welcoming for Lebanese community members

جعل المشاركة موضع ترحيب لأفراد الجالية اللبنانية

Workshop Questions
أسئلة ورشة العمل

- **How can we make our events welcoming for community members?**
  - **كيف يمكننا أن نجعل فعالياتنا ترحيبية لأفراد المجتمع؟**
- **What would help community members to take part in OurDNA?**
  - **(e.g. at events or through our walk-in pathway)**
  - **ما الذي سيساعد أفراد المجتمع على المشاركة في برنامج OurDNA؟**
    - **مثلاً في الفعاليات والمناسبات المجتمعية أو خلال التسجيل المباشر عن طريق موقعنا)**

Part 2: How we can engage the Lebanese community

الجزء الثاني: كيف يمكننا إشراك المجتمع اللبناني



Telling Lebanese community members about OurDNA



Example:

A three-month community-led campaign, designed together with Lebanese Australians. The campaign reflects community voices, values, and the things that are important to the community.

Delivered through

- trusted Arabic language radio,
- community newspapers,
- Community Facebook groups, and Instagram pages

Containing:

- Stories in Arabic and English
- Showing Lebanese community members speaking openly about health, community, and the importance of representation in medical research.

السيناريو:
حملة يقودها المجتمع الأسترالي اللبناني



مثال:

حملة يقودها المجتمع المحلي لمدة ثلاثة أشهر، تم تصميمها بالتعاون مع أستراليين لبنانيين. تعكس الحملة أصوات المجتمع وقيمه والأمور المهمة له

يتم تقديمها عبر:

- محطات إذاعية باللغة العربية الموثوق بها من قبل المجتمع،
- والصحف المجتمعية،
- ومجموعات المجتمع على فيسبوك، وصفحات إنستغرام.

تحتوي على:

- قصص باللغتين العربية والإنجليزية.
- تُظهر أفراد المجتمع اللبناني يتحدثون بشكل علني وبصورة واضحة عن الصحة والمجتمع وأهمية التمثيل في البحث الطبي.

How to engage the Lebanese community
كيف نتفاعل مع المجتمع اللبناني؟





- **What are the best ways to make the Lebanese community aware about the OurDNA program?**
- **ماهي افضل الطرق لجعل المجتمع اللبناني على دراية ببرنامج OurDNA**



- **Who should the information come from?**
- **كيف يمكننا توصيل المعلومات للمجتمع اللبناني وعن طرق من ؟**
  - **أشخاص, منظمات, إلى آخره ...**





Youth session slides:

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OUR DNA

AUSTRALIAN GENETIC DIVERSITY DATABASE

Lebanese Youth Co-Design Session

Online | 20 July 2025

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Acknowledgement of Country

At CPG, we celebrate and respect diversity in our team and our work. We believe that including all human diversity in genomic research will empower medical care that benefits everyone.

We acknowledge the First Australian peoples on whose traditional lands we live and work across the country and pay our respects to their elders past, present and emerging. We gratefully accept the invitation in the Uluru Statement from the Heart "to walk with us in a movement of the Australian people for a better future".

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Housekeeping

Introductions



Abdul Aziz Khoder

Medical student at the University of Melbourne with a background in biomedical science. He works part-time as a clinical researcher and has a strong interest in improving health outcomes for underrepresented communities. Coming from a Lebanese background, he's especially keen to support OurDNA's work with Lebanese Australians.

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Georgette Mouawad

With a background in law, public policy, and grassroots advocacy, Georgette excels in fostering inclusive dialogues and designing outreach initiatives that resonate with multicultural audiences. Her experience spans coordinating national campaigns, drafting policy analyses, and mentoring diverse groups—skills she now applies to ensure the OurDNA program's messaging is culturally impactful and sincerely inclusive

Introductions

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Let's go around and introduce ourselves. Please share:

- Your name
- Where you're dialing in from (i.e. what part of Sydney/Melbourne)
- And one thing — big or small — that makes you feel connected to your community.

