



Engaging with Culturally and Linguistically Diverse Communities for Medical Research

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Health Issues Centre
Consumer voices for better healthcare



MACH
Melbourne Academic
Centre for Health

Contents

Acknowledgements.....	3
Executive Summary.....	4
Introduction	7
Methodology.....	8
Project approach.....	8
Data collection	10
Data analysis	12
Reflections on the engagement process.....	13
Why a partnership approach	13
Testing digital platforms	13
Traditional engagement.....	18
Overall challenges to participation	19
Conclusions and recommendations on the process	20
Results of the survey.....	21
Views on medical research	21
Participating in medical research.....	23
Conclusions and recommendations from the survey	25
Appendix A.....	26
Appendix B.....	31
Appendix C.....	33

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Executive Summary

Melbourne Academic Centre for Health approached Health Issues Centre to investigate ***How can medical research institutions better engage CALD communities in medical research?*** This broad question was then refined to focus on two specific cultural cohorts –Italian Australians and Vietnamese Australians, and in particular older people and their family carers.

The research project pursued two key aims, firstly identify and test effective methods for engaging the cohort and secondly, understand community sentiments towards medical research through deploying a survey.

Engagement Methods

The engagement methods tested involved using ‘cold’ and ‘warm’ techniques. The ‘cold’ involved advertising on social media to the target audience and the ‘warm’ involved working twofold with culturally specific organisations. Firstly, working with community connectors within these organisations, and secondly using the online presence of the organisations’ to raise awareness and encourage participation.

The key findings from the engagement found leveraging cultural community connectors was the most effective approach due to the trust and presence they already hold in the community; their understanding of cultural customs and mindsets; and the significant role they play in bridging the world of medical research with the community of interest. The next most effective approach was using the online presence of the community organisations, whilst the least effective approach was using the ‘cold’/advertising approach to engage.

Conclusions and recommendations on the process

- Partnering with community connectors (either individuals or agencies) assists to understand culture and language from the inside. Community connectors can assist to fast track rapport and trust with the community.
The challenge exists in finding the right community connectors and ensuring their contributions as a partner to the project are recognised and valued. Ideally these partnerships are established early, prior to project design and ethics completion.
- Feedback from the culturally specific organisations suggests that the following changes may assist engagement with the target cohort:
 - Reduce the need to read so much information – recommendations include using easy English, providing shorter tracts of information, and supplementing or using recordings or videos to explain concepts to the target audience. This would make engagement more dynamic, helps those with poor vision, and assists with low language literacy levels
 - Continue to access senior clubs and activity groups to reach the target audience and use translations and interpreters or native speakers when engaging. Ensure avenues of engagement are user friendly and appropriate e.g. paper surveys need to be in large print
- Understanding the cultural nuances of different groups is important when designing engagement strategies and can best be achieved by codesigning with communities. Examples provided by CO.AS.IT and AVWA included:

- For Italian Australians, it was suggested creating a buzz would be helpful to generate buy-in e.g. getting the lead researcher to come and speak to the community as an event, then following this up with newspaper articles and radio promotions
- For Vietnamese Australians, it was suggested that incentives would assist with uptake, such as offering money or a prize.

Community Sentiment towards Medical Research

There was a total of 100 responses to the survey, with 40 older Italian Australian, 51 older Vietnamese Australian and nine carer surveys completed. Part of the methodology involved testing whether the cohort would complete the survey online in order to understand whether people are comfortable using technology. Technology was shown to be a barrier with the majority of responses (78) coming from the community connectors handing out paper copies of the surveys or inputting the responses on behalf of individuals.

The key findings from the survey:

- The majority of people believe that medical research is worthwhile, although there was a smaller but vocal group from the Italian Australian cohort who disagreed or strongly disagreed
- The majority of respondents indicated that medical research benefits the whole community, with the second largest group agreeing that individual benefits can be gained from medical research, whilst again a small minority from the Italian Australian cohort could not identify any benefits to medical research
- Only five out of 100(n) respondents had previous experience of participating in medical research. All were from the Italian Australian cohort, all reported positive experiences, and four out of five indicated that they would do it again
- Those who had *not* participated in medical research (the remaining 95), were asked if they would consider taking part in medical research, over half the older Vietnamese Australians and carers indicated that they would, whilst nearly half the older Italian Australians said they would *not* take part in medical research
- When asked whether there were any particular supports that would assist people to take part in medical research older Vietnamese Australians and carers prefer to have interpreters and written information available, whilst the top response from older Italian Australians was that none of the supports would work, with the next most popular response suggesting that written information in Italian would be helpful.
- Lastly, when asked what technology people were comfortable with, older Italian Australians identified none as their leading response, with the next popular response being computers followed by tablet devices. Whilst for older Vietnamese Australians and carers smartphones, followed by social media were the most popular responses. However, it is interesting to note that even though many older people may have access to technology such as smartphones or computers their level of proficiency with these mediums is unclear.

Conclusions and recommendations from the survey

- Whilst overall older people are supportive in theory of medical research, there is a lack of understanding around health and medical research that could be enhanced through education and awareness raising, and which community connectors may be well placed to help address.

- The study could have been enhanced with supplementary focus groups to explore the reasons why people answered the way they did. Whilst the community connectors were able to offer some insights, there would have been more rigour in hearing this directly from participants.
- Based on the findings and how successful engagement occurred (via traditional methodologies), the study would have benefited understanding *how* technology platforms are used by the cohorts, to consider how these could be utilised in the future.

Introduction

People from culturally and linguistically diverse (CALD) backgrounds and communities are less represented in medical research¹. These low participation rates may lead to adverse health outcome(s) because research participants may not be representative of those who benefit most from new therapies and research data may not be generalisable to the target populations.

Health Issues Centre (HIC) on behalf of the Melbourne Academic Centre for Health (MACH) with funding through a grant from the Office of Health and Medical Research DHHS, explored the question: ***How can medical research institutions better engage CALD communities in medical research?*** With the best way to understand some of the differences to focus on specific CALD communities, subsequently older Italian Australian and Vietnamese Australian's and their family member carers were identified.

The aims of the project include:

- to identify what methods/networks are effective at recruiting older Italian Australians, older Vietnamese Australians and family members to take part in an on-line survey about medical research
- to explore community understanding and attitudes of older Italian Australians, older Vietnamese Australians and family members towards medical research.

The project is specifically based around communities in the **Inner, Northern and Western suburbs** of Melbourne.

¹ Kauffman KS, dos Reis S, Ross M, et al. Engaging hard-to-reach patients in patient-centered outcomes research. J Comp Eff Res 2013;2:313-24

Methodology

Project approach

Of equal importance to the project was the ‘how’ (engagement approach), and the ‘what’ (insights on medical research) and the approach outlined reflects how these key elements were considered and designed into the methodology.

Target audience

The project identified the following cohorts to engage with:

- Older Italian Australians
- Older Vietnamese Australians
- Family member carers of older Italian Australians or older Vietnamese Australians

Older people were defined as 55 years and over. Further, eliciting the views of carers was based on the assumption that caring family members are often integral to the care of their elders and can be an avenue to hear from older people.

