



CHF

Australia's
Health Panel

RESULTS

Results of Australia's Health Panel survey on medical research participation

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Consumers Health Forum of Australia (2021)
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Introduction

'When you are young and healthy and leading a busy life, research for medical conditions is probably far from your mind. Scientific research needs to be "SOLD" as part of everyday life and open to all.'

As part of CHF's ongoing research program, of which [Australia's Health Panel](#) is a key component, we have partnered with [The George Institute](#) to be a consumer voice on the [Join Us Register](#). The Join Us Register is an initiative that links Australians who are willing and interested in participating in health and medical research with researchers who are recruiting for research projects.

Join Us is aiming to address a known gap in the healthcare system: where despite consumers generally being willing to participate in research, they are largely unaware of medical research projects occurring in Australia and don't discuss it as an option as part of their health care or health decision making.

However, CHF has also observed there is currently little research exploring why Australian consumers do or don't participate in medical research beyond a 'lack of awareness', nor if any barriers exist that are causing this disconnect between the broader public and the medical research sector.

As such, for the Australia's Health Panel survey in August 2021, asked what consumers knew about medical research, why they had/hadn't participated in medical research and how they thought participation rates could be improved.

Demographics

For this survey 191 panellists participated. They were mostly female (74%), aged 46 or older (86%) and lived in major cities of more than 250,000 people (71%). Panellists came from across every state and territory. Panellists generally reported as being reasonably healthy, with only 7% reporting they were in poor health while on 14% reported they were in excellent health. Additionally, 1% identified as Aboriginal or Torres Strait Islander, 8% as LGBTIQ+, 9% as culturally or linguistically diverse and 18% as a person with a disability.

Awareness and experience of medical research in Australia

Panellists were overwhelmingly aware that medical research happens in Australia, with 94% responding they were aware that medical research was conducted in Australia.

When asked what medical research *actually entailed*, strong majorities of panellists selected the positively framed statements of medical research activity while only minorities selected negatively framed statements (see Table 1). This suggests that panellists appeared to not only have a good understanding of the sort of activities that constituted medical research but have a positive perception of those activities. This aligns [with previous research](#) that shows Australian's are generally supportive of the idea of medical research participation.

Table 1- Panellist understanding of "medical research"

What is your understanding of "medical research"?	% Selected
Going to a research facility (e.g. laboratory, university) to test the effect of a new drug, treatment or procedure	81%
Providing information about my health or treatment through surveys, at clinic visits or via an app	73%
Having my health regularly measured and monitored and my results recorded and analysed	73%
Undergoing procedures to test new treatments or drugs	71%
Working with my health care provider (e.g. a GP, an Oncologist) to test the effect of new medications or treatments for my condition	65%
Being a "guinea pig" so that researchers can discover new treatments for a disease	39%
Undergoing uncomfortable procedures to test new treatments or drugs	34%
Other (please specify)	11%

In providing free text responses under 'Other', panellists commonly noted that:

- medical research did not have to involve humans e.g. can involve testing on animal or in petri dishes,
- medical research could involve trialing things from home e.g. desktop research or testing via phone apps and that;
- "participation" could include being a consumer representative involved in designing and conducting the research.

This strong understanding of medical research was likely due to the high degree of personal experience of participating panellists- overall just over two thirds (68%) of panellists reported that they had participated in medical research. Further, 62% reported that they had been asked about participating in a medical research project and 60% reported that they had previously looked for opportunities to participate in medical research projects.

[Given what is known from other research](#), such a high percentage of personal experience is unlikely to be representative of the general populace and suggest that high levels of health engagement of panel members have led to high levels of health research engagement. With such

a high level of interaction with research opportunities, panellists are unable to necessarily address the already known awareness gap between willingness to participate but not being presented with the opportunity to be involved. However, this high degree of awareness does mean that other barriers and enablers of consumer participation may be investigated more thoroughly - when people *are* aware of research opportunities, what things encourage or discourage them from participating?

The majority of panellists who had participated in medical research indicated they would do so again (77%) or that maybe they would do so again (17%); implying that participating was positive experience would support future participation in medical research.

This suggests that there is not a fundamental barrier for medical research participation, such as a negative understanding or poor personal experiences, that is turning Australians off from participating in medical research. Indicating that should the known 'awareness gap' of opportunities be addressed, more research projects would be able to successfully recruit the participants they need.