The Program Today

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Co-Designing OurDNA's Engagement with the Lebanese-Australian Community

1. 📣 **What is OurDNA and the Centre for Population Genomics?**
2. 💬 **Breakout Group Activity 1** | Who do you trust for health or genetics info?
3. 📍 **Breakout Group Activity 2** | How can OurDNA engage with the Lebanese-Australian community
4. 🌟 **Plenary Reflection** | What makes a successful community program?
5. 🙏 **Close & Thank You**

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Rhonda's story

- Rhonda, a young Lebanese-Australian woman, collapsed unexpectedly from a serious heart attack
- Genetic testing later revealed she had a rare genetic inherited heart condition
- Her diagnosis was delayed because genetic data from Middle Eastern communities is so limited



News

Genetic tests give clues to rare diseases

Health Genomics is poised to change health systems worldwide.

We think about 7 per cent of the population overall has a rare disease.

Link to story here

Our Mission

We believe **everyone** should benefit from advances in genomic medicine



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- **50+ team** members in Australia and New Zealand
- **Not-for-profit research initiative** funded through institutional support, government grants, and philanthropic donations

The promise of genomic medicine

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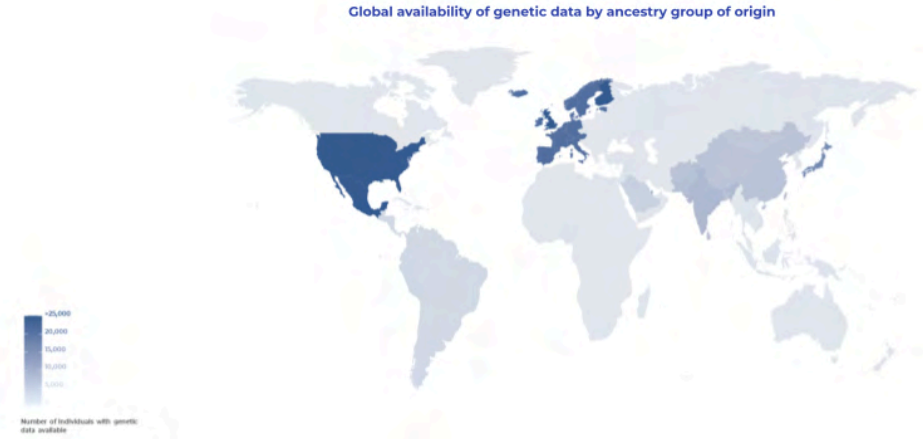
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- Improve medical **diagnosis**
- Improve **prediction** and **prevention** of illness
- Improve disease **treatment**

Millions of Australians are not represented in genomic resources

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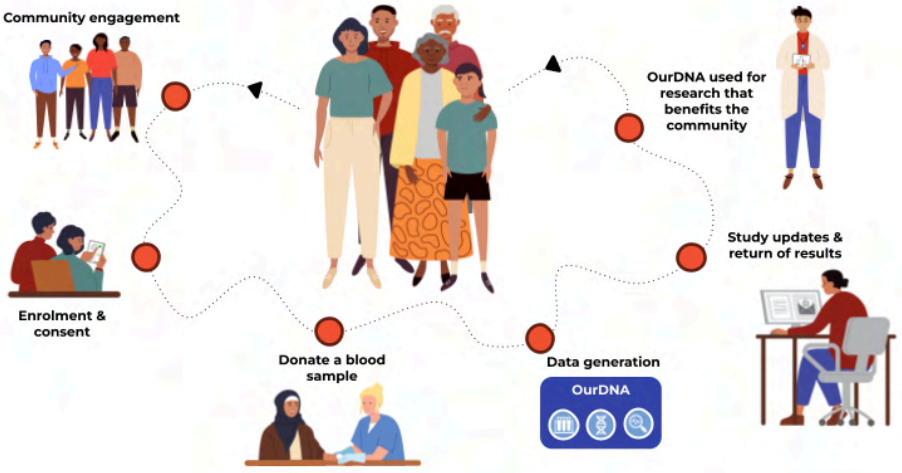


Underrepresented regions: East Africa, Middle-East & North Africa, Oceania, South-East Asia

The OurDNA journey

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Starting with Filipino, Vietnamese, Samoan, Fijian, Tongan, Lebanese, and Sudanese Australians

How will this benefit the community?