Applying for ethics

Early on it was identified that Human Research Ethics Committee approval would be required due to the vulnerability of the cohorts. Whilst this helped to ensure rigour in the processes used and the questions asked, it unintentionally created challenges and limitations, relating to the communication requirements (plain language statements and consent) and the ability to genuinely codesign and partner with ethnic specific community groups. The processes undertaken here comprise part of the findings.

Engagement methods

One of the key aims of the project was to test how effective social media was in engaging with culturally and linguistically diverse groups. The initial social media campaign involved HIC developing and launching a ‘cold’ social media campaign, which used paid advertisements to the target audience. Following this, a ‘warm’ campaign based on engagement with trusted community organisations was initiated. The ‘warm’ campaign utilised social media in addition to more traditional avenues (e.g. newsletters, awareness raising in social groups). The campaigns were run over separate time periods to differentiate between the ‘cold’ and the ‘warm’ campaign results.

‘Cold’ social media campaign

The ‘cold’ social media campaign ran at the end of 2020. Various social media platforms were investigated and Facebook was deemed the most suitable for the target audience, as it is currently the most popular social media site for older people in Australia.

Using marketing and communication principles, several different advertisements (including different taglines/provocations and photographs with mixed combinations of gender, age, ethnicity and settings) were developed for Facebook (see Appendix B).

The ads ran from HIC’s Facebook account and directed people to a HIC landing web page specific to older Italian Australians or older Vietnamese Australians or family carers who were then directed to the survey. Links to both the Plain Language Statement and Consent were provided on the landing page. Informed consent was implied using the following statement, ‘By taking the survey the respondent is giving consent and acknowledging they have understood the plain language statement.’ Participants were then invited to proceed to the survey.

All ads were loaded onto Facebook and their algorithms were used to determine distribution based on the parameters established. The parameters were set broadly to encourage the most uptake. The parameters applied can be seen in Table 1.

	Older Italian Australians	Carers for Older Italian Australians	Older Vietnamese Australians	Carers for Older Vietnamese Australians
Location	Greater Melbourne	Greater Melbourne	Greater Melbourne	Greater Melbourne
Age	65+	50-64	65+	50-64
Gender	All	All	All	All
Behaviours	Lived in Italy	-	Lived in Vietnam	-
Interests	Italy, Italian language, Regions of Italy	Italy, Italian language, Regions of Italy	Provinces of Vietnam, Overseas Vietnamese, Vietnam, Vietnamese Language	Provinces of Vietnam, Overseas Vietnamese, Vietnam, Vietnamese Language

Table 1: Applied Facebook advertising parameters to the cold campaign

‘Warm’ campaign

The ‘warm’ campaign ran in the first quarter of 2021. HIC partnered with two trusted community organisations who work with older people to assist in accessing and gathering views on medical research from within their communities. These included:

- Australian Vietnamese Women’s Association (AVWA)
- CO.AS.IT.

Both organisations were invited in as partners to undertake the following tasks:

- Review and edit all project communication materials developed to date for language and cultural appropriateness,
- Engage with their communities to promote the survey, and
- Use their knowledge of the cohort and the project to reflect on the elements that were challenging and successful.

The organisations used their own social media platforms (both chose Facebook) and their contacts through service provision to raise awareness and promote the survey.

Project tools

Two brief surveys were designed (one for older adults – Italian Australians and Vietnamese Australians, and one for family members who take on carer roles) to gather experiences and perspectives of medical research (see Appendix A). The surveys for older Italian Australians and older Vietnamese Australians were translated (NAATI certified) and then tested with people from the Italian and Vietnamese communities to sense check the language and content of the surveys. The carers survey was originally provided in English only, however under advisement from the AVWA the survey for Vietnamese Australian carers was translated and sense checked in the same format during the ‘warm’ campaign. Almost all questions were optional – the only questions requiring a response were those designed to assist with navigating people to the correct section of the survey for them.

All translations were sense checked with contacts from both the Italian and Vietnamese communities.

Feedback from these contacts included:

- both organisations commented that the materials were quite long and there were lots of steps to get through to the actual survey – unfortunately there were limited changes that could be made to the plain language statement, consent or the pathway to the survey due to ethics requirements. However, a few communication professionals reviewed to see what, if any, improvements could be made from a look and feel perspective without changing the content
- the language used for the Italian group was more conventional/modern Italian rather than ‘old’ Italian. The CO.AS.IT reviewers noted that there is a diverse range of dialects with many older first-generation migrants speaking ‘old’ Italian. It was also noted that a high percentage of first-generation Italians may have limited literacy in their native language.
- the cultural connotation of certain words, such as ‘experiment’ by the Italian group were identified as off-putting (the term was in the plain language statement).
- the Vietnamese translations were deemed better in comparison, the most notable amendment was that the informal rather than formal use of the word ‘you’ should be used.

Data collection

Survey data was collected using the SurveyMonkey platform with a total of:

- 40 responses from older Italian Australians
- 51 responses from older Vietnamese Australians
- 9 carer surveys, seven of which were completed in Vietnamese
- Overall there were 100 survey responses

The greatest uptake was when personal engagement raised awareness and asked people to respond to the survey, followed by social media promotion from a known and trusted site, the least successful was paid social media advertisements. Table 2 below shows a breakdown of where the survey responses came from.

	Total (n)
‘Cold’ campaign – social media advertising only	2
‘Warm’ AWVA social media	10
‘Warm’ AWVA personal engagement	47
‘Warm’ CO.AS.IT social media	9
‘Warm’ CO.AS.IT personal engagement	31
‘Warm’ social media for carers – cultural community not identified	1
TOTAL	100

Table 2: Engagement strategies that converted to survey responses

The surveys gathered some demographic information which can be viewed below. Please note that the carer survey omitted questions on gender and education level. This anomaly is pointed out, as it seems some carers potentially filled out the older persons survey and some older people filled out the carer survey. All results are still included as, other than demographics, all other questions between the two surveys were similar - with the difference being that participants are asked to reflect either on their own experience or the person they care for respectively.

More women than men participated in the survey, and almost all chose to disclose their gender.

<i>GENDER</i>	<i>Italian Australian</i>	<i>Vietnamese Australian</i>
<i>Female</i>	23	33
<i>Male</i>	16	15
<i>Prefer not to say</i>	1	3
<i>TOTAL (n)</i>	40	51

Table 3: Gender breakdown of survey respondents

The Italian Australians were generally older than the Vietnamese Australian respondents, with the largest group being born in the 1940's, and the 1950's respectively.