"I have participated in 2 research projects and both times I have come across them by chance. I work in the medical field but have never seen or heard anything about medical research opportunities in my workplace or with colleagues. Obviously it needs far more upfront & open advertising"

General view on participating in research

All panellists, both those with and without previous research participation experience, were generally supportive of participating in research themselves with 71% saying they would participate if the opportunity came up and a further 25% said they might participate. However fewer panellists perceived themselves as someone who would be eligible to participate- with only 59% saying they thought they would be eligible while 32% thought they might be eligible.

Those who thought they would not be eligible to participate, generally pointed towards their pre-existing conditions as impacting their involvement: either they didn't have the sort of conditions that researchers would be looking at or their other pre-existing conditions that would lead them to being excluded.

Panellists also commonly cited that their age (specifically being "too old") would lead to them being ineligible to participate or other non-specific eligibility criteria depending on the purpose of the medical research.

This suggests that common research practices of ruling such populations out via eligibility criteria may need review and consideration. Because if it is changed, these results indicate that the pool of people willing to participate will potentially expand by a significant margin and

improve the ability for researchers to recruit their participant number targets. This would have the additional benefit of making results more generalisable and valuable to the wider population as Australia’s demographic profile changes with an ageing population and increasing chronic illness.

When asked what they would do to find out about participating in medical research in Australia, there was a broad array of activities panellists would pursue (see Table 2)

Table 2- How panellists would look for medical research opportunities

If you wanted to find out about participating in medical research in Australia, which of the following would you do?	% Selected
Ask an organisation that supports people with my health condition e.g. asking Asthma Australia about medical research on asthma	51%
Ask a specialist who is dealing with a specific area I am interested in e.g. asking my oncologist about medical research related to cancer	49%
Google it	40%
Contact a research institution e.g. a university	38%
Ask my GP	32%
Do nothing and wait to be asked	19%
Other (please specify)	16%
Ask a different health professional (please specify)	5%
Look in My Health Record	5%
Ask friends/family member	3%

Additionally, when asked what they would do first, the single most popular answer was ‘Google it’ (26%), followed by asking an organisation that supports people with their health conditions (22%), asking a specialist who is dealing with a specific area they are interested in (19%) and finally asking their GP (11%). With the other option.

Overall, this shows there is no ‘silver bullet’ in terms of a potential pathway to learning about research that all Australians will think to look into should they have an interest or willingness to be involved in medical research. So efforts to address the medical research ‘awareness gap’ will likely need to utilise a broad array of pathways and mechanisms to connect with health consumers.

“Very important to sensitively (and though careful research design) address barriers to participation in research according to gender, age, language etc. Historically women excluded due to ‘hormones’ and risk of pregnancy, older people due to chronic health conditions, medication use. People with cognitive impairments have been un-consenting experimental subjects in the past, but now risk exclusion from research that could be of direct and indirect benefit.”

Value of participation

"I have had the opportunity and sort opportunities to be involved as a consumer representative on medical research program and it has provided valuable knowledge, experience and overview of how these programs/trials work. Having more consumers involved provides an avenue for consumers to share their experiences which in turns assists with the fear of being involved with trials etc"

Panellists had a strong belief that participating in medical research had value for the overall Australian community, with 87% agreeing that the benefits outweighed the costs. In explaining why, the panellists near-universally noted that more participants in medical research would lead to better healthcare in one fashion or another. Whether by allowing for new treatments or medicines be developed, ensuring that medicines/treatments were effective in a larger variety of people or simply ensuring that taxpayer funds used to support research had the most value for money.

Interestingly while panellists also overall believed that participation would have a benefit for them personally, it was a smaller majority of only 66%. This lesser certainty appeared to boil down to being dependent on the specifics of individual research projects- whether the panellists felt the research project would have a personal connection to them (e.g. they had the condition being researched) and whether the particular logistics of the research aligned with their needs (e.g. the risks were worth accepting, the time commitments or location to visit didn't conflict with their other commitments).