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Provide an **immediate improvement** in the diagnosis of families affected by rare conditions



Provide a foundation for **future, larger projects** that will **improve the prediction of risk** for common diseases such as heart disease or diabetes

Will be used to **identify genes** that might be important for the **development of new therapies and medicine**

OurDNA engagement with Lebanese community in Sydney and Melbourne

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Who can take part?

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- Identify as part of the Lebanese community
- 18+
- Eligible for Medicare
- Able to donate in Victoria or NSW
- Do not have severe genetic condition (e.g. muscular dystrophy or cystic fibrosis)

Participation pathways in OurDNA







OurDNA often joins festivals and groups' events in other communities.

At these events:

- You can learn more about the program and speak with our team
- If you are interested, you can donate a small blood sample on the spot
  - Our team can help you consent through the OurDNA app
  - Trained blood collectors can safely collect your blood
  - Everyone who takes part will receive a $100 voucher

You can tell your friends or family about OurDNA later. They can also sign up with the app and visit a Melbourne Pathology or Douglas Hanly Moir clinic sites



Activity Time
Join the Miro Board

https://shorturl.at/YeJUq

https://miro.com/app/board/uXjVJcF7auA=/?share_link_id=303808364070

We'd love your feedback!

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- **We thank you for your contribution.**
- These co-design sessions form an important part of OurDNA engagement with the Lebanese-Australian community.
- To receive your $100 gift-card, please ensure that your contact details (email/phone) were inputted correctly into the signup form. You will receive the voucher next week.
- If there is anything we can do better to improve the experience or in the delivery of these sessions, please let us know by scanning the QR code



Appendix 2: Post-It Notes

Melbourne workshop

Part 1: How we can improve the participant pathway for the Lebanese community

Questions:

- How can we make our events welcoming for community members?

- What would help community members to take part in OurDNA? (e.g. at events or through our walk-in pathway)

Building trust

- Understand the political division with the Lebanese community
- Partnership with key community organisations like VASS
- Knowing of the sponsorship of community events
- Using logos and names of organisations like VASS
- Connecting with high respected trusted and active people in the community
- Reference from key people
- Trust in the organisation + facilitator
- Assurance of confidentiality
- VASS is very well known in community, experiences + organised
- We should contact and integrate in scientific researches
- ب كلامي عن البرنامج, واقنع العائلة للمشاركة

(Translation: By talking about the program, I convince my family to participate)

- كل شخص عنده رأيه وعن النتيجة القرار لهم

(Translation: Each person has their own opinion and the outcome of how to engage is their decision)

- بأنه لا خطر عليهم من هذه الناحية بالعكس كله مفيد للمستقبل

(Translation: That there is no risk for them from this aspect. On the contrary, it is all beneficial for the future)

- ما الذي يساعد مجتمعك على الشعور بالثقة

(Translation: What helps your community feel confident)

Information, communication, language (including questions)

- How long the research will take
- What about fibromyalgia
- Don't like website + links not good in technology
- Interpreter needs to be of Lebanese background
- Being informed on what the program is about and how it will benefit our community
- To show people evidence on how this DNA testing will benefit and has worked
- We need such info
- Good to know about the diseases
- Knowledgeable people and explain the content perfectly
- كيف يمكننا الحصول على معلومات تتعلق بجينات الشخص ؟

(Translation: How can we receive information about a person's genes?)