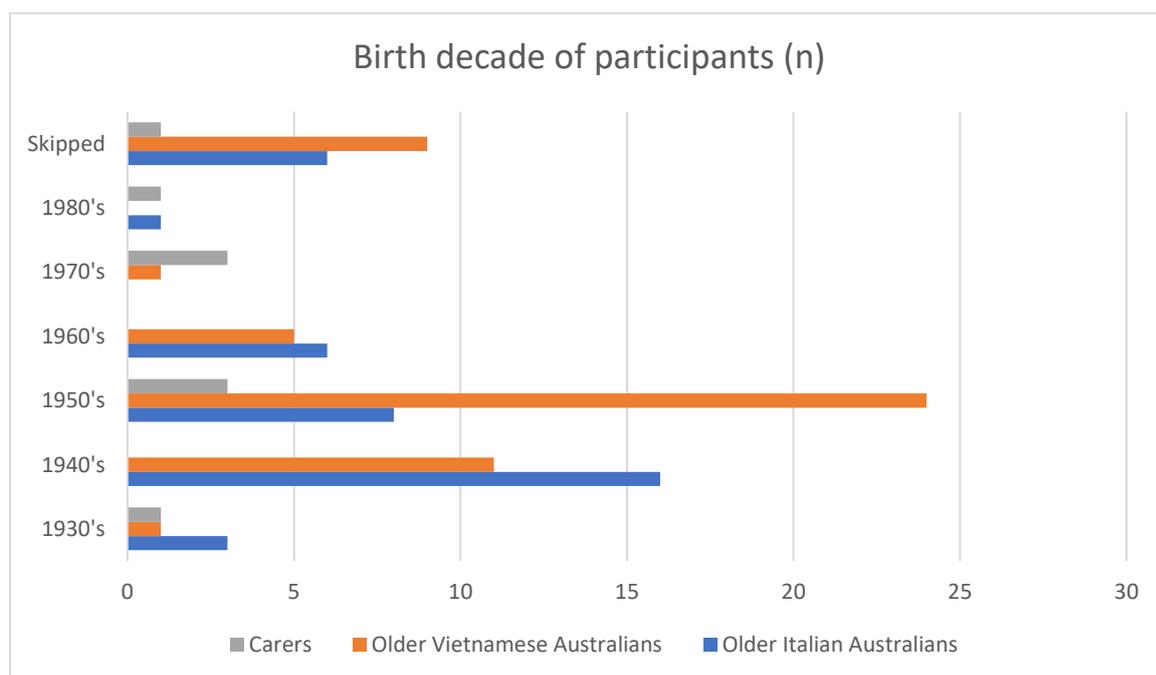


Figure 1: Birth decade of survey respondents

It is observed that more Vietnamese Australians than Italian Australians have completed high school. However, it is noted that the Vietnamese Australians were a slightly younger cohort, and a cross reference between year of birth to education levels shows of the Italian Australians born after 1950 most had completed high school.

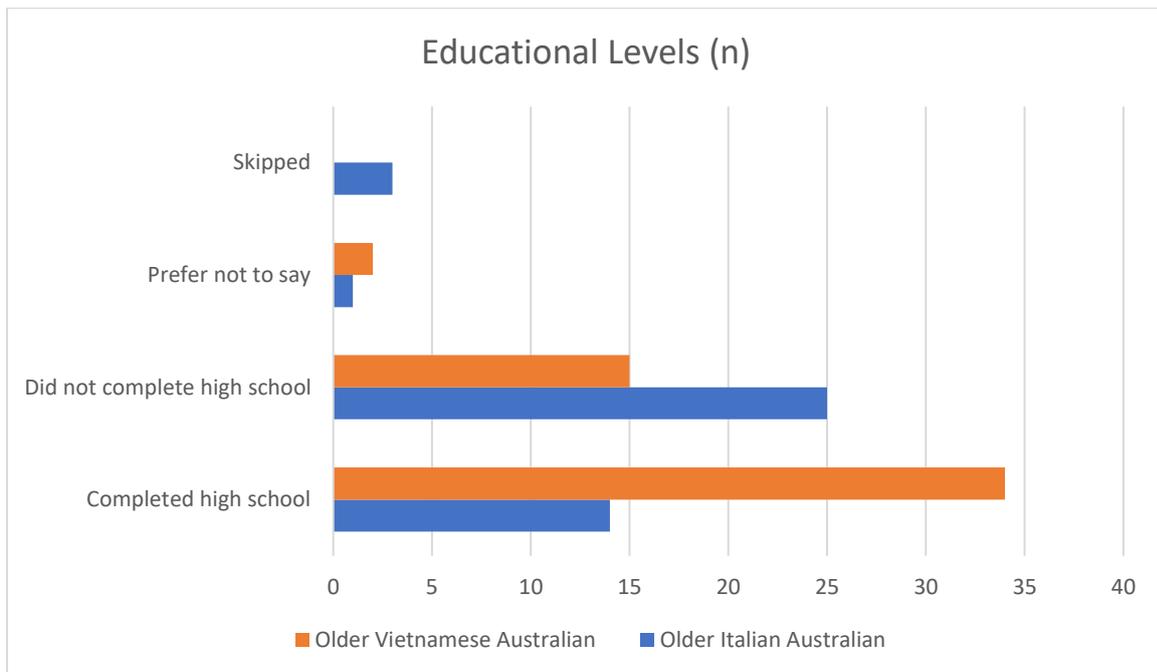


Figure 2: Education Levels of survey respondents

Data analysis

All open-ended responses in Italian or Vietnamese were extracted and translated by NAATI accredited translators.

All personal identifying information were removed and a thematic analysis was applied.

Reflections on the engagement process

Why a partnership approach

As a consumer health peak body, HIC's approach is to champion and partner with the consumer voice. This meant that HIC sought to partner with Italian Australian and Vietnamese Australian organisations to respect and understand the cultural considerations and nuances of these communities, and to enlist their expertise and support. Further, partnering with ethnic specific services helped to build credibility and trust with the community, and created a bridge between the community and the health research sector.

Whilst CO.AS.IT. and AVWA were invited to partner this only occurred after project sign off, it was a notable error of the project and a key learning that they should have been included from the outset. Significantly, the development of the surveys were undertaken between MACH researchers and HIC without inviting the relevant community to both codesign and test it broadly.

Lastly, HIC would like it noted, that the ethnic specific organisations invited to partner with the project were paid for their time. This may seem a minor point but was in fact critical as all too often researchers approach community organisations for support and expect they can assist out of goodwill. Though they might wish to assist, community organisations have their own deliverables to achieve. Therefore paying community organisations helps to create the space for their participation, recognises the value and expertise they bring, and redresses the power imbalance that can often exist between researcher and services. The results achieved here would not have been possible without the contributions of CO.AS.IT and AVWA.

Testing digital platforms

We live in an age and country where being online and able to access social media is a part of daily living for many, including older Australians. This research project looked to test if social media would be an effective way to reach older Italian Australians and older Vietnamese Australians, and their family carers. Facebook was chosen as it has the most active users per month and is the most popular social media platform with older Australians.² In fact, there are over 1,600,000 Facebook users aged 55-64, and 1,200,000 aged over 65+ in Australia.³

In theory, the benefits of digital platforms are that they work 24/7 on your behalf, they allow the end user to engage at a time which suits them, at their own pace and in a setting of their choice. Further, digital platforms can be easily shared and can reach beyond some of the traditional avenues. The developers' dilemma is in determining the best method(s) to engage. HIC took a staged approach to test the efficacy of social media via a range of approaches. Firstly the 'cold' campaign was tested and later the 'warm' campaign.