Value of participation



87% agreed benefits outweighed the costs

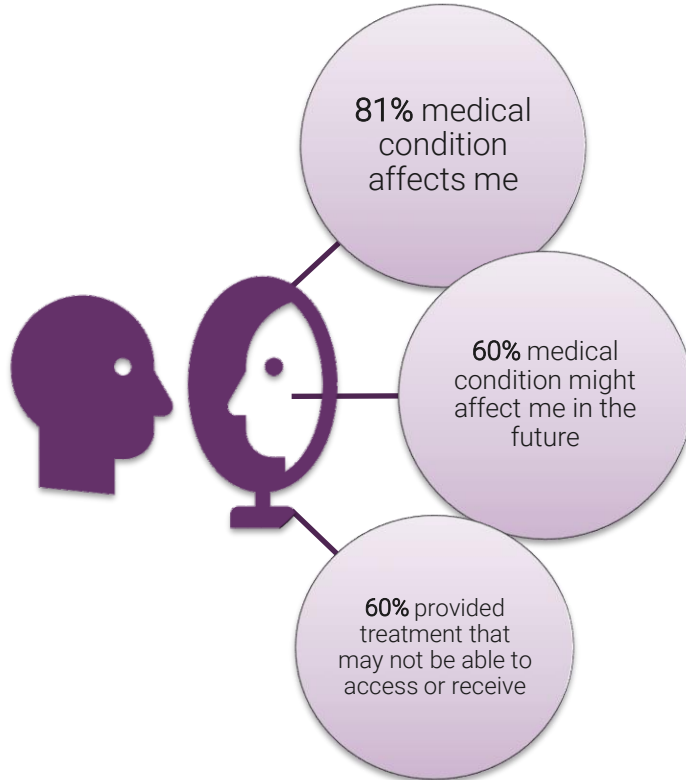


66% reflected personal benefit

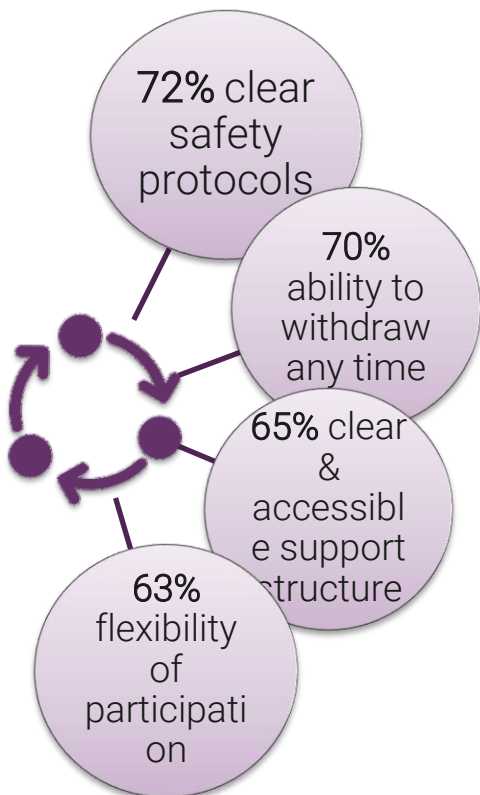
Participation enablers

Panellists were asked what sort of things would be needed to encourage them to participate in medical research or had encouraged them to participate in the past when given the opportunity. The top reasons fell into two categories:

1. Direct personal benefits:
 - The project involves a medical condition that currently affects me (81%)
 - The project involves a medical condition that might affect me in the future (60%)
 - The treatment being provided is a treatment that I would otherwise not



be able to access or receive (60%)



2. Consumer supporting processes and procedure:

- Clear safety protocols, including monitoring of potential problems and the ability for me to report problems (72%)
- The ability to withdraw at any time (70%)
- Clear and accessible support structure for participants e.g. dedicated nurse team to ask questions (65%)
- Flexibility in how/when I participate e.g. multiple options to schedule appointments for when it suits me best (63%)

Interestingly being provided with direct compensation for participation was not a large incentive for most panellists, with only a minority wanting direct financial compensation (33%) or some form of non-financial compensation (13%).

Focusing on the subset of panellists who had not previously participated in medical research, as targeting people like them will increase overall participation rates, those seven reasons either remained roughly as important or became substantially more important.

Unexpectedly, knowing someone else who had previously participated in medical research was only an enabler for a minority (23%) of panellists. Even amongst only panellists who had not personally participated, this only rose to 29%. Additionally, while only 7% reported that non-English resources would encourage them to participate, amongst CALD and ATSI panellists that substantially rose to 22%.

See Table 3 for the full breakdown of results for both all panellists and panellists with no personal experience of medical research participations.