- توفير تحسن فوري لتطوير علاجات جديدة

(Translation: Providing immediate improvement for the development of new treatments)

- ما الذي يساعد عائلتك على على المشاركة New and valuable info

(Translation: What helps your family to participate: *New and valuable info)*

- بواسطة الشرح للأصحاب والأقارب بشرح مفصل ومفيد لهم نشجعهم بأنه بحث مفيد لنا على المستقبل

(Translation: By explaining to friends and relatives in a detailed and useful way, we encourage them that this is useful research for us in the future)

- نشرح لهم كم هو مفيد هذا الموضوع للجالية اللبنانية

(Translation: We explain to them how useful this topic is for the Lebanese community)

Outreach channels and community venues

Events

- Key events and key people
- Collaborate through VASS to do community events > learn when they visit VASS
- على دراية بالنشاطات المجتمعية التي تحدث
نشاطات مثل "عيد الأضحى"

(Translation: Familiar with community activities taking place, such as Eid al-Adha.)

Community events with DNA staff في فعالية مجتمعية
Translation: *Community events with DNA staff* At a community event

- من خلال اجتماع مجموعة من الأفراد مثل: مجموعة من فئة النساء في نفس العمر, وايضا من خلال مواقع التواصل الإجتماعي مثل FB, Instagram, من خلال الاحتفال بالمهرجان مسرحي

(Translation: Through a group of individuals meeting, such as: women's groups of the same age, and also through social networking sites such as FB, Instagram, by celebrating the theatrical festival)

Platforms

- Radio
- Social media
- Awareness, ethnic radio - co-ordinate with VASS
- 1- انا عندي رأي ان اسمع على الراديو

(Translation: I have an opinion that I listen to the radio)

Event design and practical support

- Events > food
- Design activities to suit their age, sub cultural and background
- Staff payment
- Bilingual and bicultural staff and pay them for their time
- Timing need to suit the community
- Tailor for sub cultural groups
- School holiday programs etc.
- Smaller groups - people feel more comfortable
- Compensate for time, incentive, transport option
- In-person someone to answer your questions
- Prefer on the weekend
- Funding for VASS to run the event
- Transport and language assistance

- By organising a lunch for participants, doing activities for different age groups
- إعطاء بطاقة تساعد بفحص DNA عند دخول مستشفى خصوصا عند العمليات

  (Translation: Providing a card that helps with DNA testing when entering a hospital, especially during operations.)

- كيف يمكننا أن نجعل المشاركة أكثر راحة ؟ Zoom, Video call, social gathering and light lunch

(Translation: How can we make participation more comfortable? *Zoom, Video call, social gathering and light lunch*)

- نعمل جمعة عائلية أو جمعة أصحاب بشاركو بكل ترحيب

(Translation: We hold a family gathering or a friends gathering, they can participate in most welcome way)

- من خلال اكتشاف أو المعرفة أحتمال الأمراض الوراثي, وايضا من خلال مشاركة مجموعة من العائله مثل فرد يشجع الآخر

  (Translation: By discovering or knowing the possibility of having genetic diseases, also through the participation of groups of families one individual can encourage another)

Part 2: How we can engage the Lebanese community

- What are the best ways to make the Lebanese community aware about the OurDNA program?
- Who should the information come from?

Building trust

- Someone with credibility
- Understand: religious differences, political differences, village differences
- The leaders of community members should be aware of providing information sessions
- We should be knowledgeable on each research
- الأعضاء المجتمع الذي يجب اللجوء إليها, هي المراكز الصحية و المؤسسات التابعة لهذا الموضوع و ايضا المدارس والجامعات

  (Translation: The community members that should be reached out to are health centers and institutions affiliated with this topic, as well as schools and universities)

Information, communication, language (including questions)

- Prevention of getting ill later
- Focus on benefit support treatment in future of community
- Examples from Lebanese community
- Young people don't listen to radio or read newspaper
- Create units on this project to provide info
- مترجمين لبنانيين واضحين مثل "اليزبيث سلامة" القاء مضبوط وواضح "انام بركات"

  (Translation: Clear Lebanese translators like "Elizabeth Salama", precise and clear recitation, like "Inaam Barakat")