Findings of the 'cold' campaign

The 'cold' or advertising campaign tested a range of images and provocations to the target audiences, with the most successful ads boosted and the underperforming ads switched off. It is

² Facebook on top but Instagram and Pinterest growing fastest, 17th May 2019, Roy Morgan <http://www.roymorgan.com/findings/7979-social-media-trends-march-2019-201905170731>

³ Statistics compiled by SocialMediaNews.com.au for March 2021. Source: Vivid Social - Social Media Agency. Figures correct as of 31/03/21

labelled a ‘cold’ campaign in the marketing sense of cold calling on someone unsolicited to convince them to participate.

The results from the ads placed in Facebook can be seen in Table 4. These ads ran from HIC’s Facebook platform. To assist in reading the table below, know that *link clicks* are the number of people who open an ad to see the post; *impressions* are the number of times your content is displayed in a feed, no matter if it was clicked or not; *reach* is the total number of people who see your content; and *cost per click (CPC)* is the amount you pay for the ad when a viewer clicks on or opens the link/ad.

Table 4: Ad set by audience breakdown

	Link clicks (n)	Impressions (n)	Reach (n)	Cost per click (CPC)
Older Vietnamese Australians	453	39,676	17,564	\$1.23
Older Italian Australians	451	44,252	18,208	\$1.23
Carers for older Vietnamese	262	28,040	14,791	\$1.06
Carers for older Italian	239	48,572	20,396	\$1.16

The most successful campaigns in each group can be seen below between Figures 3 to 6.

Older Italian Australians – equal first “Would you ever consider taking part in medical research?” on the left and “What would stop you taking part in medical research?” on the right



Figure 3: Best performing Facebook ads for older Italian Australians

Older Vietnamese Australians – “What would stop you taking part in medical research?”

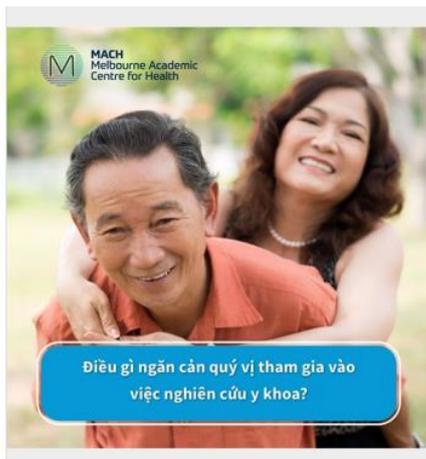


Figure 4: Best performing Facebook ads for older Vietnamese Australians

Italian Australian Carers



Figure 5: Best performing Facebook ads for Italian Australian carers

Vietnamese Australian Carers



Figure 6: Best performing Facebook ads for Vietnamese Australian carers

Whilst on balance the ads performed on a par or better than the average, (a study found the average CPC to be about \$1.72US across multiple industries),⁴ where it counted, survey completions – the results were poor with only two surveys completed; one from the carers and one from the older Vietnamese Australians.

The underperforming survey results were discussed with both marketing professionals and the ethnic specific organisations. The insights from marketers were that the subject matter was a challenging one to sell –if you were too old then you would potentially not qualify for medical research but if you were too well or healthy then the question would be of little interest to you. The second issue that marketers, and the main issue ethnic specific services identified, was the pathway to the survey. Both felt there were too many steps to get to the survey, and that the plain language statement and consent were too long. However, as the consumer information resources had already been approved by the ethics committee, only minimal changes could be made to the consent and plain language statement documents, rather efforts in the design tried to ameliorate the effect. Some of the pathway challenges are explored further under reflections on *the design process and ethics*.

Figure 7 below is a screenshot of the carers website⁵, which shows how the designers dealt with the plain language statement and consent, which started with the *why* – why is this relevant to me, rather than the *who* – who we are is not motivator to respond. Interestingly, two of the community connectors from AVWA suggested a monetary incentive would have helped with participation, even a small sum of \$5.

⁴ Facebook Ad Benchmarks for YOUR Industry [Data], Mark Irvine, August 5, 2020 [Facebook Ad Benchmarks for YOUR Industry \[Data\] | WordStream](#)

⁵ Link to the webpage <https://hic.org.au/medical-research-cald-carers-english-traditional/>



Does medical research help older family members?

Does medical research help older family members?

Would an older member of your family ever consider taking part in medical research?

Their input could help.

What would prevent an older family member from taking part in medical research?

It may be easier than they think.

How do you know the medicines your older family members take, actually work?

It's important to know that drugs work for your older family members.

How do you know if medical research helps the people you care for as they get older?

It plays an important part for everyone.



Do you make health-decisions for family members over the age of 55, who are either Italian Australian or Vietnamese Australian?

If you identify as a person who helps make health-related decisions for a family member who is Italian Australians or Vietnamese Australians over the age of 55, we would like to ask you what your thoughts are about medical research. We are also trialling different methods of recruiting people of diverse backgrounds to medical research.

Medical research can include experiments performed in a laboratory or clinical trials conducted in a hospital or finding new ways to run GPs clinics. You may be most familiar with clinical trials, where doctors test new drugs on patients. Very few Australians born in Italy or Vietnam participate in clinical trials so we are hoping to find ways that will encourage them to volunteer. Doing so will ensure the findings from clinical trials are relevant to everyone.

This study is funded by the Melbourne Academic Centre for Health (MACH), a government-funded organisation that promotes research across Melbourne-based hospitals and The University of Melbourne. Health Issues Centre, a not-for-profit organisation, is running this survey on behalf of the Melbourne Academic Centre for Health (MACH).

Take the survey

We'd love to hear what you think!

By taking the survey the respondent is giving **consent** and acknowledging they have understood the **plain language statement**.

PROCEED TO SURVEY

Figure 7: Screenshot of the carers landing webpage

Findings of the 'warm' campaign

In the second phase the project moved to engage via 'warm' methods by leveraging the reputation and trust that CO.AS.IT. and AVWA have built with their communities. These organisations used a mix of traditional (in person) and online (Facebook) engagement techniques. This section only examines online efforts.

CO.AS.IT. has a Facebook following of 3,373 at the time of reporting. CO.AS.IT. chose not to cause confusion with two similar surveys (older people and carer), so only the older person survey was promoted. The Facebook posting received four likes and three shares, through these efforts nine surveys were completed (Figure 8).



Figure 8 – CO.AS.IT. Facebook post targeting older people

AVWA have a following of 2,212 on Facebook. For the 'warm' campaign AVWA put out two Facebook postings, one for older people which had 18 likes, seven comments and one share (Figure 9); and a carers post that followed a month later, this post gathered 113 likes, two comments and seven shares (Figure 10).