Table 3- Panellists reported enablers of medical research participation

Medical Research Participation Enabler	All Panellists	Panellists with no research experience
The project involves a medical condition that currently affects me	81%	85%
Clear safety protocols, including monitoring of potential problems and the ability for me to report problems	72%	75%
The ability to withdraw at any time	70%	80%
Clear and accessible support structure for participants e.g. dedicated nurse team to ask questions	65%	75%
Flexibility in how/when I participate e.g. multiple options to schedule appointments for when it suits me best	63%	69%
The project involves a medical condition that might affect me in the future	60%	59%
The treatment being provided is a treatment that I would otherwise not be able to access or receive	60%	64%
The project involves a medical condition that affects someone I care for	59%	55%
General altruism and a desire to help people and the community through improved medical knowledge	57%	49%
The treatment being provided is free of charge and would otherwise not be affordable to me	57%	61%
Patients/Consumers were involved in the design and administration of the research project	55%	57%
Minimal inconvenience to my other activities from participation	51%	59%
General interest in participating in research	47%	43%
The project involves a medical condition that might affect someone I care for in the future	35%	31%
Getting paid to participate	33%	30%
Knowing someone who had participated in research previously (and had a positive experience)	23%	29%
Some form of non-financial compensation (please specify)	13%	13%
Information is able to be provided to me in a non-English language of my choice	7%	10%
Other (please specify)	6%	7%

Overall this again suggests there is no single ‘silver bullet’ of action or activity that a medical research project can do to increase its appeal to consumers but that a broad array of actions can be taken. While the ‘Direct personal benefits’ category of enablers will generally be restricted by the nature of the research project’s focus, the ‘processes and procedures’ enablers are generally agnostic to the research focus and can likely be easily accounted for if consumer considerations are meaningfully accounted for in the research design process.

“I think both researchers and community members need education about best the best practice principles of partnering together successfully so the experience is a helpful one for all. It shouldn’t be just a process of patients having research ‘done’ on them, but one in which they feel fully engaged from the beginning (helping to frame the research question/aim) to the end (being informed of outcomes and helping with dissemination/translation of new knowledge)”

Participation barriers

Conversely when asked what barriers there were to research participation, while there were no universally common ones the most consistent barriers were logistical: travel requirements (64%), financial costs to participate (53%) and time required to participate (52%). While ‘distrust of the organisation or individuals involved in the research’ what the only other reason to be a barrier for a majority (53%) of participants.

When looking at the subset of panellists who had no prior research experience, those four reasons all increased the proportion of panellists that felt those were barriers, while additionally ‘Fear of being harmed by a new drug or treatment’ also was selected by a majority (59%). Further reinforcing the importance of addressing these factors in medical research projects in order to increase participation by consumers.

Table 4- Panellists reported medical research participation barriers

Medical Research Participation Barrier	All Panellists	Panellists with no research experience
Travel/geographic distance required to participate	64%	71%
Distrust of the organisation or individuals involved in the research project	53%	56%
Financial cost of participating e.g. missing work, travel & accommodation etc	53%	60%
Time required to participate	52%	56%
Fear of being harmed by a new drug or treatment	45%	59%
I was specifically excluded from the research due to their criteria for participation	41%	45%

Concern of medical research negatively interacting with a health condition or medication I take	39%	49%
Fear of unknown or unexpected side effects	39%	48%
The research was being funded by a private company with the intention of generating a profit through a commercial product	39%	46%
Lack of a support structure for participants	35%	39%
The particular focus of the research project did not currently affect me and does not seem likely to affect me in the future	23%	29%
Concern over protection of my information and/or privacy	23%	24%
Concern over being given the 'placebo arm' rather than the actual treatment	17%	22%
The level of discomfort or pain in participation was higher than I was comfortable with	16%	18%
Too much paperwork	14%	13%
Other (please specify)	9%	10%
Knowing someone who had participated in research previous (and had had a negative experience)	8%	11%
Don't want to be a 'guinea pig'	6%	11%
Lack of resources in my own language explaining the project	5%	3%
Needles	5%	6%
General disinterest in participating in medical research	3%	5%

Interestingly effectively all of the barriers were selected by a larger proportion of panellists with no research experience than the general Panellists. While there is no way to tell from the information in the survey why this is, it is likely worth researching this difference further.

"People are often put off by trial consent forms and waivers. Signing that you accept you could die is a big deal for anyone. These forms should be discussed extensively with participants by staff and counsellors. People need to understand the risks but also the likelihood of the risks in a context they understand."