- بالنسبة للصحة أكثر الأمراض يريدون أن يتعرفوا على الفئة الوراثية التي حصلوا عليها

(Translation: For health, most people with diseases want to know the genetic group they have)

Outreach channels and community venues

Events

- Eid festival 6th June

- المهرجانات القريبة

(Translation: Nearby festivals)

Venues

- Alawi Social Centre
- Clinics and doctors, flyers at doctors Centre in arabic about the program
- Schools majority > parents groups, arabic speakers
- Mosques on Friday, churches or Sunday
- Doctors, clinics many Lebanese doctors, flyers, TV > Arabic
- TAFE: Kangan TAFE, holmesglen, Victoria University
- Resolve medical, Centre: Coburg
- St. Vincent hospital has a list of Arabic speaking Drs.
- Target RTO's/ TAFEs
- Religious places churches/ Mosques
- Target schools
- Preston Mosque
- HIYC Roxburgh Park
- St. George Orthodox Church Thornbury
- Meadow Heights Mosque
- Thornbury, Maronite Church
- Target religious places كنائس وجوامع keon reservoir
- مراكز العبادة (مساجد, كنائس)

(Translation: Places of worship (Churches, Mosques)

- مراكز الخدمات (Groups)

Translation: Service Centers (Groups)

Platforms

- Radio is good
- SBS radio
- Newspaper
- Youtube > Commercials > Promote in language
- Facebook + Instagram, VASS, Mish Mish, Bashar Houli
- SBS Radio
- Local papers
- Middle Eastern radio station, do an ad and start it with $100
- التواصل بواسطة الفايسبوك جمعية الكنائس جمعيات خيرية

(Translation: Communication via Facebook, Church Associations, Charitable Associations)

- من خلال الفئات العمرية مثل فئة الشباب تعتمد المواقع التواصل الاجتماعي

(Translation: Through age groups such as youth, social networking sites depend on)

- مثل فئة الكبار: من خلال الراديو, السنتر, مراكز صحية

(Translation: For the adult category: through radio, centers, health centers)

Organisations

- VASS can run cross cultural session > provide the contacts
- Whittlesea, Epping Community connection HAYA
- معلومات عن طريق VASS

(Translation: Information through VASS)

- الجمعيات

(Translation: Associations)

People & Locations / Other

- St Albans > villages in Lebanon
- Villages, e.g. St. Albans, Brunswick etc, 80% schools Lebanese
- More than radio, priests, Sheik, have everyone's phone numbers
- Target our students in our collage

Event design and practical support

- Information sessions are best
- Free food > event
- Good music
- Dabke group
- Money incentive

Miscellaneous

- Search the population and each community

Sydney workshop

How we can improve the participant pathway for the Lebanese community

- How can we make our events welcoming for community members?
- What would help community members to take part in OurDNA? (e.g. at events or through our walk-in pathway)

How we can engage the Lebanese community

- What are the best ways to make the Lebanese community aware about the OurDNA program?
- Who should the information come from?

Here is the data from the Sydney workshop categorized into the agreed sections.

Building trust

- Fear of using the results + unethical researches
- Lack of trust socially of the blood collection
- Ensure confidentiality concerns are addressed e.g. can data be leaked, who has access
- Create what we call: local ambassadors, Story telling: use media + storytelling
- Need more information. Do they care about us ? if they do, why don't they are about the children is Palestine
- Most people are willing to participate, but need someone from a medical background willing to address their questions directly to overcome their scepticism. Preferably someone of the same background who is trusted.
- Stories like Rhonda's would help show that participation in these programs has amazing results & can help decrease mistrust. Perhaps interviews with these families could help as well.
- Trusted health care and legal bioethicist of Lebanese background to present the information
- To get in contact with leaders of the organisations that the community trust and the leaders help convince their people to be involved in this program
- Clarify that the $100 incentive is not bribe, it is only a small token of appreciation
- Community trust, Good community rapport
- Awareness of cultural practises and work with it
- Protocols taken for unethical usage of blood, TRUST, simplify genomics
- I need more details and more workshops to understand the program before I spread the word
- I have to be convinced first before I advocate this program
- Connect similarities between current programs and already existing or trusted organisations or programs/ …. In Australia or Lebanon
- The stance the Aus gov has taken regarding Gaza has broken trust in western, government, medical and humanitarian systems and organisations, To increase involvement trust needs to be built again
- Mistrust following Covid-19 vaccine and side effects
- Need to be more transparent regarding funders and where data will go. There is distrust of organisations
- Rapport + trust with representative
- Murdoch institute is affiliated with Murdoch press (right wing)
- Sarah Murdoch is wife of Lachlan Murdoch CEO of Murdoch press
- MCRI alignment with Murdoch → somehow going to Murdoch press
- …… Murdoch is not using your information for anything else
-