Figure 9 – Facebook post from AVWA targeting older person



Figure 10: Facebook post from AVWA targeting carers

AVWA’s communication team revealed that they have only recently begun to reinvigorate their communication platforms but know that the average profile of their social media follower is a woman with young children in her early to mid 30’s. As a result it was decided to test the carer post by boosting (paying to promote it)⁶, the collective results of the Facebook posts can be seen in Table 5.

	<i>Older Vietnamese Australian post (n)</i>	<i>Carers post (n)</i>	<i>Carers post – boosted (n)</i>
<i>People reached</i>	535	724	2,900
<i>Engagements</i>	35	51	179

Table 5: Results of AVWA’s Facebook post

Further, AVWA put the project in the noticeboard section of their website in English and Vietnamese for the duration of the campaign, the English webpage received 20 views, with an average time spent of 1:39 minutes, whilst the Vietnamese webpage had eight views, with an average time spent of 4:02 minutes (see Appendix C).

Through a combination of these efforts 10 surveys were completed, seven of which were the carers survey, this aligns with the profile of their social media user.

Traditional engagement

The second part of the ‘warm’ campaign used more traditional engagement techniques, and these proved to be the most successful. 47 Vietnamese Australians and 31 Italian Australians responses were gathered when a more personal approach was utilised. AVWA and CO.AS.IT. called clients and carers, and went out to older people social clubs and activity groups to raise awareness, answer questions, and assist people to complete the survey.

Why did it work?

- The subject matter was not something that most people had considered, and according to community connectors many did not have a clear understanding of what medical research is so the ability to ask questions and receive answers helped with buy-in. (Whilst the plain language statement had the answers to many of the questions, it was 2.5 pages long)
- It was a personal approach - people know, work with and trust CO.AS.IT. and AVWA, and the community connectors were seen as one of their own
- The community connectors listened and adapted – after pushing the online survey for weeks with low uptake, hard copy surveys were distributed. This allowed responses to happen in the moment, rather than need to engage with computers, tablets or smartphones to complete.

Some of the barriers

- Covid-19 – support and social groups for older people halted in 2020 as a result of the pandemic, and were slow to restart in 2021
- Labour intensive – the community connectors needed time to reach out to people, coordinate visits to groups and then after paper surveys were completed, time to input paper responses.

⁶ Jointly, HIC and AVWA chose a small nominal sum of \$60 to test.

Some of the benefits

- The community connectors were able to gather additional insights into the community beyond what was asked in the survey.

Overall challenges to participation

The process for engaging with older Italian Australian, older Vietnamese Australian and their family carers was always going to have some challenges, some were known and others unexpected.

Engaging with digital platforms

From the outset it was recognised that digital technology could prove problematic for some participants.

- It was reported that older Italian Australians do not really use social media, rather they prefer print (Il Globo) and radio (SBS). Further, during Melbourne's Covid-19 lockdown CO.AS.IT tried to continue its social programs for older people remotely but it emerged that the majority could not participate without the support of a family member / carer
- Similarly, AVWA reported that older people prefer print, television and radio over social media, whilst younger Vietnamese Australians are prolific users of Facebook and WhatsApp.

Carers

Early on it was assumed that carers would be the easiest group to engage with online – assumptions made were - they are younger and more tech savvy, possibly more educated, and literate in English. This meant that less effort was put into engaging with carers through traditional techniques. However, the lowest response rate came from carers.

Discussions with the community connectors reflected that:

- Carers are time poor – many are working full time and/or have children of their own to look after
- The Italian Australian community connector reported speaking to family carers who were interested in the survey but who indicated that they would prefer to complete the survey with their parent present
- The Vietnamese Australian community connectors indicated that even those in the carer group were often more comfortable and had better literacy levels in Vietnamese than English. As a result the researchers translated the carer survey and AVWA promoted the carer survey in Vietnamese.

Literacy

- Language literacy
 - both the Vietnamese and Italian community connectors commented that older people have low literacy levels in both written and spoken English
 - as noted earlier, the family carers for the Vietnamese community are also not as comfortable or proficient in English
 - a considerable number of older Italian Australians have low literacy levels in reading and writing in their native language; attributable to low educational levels the consequence of World War II
- Health literacy
 - there is low health literacy with many older people, it was reported that the ability to read and understand basic health material can be challenging

- noted from the Italian community was the considerable number of individuals with chronic conditions with poor knowledge of the treatment and management of their condition
- Digital literacy – it was reported that there was low ability in the access and use of IT mediums from older people, especially the Italian Australian community.

Covid-19 and mindset

This research project occurred against the background of Covid-19, first with the long lockdowns in Melbourne and more recently with debates about medical research and vaccine developments. Whilst this seems to have little reported impact with Vietnamese Australians in the survey, it was reported that it has fueled the distrust the Italian Australian community feel towards medical research and is evident in some of their survey responses. One comment stated ‘I wish they’d filled out the surveys a week before clotting was connected to Astra Zeneca’.

Project design and ethics

Whilst the aim of the design process and ethics is to ensure rigour and good practice to research projects, it can create unintended barriers.

- The plain language statement was 2.5 pages long, community connectors and older people commented that it was a lot of information to read before reaching the survey.
- One commented that consent forms are off putting and intimidating (whilst not endorsing removing consent, the point is taken that consent forms should be reexamined in partnership with easy English experts and target audiences to be more user friendly.)
- The overall pathway to the survey was long with lots of information to process before reaching the survey – it was commented that it took longer to read all the information than to respond to the short survey.
To fulfill ethical requirements, the pathway was social media post, web page, then link to survey. Communication professionals suggest the least amount of clicks to reach destination would aid the user experience and improve uptake.
- As noted earlier, the project would have benefited by being codesigned from the outset with community connectors who can understand and bridge culture and research. Their efforts would have been most welcome especially in the development of statements to the community.

Conclusions and recommendations on the process

- Partnering with community connectors (either individuals or agencies) assists to understand culture and language from the inside. Further community connectors can assist in fast tracking rapport and trust with the community. The challenge exists in finding the right community connectors and ensuring their contributions as a partner to the project are recognised and valued. Ideally these partnerships are established early, prior to project design and ethics completion.
- Specific insights from CO.AS.IT. and AVWA to consider when engaging and working with Italian Australian and Vietnamese Australians communities include:
 - Reducing the need to read so much information – recommendations include using easy English, providing shorter tracts of information, and supplementing or using recordings or videos to explain concepts to the target audience. These steps would make engagement more dynamic, helps those with poor vision and assists with low language literacy levels

- Continue to access senior clubs and activity groups to reach the target audience and use translations and interpreters or native speakers when engaging. Ensure avenues of engagement are user friendly and appropriate e.g. paper surveys need to be in large print
- For Italian Australians, it was suggested creating a buzz would be helpful to generate buy-in e.g. getting the lead researcher to come and speak to the community as an event, then following this up with newspaper articles and radio promotions
- For Vietnamese Australians, it was suggested that incentives would assist with uptake, such as offering money or a prize.

Results of the survey

The surveys aimed to uncover people’s understanding and perceptions of medical research, and what might support their participation. Whilst there were many similarities between Italian Australians and Vietnamese Australians (both older people and carers alike) there were some differences as well. The following section unpacks the results of the surveys.