Connecting consumers with medical research opportunities

In regards to how people could be made more aware of medical research participation opportunities via existing health care structures, the most popular option was being advised by health professionals about research specifically in their health area (68%) e.g. optometrists telling people about eye related medical research. Almost as popular was targeted embedding in hospital settings (62%) e.g. integrating cancer research opportunities into cancer wards.

Panellists were split on having discussions with their GP (51% in favour) or being notified via a My Health Record setting (49% in favour). This suggests that while there are many pathways which could have medical research opportunities linked through them, none are particularly more popular or supported and thus worth prioritising over any other.



The most common additional options suggested by consumers were:

- Consumer health peak bodies- whether subject specific (such as Asthma Australia for Asthma related research) or location specific (such as Health Consumers Council for WA based research)
- General advertising, whether through social media or more traditional formats. Including potentially an official Government 'Public Awareness campaign'.
- A specific website or online noticeboard where people could sign up to find out about potential research opportunities.

Given these three options were independently suggested by dozens of panellists each via free text, they should all be pursued in addition to the three initially suggested options as clearly supported by consumers. Noting that the last consumer suggestion is essentially is what the Join Us Register is.

The value of the Join Us Register or similar was bolstered by panellists most favouring (66%) a purpose specific, central database about medical/health research as the place to register both interests and disinterest in medical research participation. Smaller majorities of panellists supported having the ability to register interest/disinterest in medical research with specific health professionals (58%), via embedding in the hospital system (56%), a setting in My Health record (53%) or with your GP to note in your full medical record (50%).

Table 5- Panellist support for different health infrastructure mechanisms to recruit for medical research

Potential consumer engagement mechanism	Could this be used to make people aware of medical research opportunities (% Yes)	Should this be used to let people register interest/disinterest in medical research opportunities (% Yes)
With specific health professionals for their relevant areas	68%	58%
Embedding in the hospital system	62%	56%
With a GP	51%	50%
My Health Record	49%	53%
A specific, central database for medical/health research	N/A	66%



Panellists had no clear preference between a participation recruitment process that favoured having consumers broadly register their interest in medical research or having consumers being specifically targeted/recruited to participate based on their health or healthcare history. 11% of panellists favoured the former, 9% the latter while 73% supported both being done concurrently.

Overall, this indicates consumer support for a wide array of pathways and mechanisms by which they should be able to be connected with medical research opportunities- whether proactively signing up in a central register and with specific health professions or being specifically contacted via targeted recruitment. However, while it is positive that consumers do appear to support using multiple pathways, should this happen it must be done in such a way that the different pathways are linked such that individual consumers aren't approached multiple times with redundant opportunities and then 'put off' medical research due being repetitively asked about it.

"Overall I feel there needs to be a more central, coordinated platform that has all the medical research projects going on at the moment in the country, so the admin isn't so ad hoc. Usually if I've come across a research program it's a fluke!"

Conclusion

In summary, this Australia's Health Panel survey found that Australians have a positive and accurate understanding of medical research in Australia and those who have personal experience participating in medical research largely have a positive experience.

Australians largely think that medical research is beneficial to themselves and the wider community, however standard practices around eligibility/exclusion criteria need to be reviewed to ensure that willing participants are not unnecessarily excluded and that results will be applicable to the wider population.

A range of participation enablers and barriers were identified and while none of them were overwhelmingly the most common; many of them were pragmatic ones that could be easily accounted for in research design processes. Primarily to maximise the ease for consumers to participate and secondarily to maximise the benefits of participating.

Lastly panellists were supportive of using a broad array of pathways to let people know about medical research participation- with a central location similar to the Join Us Register being the most preferred mechanism for consumers to proactively 'sign up' for opportunities.

CHF will use the results of this survey to continue to advocate for greater involvement of consumers in research as part of our research program by encouraging people to register with Join Us, by sharing research opportunities through our networks and by advocating for more consumers to be involved in the design of research projects.

"I wish there was MORE medical research in Australia. I don't think the general public has any understanding of how clinical trials work OR how new drugs are approved and registered here. A public education and awareness campaign would help. Just the misinformation surrounding the development and availability of COVID vaccinations shows how little people understand about how drugs are trialled, approved and registered."

The Consumers Health Forum of Australia would like to thank all panellists for giving up their time to participate in this survey.

Any questions about this survey and its findings can be directed to info@chf.org.au.