- ما الذي سيساعد المجتمع على المشاركة بمشاركتنا نحن اولا

(Translation: What will help the community participate, with our participation first)

- الثقة بمن يدعو المواطنين لإعطاء عينة دم وفحص DNA

(Translation: The trust in who invites people to give blood samples and DNA testing)

- من خلال اشخاص موثوق بهم, مثل كاهن, الشيخ, طبيب العائلة

(Translation: Through trusted individuals, such as a priest, sheikh, or family doctor)

- وضوح اهداف, إبعاد رجال السياسة عن هذا المشروع

(Translation: Clarity of objectives. Keeping politicians away from this project)

Information, communication, language (including questions)

- Does the DNA research align with religious benefits, why DHM seem to be important
- Keep the message simple but address community concerns
- Short videos, multilingual materials
- Explain simply what genomics is to come to their way of understanding
- Questions + answers
- Asking why the fear of holding $ testing DNA & genetic blood testing. Doing these tests what are the concerns
- Have educational resources available that share the benefits of this research project in a clear of simplified manner
- Genetics connected from birth, new born screening test
- Simplifying the information delivery, especially the use of medical terms and abbreviations
- Medical terms simplified
- Brief interpretive summary of raw genetic data e.g. clear or disease present, For an individual is incentive
- Explain the definition of genomics (illustration, mapping, pictures)
- DNA, Plasma, Cells …. Why wouldn't the muscular dystrophy, fibrosis cystic test, could …. Or cerebral palsy tests
- نعلم الناس حوالينا بهذا البرنامج ويكون مفهوم لديهم

(Translation: We inform people around us about this program and make it clear to them)

- شرح مفصل من قبل المسؤولين للتوضيح

Translation: Detailed explanation by who's responsible for clarification

- هل يتقبل المجتمع اللبناني الاسترالي فكرة تحليل الدم

(Translation: Will the Lebanese-Australian community accept the idea of blood testing/ sequencing)

- شرح مفصل والرد على كل تساؤلات الناس

(Translation: A detailed explanation and answers to all people's questions)

- يجب توضيح إفادة هذا المشروع في الطبابة المستقبلية

(Translation: The benefits of this project for future medical care must be clarified)

- إقامة دورات توعية من قبل الأخصائيين لشرح اهمية هذا المشروع بعيدا عن المعلومات المضللة

(Translation: Holding awareness sessions by specialists to explain the importance of this project, away from misleading information)

- ما الذي سيساعد أفراد المجتمع على المشاركة في البرنامج OurDNA

(Translation: What will help community members participate in the OurDNA program)

Outreach channels and community venues

Events

- Big community events: churches , Mosques
- Piggy back on other events, Eif, Easter festivals, Markets etc.
- Events like Eid festivals

- Open day at Mosques, churches
- كيف يمكننا أن نجعل فعالياتنا ترحيبية لأفراد المجتمع

(Translation: How can we make our events welcoming to community members)

- وسائل الإعلام على كافة مستوياتها

(Translation: Media platforms at all levels)