Views on medical research

How people view and understand medical research, assists medical researchers to plan and communicate with the community about medical research. In this section two key concepts were explored – whether medical research is worthwhile and what are the perceived benefits of medical research.

In the first instance, survey respondents were asked to rate the importance of medical research. Figure 11 shows that the majority agree medical research is a worthwhile activity.

Though small in number, there was a contingent who hold negative views of medical research, most of whom come from the Italian Australian cohort.

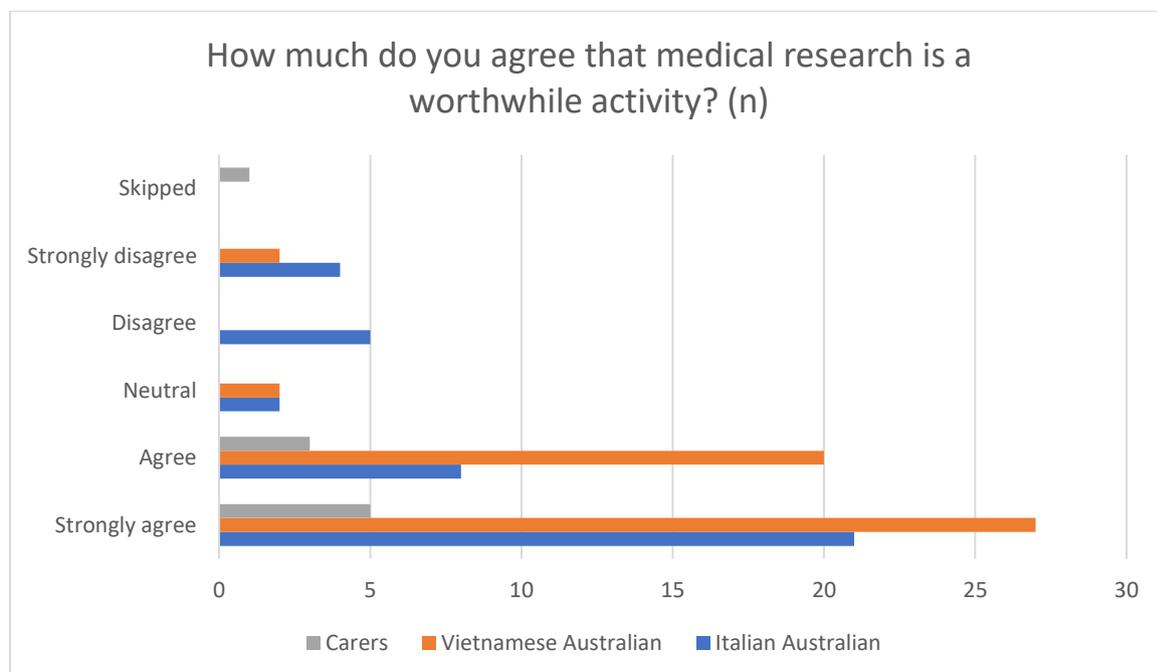


Figure 11: How much do you agree that medical research is a worthwhile activity?

Further, the open ended question was posed – *what do you think the benefits of medical research are* – to build the researchers understanding of how respondents view medical research. The key sentiments expressed were:

- Across all cohorts, the dominant sentiment was that medical research benefits the community as a whole in helping to find a cure or solution to health issues / conditions and to improve health practices. Commonly expressed views include:

‘good for finding a cure’ (IA)

‘to heal sick people’ (IA)

‘enable research to progress’ (IA)

‘ensure safety when using the drug’ (VA)

‘for the treatment of incurable diseases’ (VA)

‘prevent mistakes from happening’ (VA)

‘improve accountability and service quality’ (C)

- Cultural note – the Vietnamese Australian respondents used the word *safety* (or a derivative) frequently to describe the benefits, which was striking in its repetition. The word appeared a total of 18 times to this question from 51 responses.

- The next most commonly expressed benefit of medical research, was the benefits experienced at an individual level. Medical research benefits individual health and wellbeing, sentiments include:

‘peace of mind when using drugs’ (VA)

‘to help us and future generations’ (IA)

‘know you are safe while taking medication’ (VA)

‘possible better health during old age’ (IA)

‘detailed studies to enjoy a good life’ (IA)

- From the Italian Australians nine respondents spoke about seeing no benefits to medical research⁷. Sentiments expressed were along the line of:

‘I do not trust’

‘not many benefits’

No negative sentiments were expressed from the Vietnamese Australian or carer cohorts.

- A small group expressed uncertainty of how medical research is a benefit.

⁷ Note from earlier the timing of the survey ran across the initial Covid-19 vaccination rollout, where there was widespread concern as to the efficacy of Astra Zeneca

Participating in medical research

When it comes to participating in medical research respondents were asked about three key areas, firstly if they had ever participated in medical research – if so, how they found the experience; secondly, if they would consider taking part in medical research; and lastly, what would support them to participate.

Of all 100 respondents, a total of five people indicated that they had had experience of being part of medical research, all five were from the older Italian Australian cohort. All reported positive experiences and four indicated that they would participate again if it was relevant to them, with one undecided.

Those who had *not* participated in medical research (the remaining 95), were likewise asked if they would consider participating in medical research if it was relevant to them, the results can be seen in Figure 12. Over half the Vietnamese Australians and carers indicated that they would consider participating in medical research. Whilst nearly half the older Italian Australians said they would *not* take part in medical research - this contrasts with the older Italian Australians who have had experience of medical research.

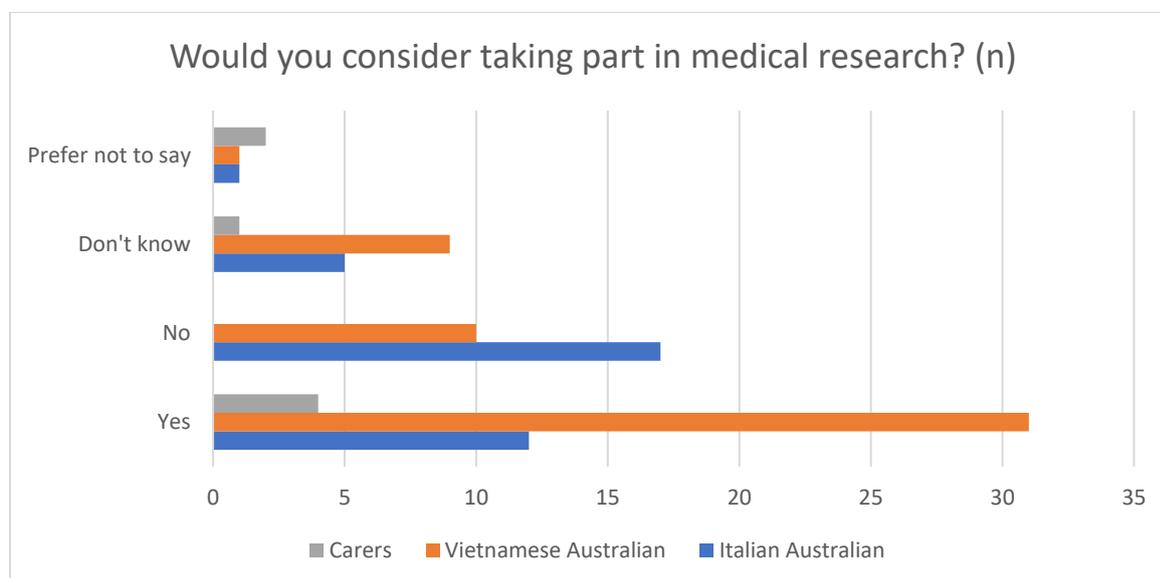


Figure 12: Would you consider taking part in medical research if it was relevant to you? From those who had not participated in medical research in the past. Note two carers skipped this question.

All respondents were asked what could support their participation in medical research, this was a multichoice question with the option to provide additional comment. Figure 13 shows that Vietnamese Australians and carers prefer to have an interpreter and written information available, to help them learn more from medical researchers, whilst the top response from Italian Australians was that none of the suggested supports would work. However, the next most popular response from Italian Australians was for written information. Further, the additional comments made relate to the need for transport, monetary compensation (from someone who is unsure they would participate in medical research), a couple of the respondents indicated that they are proficient in both languages and would like to receive any information in English and Italian/Vietnamese.

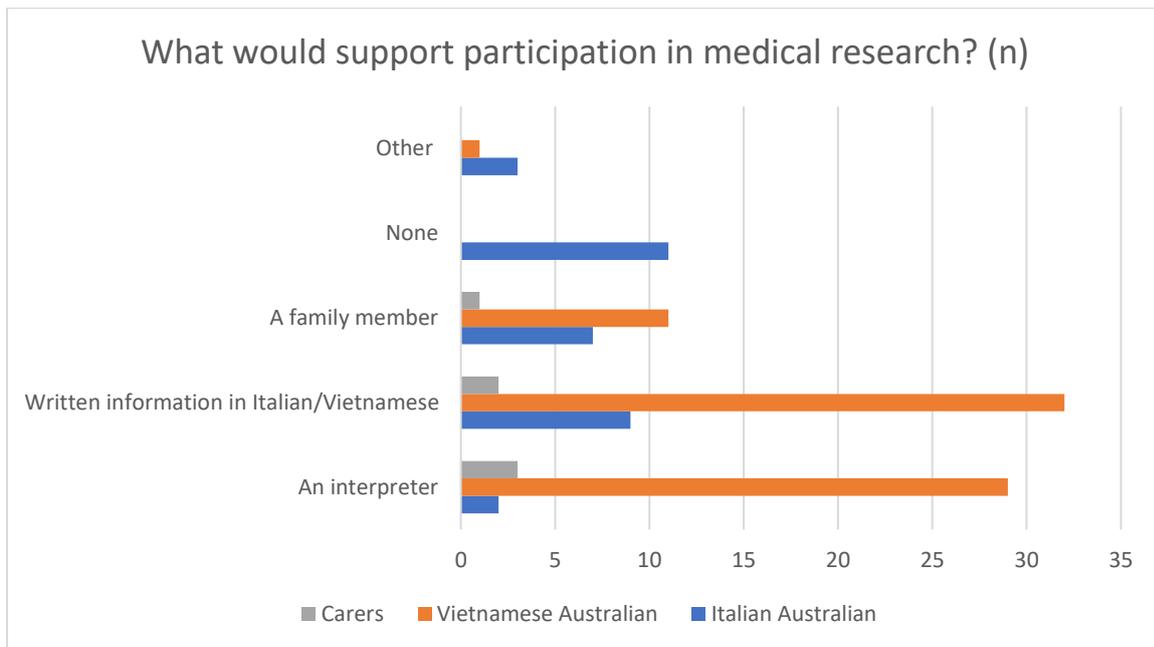


Figure 13: Survey question - *If you were to meet with medical researchers to learn more about a study, which of the following would you need? (multichoice)*

Lastly, when asked what technology people were comfortable with, older Italian Australians identified none as their leading response (consistent with overall responses to questions about participating in medical research). However, as Figure 14 shows the next popular responses for older Italian Australians were computers followed by tablet devices, whilst for older Vietnamese Australians and carers smartphones, followed by social media were the most popular responses. Whilst the results indicate many people have access to devices and apps it is unclear how widely these are used or levels of proficiency.

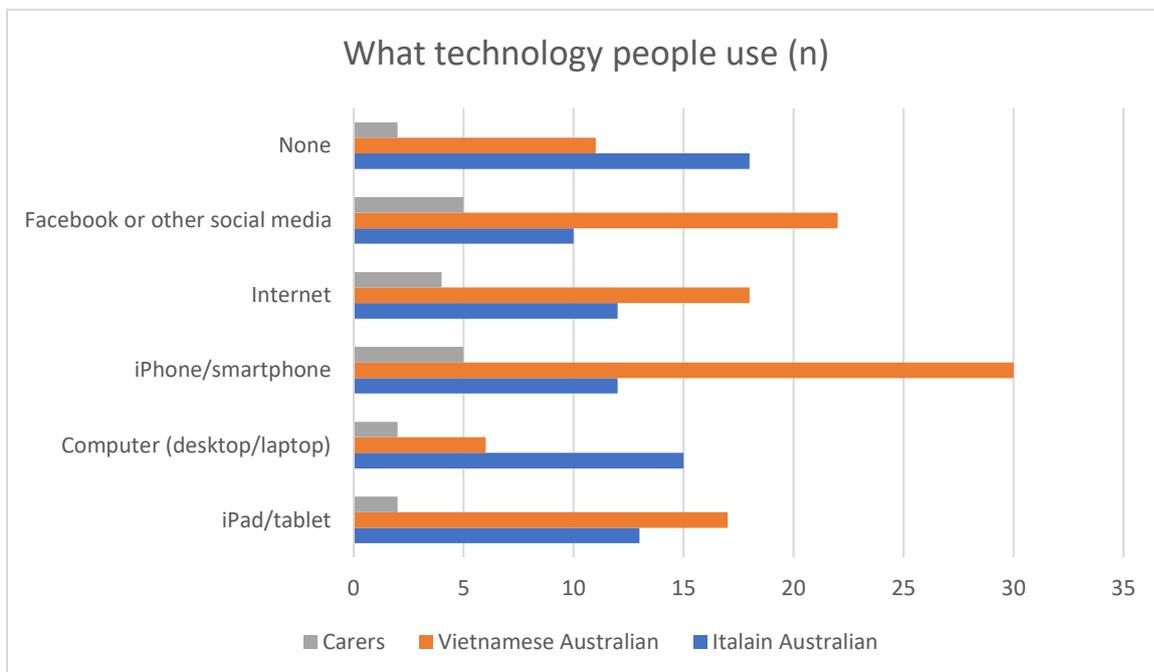


Figure 14: *Which of the following are you comfortable using? (select all that apply)*

When it came to views on participating in medical research the responses were more varied compared to people's views on medical research. In particular, the Italian Australians held more diverse views even amongst themselves, as well as when compared amongst cohorts.