Venues

- Drs. walk-in (community's, SSI, multicultural centres
- Services → community access programs agecare
- Doctors → explain, musical events, schools, high schools, tv, sport
- Go talk in hospitals where parents are more willing to understand and participate
- At schools religious community
- Go to universities
- Go to community centres that have Lebanese events
- Mosques
- Churches
- أماكن العبادة

(translation : Places of worship)

- المراكز الدينية والمدارس

(translation: Religious centers and schools)

Platforms

- Marketing, flyers - food, freebies, Cookies (made) Cupcakes
- Social media, famous person or known to have an issue in genetics, family wise experience
- GP, doctors, Community services providers, Organisations, Religious centres, Media (public)
- Marketing, make it more attractive to join
- الأذاعات

Translation: Radios

- نجعل الفعاليات ترحيبية باعلانها للناس التواصل الاجتماعي Social media

(Translation: We make events welcoming by announcing them to people on *social media*)

Organisations

- Community's SSI Multicultural centres
- Partner with community and religious groups and leaders to attend regular events and functions with a mobile caravans/ booth for DHM with religious and community leaders being the first volunteer/ doners
- Each of Australia's major universities have a pretty large Lebanese society that often promotes events for the community & will even help to host them. They can help the word out to families
- Lebanese society @unsw, usyd, uts, YALA on instagram
- Future Australian Lebanese
- Approach aged care service providers

People & Locations / Other

- Going to healthcare professions so they can pass on the message of OurDNA to their participants and families

- Evolving cultures, celebrities ie. politician, sport and others
- دكتور العائلة وأفراد العائلة والأصدقاء

(Translation: Family doctor, family members and friends)

- احتكاك مباشر مع الناس و مقابلات

(Translation: Direct interaction with people and interviews)

- أفضل طريقة لإيصال الفكرة وضمن تطبيقها في شريحة كبيرة في المجتمع, هو من خلال رجال الدين في الكنيسة أو الجامع

(Translation: The best way to communicate the idea and ensure its implementation among a large segment of society is through clergy in churches or mosques)

- الاستعانة برجال الدين المتنورين

(Translation: Seeking the help of enlightened religious men)

Event design and practical support

- Need people available to answer questions during consent process
- Some Lebanese people (specially older generation) may be illiterate - may need other ways for consent
- The happy noise that attracts the crowd to the event , shows that it is the event/ practice, not to miss out
- Good social communication and facilitation and events with …. Activities → food, games, …activities age related
- In home pathology collection
- تشجيع الناس على تقديم عينات دم. وعمل الفحوصات

(Translation: Encourage people to provide blood samples and get tested)

- دعوات خاصة

(Translation: Special invitations)

Miscellaneous

- Impactful
- App is there, it is not activated yet you could access it but not sign up to the program yet

Youth workshop

Identify sources of health/genetics information within the Lebanese-Australian community
Individuals you go to for trusted advice

- Local long time GP - good rapport
- my trusted GP
- GP
- family in medicine
- people coming from medical background
- friends in medicine
- religious leaders/sheikhs with background of health and wellbeing
- online dieticians
- people who have had experiences/symptoms

Group 2

- GP
- Sharing familial genetic issues with family members
- Reporters
- Anyone who look qualified eg Dr Oz
- Dr Phil
- Oprah
- Parents

Places you feel comfortable talking about health

- Dr clinic
- Many people I know don't trust hospitals
- Religious places/ Mosques
- to an extent hospitals

Group 2:
Friends

Online platforms and spaces where you would receive info

Group 1:

- WebMD
- Mayo clinic website
- RACGP guidelines
- Google Result AI
- Grok
- ChatGPT
- RCH cpg and guidelines
- whatsapp/facebook?

Group 2:

- Google
- Instagram
- TikTok
- WhatsApp
- Chanel 7/ Chanel 9 (parents)

Practices, habits or behaviours related to sharing or seeking health info (e.g. forwarding messages, asking family chat)

Group 1

- Forwarding msgs
- asking relatives.
- trying to navigate literature themselves

Group 2:
N/A

Why do I trust them?