Conclusions and recommendations from the survey

- Whilst overall older people are supportive in theory of medical research, there is a lack of understanding around health and medical research that could be enhanced through education and awareness raising, and which community connectors may be well placed to help address.
- The study could have been enhanced with supplementary focus groups to explore the reasons why people answered the way they did. Whilst the community connectors were able to offer some insights, there would have been more rigour in hearing this directly from participants.
- Based on the findings and how successful engagement occurred (via traditional methodologies), the study would have benefited understanding how technology platforms are used by the cohorts, to consider how these could be utilised in the future.

Appendix A

Survey questions for older Italian and Vietnamese Australians (in English)

Survey of older Italian Australians and older Vietnamese Australians about medical research

1. How much do you agree that medical research is a worthwhile activity?

- Strongly agree
- Agree
- Unsure
- Disagree
- Strongly disagree

2. Have you ever participated in medical research?

- Yes (go to Q3)
- No (go to Q6)
- Prefer not to say (go to Q6)

3. How would you describe your experience?

4. Would you consider participating in another study if it was relevant to you?

- Yes (go to Q5)
- No (go to Q8)
- Don't know/unsure? (go to Q5)
- Prefer not to say (go to Q5)

Please explain

5. If you were to meet with medical researchers to learn more about a study, which of the following would you need (tick all that apply)? (go to Q8)

- an interpreter
- written information in Vietnamese/Italian
- a family member with you
- none of the above

other, please explain-

6. Would you consider participating in medical research if it was relevant to you?

- Yes (go to Q7)
- No (go to Q8)
- Don't know/unsure? (go to Q7)
- Prefer not to say (go to Q7)

Please explain

7. If you were to meet with medical researchers to learn more about a study, which of the following would you need (tick all that apply):

- an interpreter
- written information in Vietnamese/Italian
- a family member with you
- none of the above
- other, please explain-

8. What do you think the benefits are of medical research?

9. What year were you born?

-
- Prefer not to say

10. Select which gender best represents you

- Male
- Female
- Other
- Prefer not to say

11. In what country were you born?

- Australia
- Italy

- Vietnam
- Other, please state

12. What is your preferred language?

- English
- Italian
- Vietnamese

13. What is the postcode of your home address?

-
- Prefer not to say

14. Did you complete high school?

- Yes
- No
- Prefer not to say

15. Which of the following are you comfortable using?

- None
- iPad/tablet
- Computer (desktop/laptop)
- iPhone/smartphone
- Internet
- Facebook

Survey question for family members (in English)

Your opinions on medical research (family members/carers survey)

1. How much do you agree that medical research is a worthwhile activity?

- Strongly agree
- Agree
- Unsure
- Disagree
- Strongly disagree

2. Has an older older-Italian or older-Vietnamese Australian family member you care for, ever participated in a medical research?

- Yes, go to Q3
- No, go to Q7
- Prefer not to say, go to Q7

3. How would you describe their experience?

4. If your family member wanted to meet with researchers to learn more about a new study, which of the following would they need (tick all that apply)?

- an interpreter
- written information in Vietnamese/Italian
- a family member in attendance
- None of the above
- Other, please explain-

5. Would you trust medical researchers to take care of your family member if they decided to again participate in medical research? (go to Q8)

- Yes
- No
- Prefer not to say

Please explain

7. If your family member were to meet with medical researchers to learn more about a new study, which of the following they need (tick all that apply)?

- an interpreter
- written information in Vietnamese/Italian
- a family member in attendance
- None of the above
- Other, please explain-

8. Would you trust medical researchers to take care of your family member if they decided to participate in medical research?

- Yes
- No
- Prefer not to say

Please explain

9. What do you think is the purpose of medical research?

10. Which of the following is your family member comfortable using?

- None
- iPad/ tablet
- Computer (desktop/laptop)
- iPhone/Smartphone
- Internet
- Facebook

11. What year were you born?

-
- Prefer not to say

12. In what country were you born?

- Australia
- Italy
- Vietnam or
- Other.....

13. What is the postcode of your home address?

-
- Prefer not to say

Thank you for your participation. The results of the survey will be posted on HIC's Facebook page in 2 months-time and published in your local community newsletter.

Appendix B

Each ad sat within HIC's Facebook page and branding, text above graphic read:

If something goes wrong with your health, you may rely on medicines to get better – but how do you know they work?

Did you know that medical research needs to be done before treatments are approved? But what happens if research doesn't include people from your ethnic background? Do the results still apply to you?

We'd like to hear your views: [URL goes here]

The suite of Facebook ads tested





Appendix C

English webpage from AVWA

COVID-19 Info | Update For Community

Facebook | Instagram | Search | Work with us | Webmail | English | Tiếng Việt

AUSTRALIAN VIETNAMESE WOMEN'S ASSOCIATION INC. HỘI PHỤ NỮ VIỆT ÚC

Home | About Us | Services | Information | Donations | Contact Us

Does medical research help you?

Information / Health Issues Centre

About Health Issues Centre



Health Issues Centre (HIC) is a peak consumer health advocacy NGO listening to the voices and experiences of everyday people to help shape policy decisions and service delivery in the health system.

We work on a combination of commissioned projects and campaigns that we have identified as significant priorities for all Australians.

Does medical research help you?

Would you ever consider taking part in medical research?
Your input could help.

What would stop you taking part in medical research?
It may be easier than you think.

How do you know your medicines work?
It's important to know that your drugs work.

How do you know if medical research helps you?
It plays an important part for all of us.

If you're over the age of 55 and are either Italian Australian or Vietnamese Australia, we want to hear from you!

You may not know this or maybe you haven't thought about it before, but medical research plays a vital role in the success of the medications you take. Medical research helps scientists know how a drug will behave with a particular group of people, to help minimise side effects and improve effectiveness.

Medical research can include experiments performed in a laboratory or clinical trials conducted in a hospital or finding new ways to run GPs clinics. You may be most familiar with clinical trials, where doctors test new drugs on patients. Very few Australians born in Italy or Vietnam participate in clinical trials so we are hoping to find ways that will encourage them to volunteer. Doing so will ensure the findings from clinical trials are relevant to everyone.

This study is funded by the Melbourne Academic Centre for Health (MACH) a government-funded organisation that promotes research across Melbourne-based hospitals and The University of Melbourne. Health Issues Centre a not-for-profit organisation is running this survey on behalf of the Melbourne Academic Centre for Health (MACH).

FAQs

Taking The Survey

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HEAD OFFICE 30-32 Lennox Street, Richmond, VIC 3121 9428 9078 9428 9079	BRAYBROOK 107, 6-12 South Road, Braybrook, VIC 3019 9396 1922 9396 1923	SPRINGVALE 19/134 Springvale Road, Springvale, VIC 3171 9546 2699 9546 4188	OPENING HOURS Monday to Friday 9:00am to 5:00pm AEST Excludes: Public Holidays
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