Group 1:

- lack of personal level of care
- conflict of interest

- research/evidence based practise
- genuine care
- Most ethnics trust hospitals. Royal Melbourne is an example.
- Most people lie about their catchment area to go into Royal Melbourne etc
- have proven effective in the past
- BIG NAME!
- known gp for a long time, whole family trusts them
- Perception and what is trust
- reliability with time.

Group 2:

- Generational aspect includes professional cynicism with particular resources
- When information validates preconceived ideas it valides it
- Tools or lack thereof in interpreting research, leads to further confirmation bias and sticking to traditional forms of information (we are an oral based tradition, which emphasises local community)
- Language barriers interfere with trust from more reliable sources
- Hard to separate love of food (as way of bonding) prioritised over dietary needs to treat health concerns
- Respect parents and families opinions, where there is a lack of online medical sources
- Misinformation is prevalent
- Important, professional titles that indicate legitimacy in their medical opinion
- Titles give the assumption that they are the expert
- Distrust of big pharma, yet trust of GPs and requires discerning the difference between personal titles and people they have personally interacted with rather than ambiguous corporations and institutions
- culturally, MENA people are community based and don't subscribe to an individualist society so we trust people we know and those we already trust who have vouched for particular medical opinions
- Respect for elders, who tend to distrust medicine and who rely on news sites that are less reliable
- When big pharma fails to give us the answers, people see labels like 'natural' and 'organic' as reliable
- Agricultural land encourages connection with organic
- If someone else is lebanese it is easier to build trust, whether they are online or not
- A lot of people in our community are on medication (cholesterol, blood pressure) who don't realise that when you combine natural meds with pharma meds you cause further complications, which then leads to further distrust in big pharma.
- they consider meds a money grab and something that they can treat themselves
- short term patience with results from the medication they take, then encourages distrust
- Sunscreen issue (where lots of sunscreens don't protect to the degree promised) combined with covid vaccine rhetoric (not well researched) led to further distrust
- Not enough targeted information towards MENA communities during COVID like targeting 'what is it', 'why you should trust it', 'why you should do it'

Where should OurDNA show up:

Spaces:

- gp clinic (depends on the GP)
- lebanese cafes/restaurants (al alamy, A1 bakery)
- non pharmaceutical places
- not good to show up at hospitals - seems like exploiting really sick and vulnerable people?

Events:

- university societies
- religious events, eid festivals
- Youth Group events

Platforms:

- facebook & whatsapp for older people
- intragram and tiktok for younger people
- don't blindly advertise: its about who posts it as well

Champions:

- community leaders, Bachar Houli, Adam saad
- religious leaders belal assaad, mohammed hoblos

Groups and organisations:

- Trust local govt more than state and federal govt; showing up at local govt events
- Fatima Payman endorsement?
- Need to be really transparent about why you are getting donations
- financial incentives - mixed thoughts coercive vs makes people more likely to engage?
- don't overwhelm people

Spaces

- University spaces eg lebanese clubs
- Schools, particularly areas with prevalent Lebanese communities
- Places of worship particularly as they are community spaces
- Youth groups associated with religious spaces
- Village councils e.g. imar hall, dar al awda
- United lebanese council
- Arab council
- Australian Lebanese Chamber of Commerce
- Acai shops
- Mosque
- Church
- GP Clinics

Events

- Human Appeal events sponsorships
- BBQs
- Community festivals

- Markets targeting Lebanese people
- Ramadan night markets
- Village eid

Platforms

- Facebook
- Snapchat
- Instagram
- Tiktok
- Whatsapp

Champions

- Sponsorship from local francis (e.g. el jannah, glenroy football club)
- bachar houli
- Samira from masterchef
- Adaam Saad from AFL
- Abdul abu Hamsa
- Bilal Assad
- Singers
- A1 Bakery
- Mt lewis pizzera
- Tibbas
- youtubers - no garlic no onions

Groups & Organisations

- Pathology labs through additional forms
- lebanese australian association