



**Australian Government
Department of Health and Aged Care**

FINAL Report on findings from the National Health and Medical Research Community Qualitative Research

3 April 2025

Acknowledgments

ORIMA pays respect to Aboriginal and Torres Strait Islander Peoples past and present, their cultures and traditions and acknowledges their continuing connection to land, sea and community.

We would also like to acknowledge and thank all the participants who were involved in our research for their valuable contribution.

Quality and Compliance Statement

This project was conducted in accordance with the international quality standard ISO 20252, the international information security standard ISO 27001, as well as the Australian Privacy Principles contained in the Privacy Act 1988 (Cth). ORIMA Research also adheres to the Privacy (Market and Social Research) Code 2021 administered by the Australian Data and Insights Association (ADIA).

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Report summary

In May 2024 the Australian Government announced the development of a **National Health and Medical Research Strategy (the National Strategy)**. This is a plan that will help decide what types of Health and Medical Research get prioritised in Australia. ORIMA Research spoke with members of the general public to understand what they think about Health and Medical Research. This report shares the findings from this research.






There were **158 people who participated in the research** (who will be referred to as participants in this summary). They participated through focus group discussions, one-on-one interviews and online discussion board forums. The research was done in November 2024 and January 2025. Participants included:

- People from a range of age groups;
- Parents/carers;
- Culturally and linguistically diverse peoples;
- People with disability;
- People with chronic illness;
- First Nations peoples;
- Individuals with low trust in health and medical research; and
- People from lower socio-economic backgrounds.

Key research findings

	<h3>Awareness and understanding of Health and Medical Research</h3> <p>Participants knew some basic information about Health and Medical Research in Australia (e.g. that research can help find out how to treat and avoid disease). However, they were unsure about:</p> <ul style="list-style-type: none"> • Who decides what research is done; • How it is paid for; • What steps are used to make sure the research is done properly; and • How the research findings lead to new treatments and impacts on people's health. <p>Most participants did not look for information about Health and Medical Research, unless it was important to their health or the health of their family and friends.</p> <p>More findings about understanding of Health and Medical Research are included in Chapter 2.</p>
	<h3>Views of the Health and Medical Research field in Australia</h3> <p>Participants felt that Health and Medical Research was important. They felt it could help people to stay healthy by improving knowledge about health and how to treat disease. Overall, participants thought that Health and Medical Research was done well in Australia, but that there were also things that could be improved.</p> <p>Participants expected Health and Medical Research to:</p> <ul style="list-style-type: none"> • Be done with the goal of improving people's health; • Help with the health issues that communities care about;

	<ul style="list-style-type: none"> • Be shared so that people understand what is being researched; and • Be done properly and ethically, but not take too long. <p>More findings about views of Health and Medical Research are included in Chapter 3.</p>
	<p>General public involvement in Health and Medical Research</p> <p>Most participants felt that the general public should have a say in the priority areas for Health and Medical Research in Australia. They felt this would make sure that money goes towards research that people think is important. Participants expected that health statistics and advice from experts should also help to decide these priority areas.</p> <p>Most participants wanted simple ways to have their say (e.g. by completing surveys or providing access to their health data). A few participants with specific interest areas wanted more in-depth opportunities (e.g. being on committees or advisory groups).</p> <p>More findings about general public involvement are included in Chapter 4.</p>
	<p>National Health and Medical Research Strategy</p> <p>Most participants had not heard about the National Strategy, but thought that having a strategy was a good idea. They had questions about it and wanted to know more information about what it would include.</p> <p>Participants felt it would be hard for the National Strategy to cover all of the things that people across Australia would be interested in. They had ideas about how priority areas for Health and Medical Research could be decided. These included making sure research considers:</p> <ul style="list-style-type: none"> • Diseases that affect the most people; • Areas of health that have the biggest impact on how well people live; • How to promote good health; • Impacts on access to healthcare; • Health emergencies; • Costs for the health system; and • Holistic health and wellbeing. <p>More findings about the National Strategy are included in Chapter 5.</p>
	<p>Communications about Health and Medical Research</p> <p>Participants felt that it was important to communicate with the general public about Health and Medical Research and the National Strategy. They felt that this would help people:</p> <ul style="list-style-type: none"> • Find out about opportunities to have their say about what is researched; • Understand what is happening in research; and • Learn more about health and science. <p>Participants felt that information about Health and Medical Research should be shared in a way that is simple. They wanted options for more detailed information if</p>

they were interested. They also felt it would be helpful to share case studies and examples of real-world impacts of research.

The research found some **challenges to communicating about Health and Medical Research priorities**, including that:

- People have different levels of understanding about research;
- People have different topic areas of interest; and
- There can be false or incorrect information about Health and Medical Research available that can lead to confusion or mistrust.

More findings about communications are included in **Chapter 6**.

1. Introduction

Background

The **Australian Government Department of Health and Aged Care** (the Department) oversees national health policies, programs and services and plays a critical role in shaping Australia's health and aged care sectors. An important part of the Department's role is **overseeing Health and Medical Research** in Australia, including funding, ethics, public engagement, strategic planning, monitoring and evaluation. These activities aim to improve health outcomes and the quality of health care for everyone in Australia.

To support Health and Medical Research in Australia, the Minister of Health and Aged Care announced the development of a **National Health and Medical Research Strategy (the National Strategy)** in May 2024. The National Strategy will provide an overarching direction for Health and Medical Research in Australia. It will build on Australia's strengths and address gaps to help improve lives through research.

A range of activities were commissioned to support the development of the National Strategy. To **understand community views on Health and Medical Research**, the Department engaged ORIMA Research to conduct qualitative research with members of the general public who may not regularly engage with this topic. This research sought to understand general public perspectives on Health and Medical Research in Australia and identify priorities to ensure the National Strategy is relevant and beneficial across the community. This report presents the findings from this research.

Research objectives

The primary aim of the research was to explore the **general public's understanding, perceptions and attitudes in relation to Health and Medical Research** in Australia. Specifically, the research explored three key areas:



Funding

- Explore the general public's understanding and perceptions of how Health and Medical Research is funded.
- Identify views about the perceived effectiveness of research funding and the extent to which funded research delivers perceived value and benefits to the community.



Priorities and meeting community needs

- Explore the role of the community in Health and Medical Research and how to engage community in research, including in identifying health priorities.
- Identify factors that impact trust in academia/researchers, policy makers and government.
- Explore specific challenges in engaging with Health and Medical Research.
- Identify considerations for research policies that are important to communities.



Communication

- Identify how community currently accesses information about research, including about research funding.

- Explore how credibility of research is assessed by the general public, including information from academia/researchers, policy makers and government.
- Explore how research funders can support engagement with community members, in a way that is inclusive and culturally safe.

Research methodology

The research was qualitative in nature involving a total of n=158 participants across 5 face-to-face focus groups, 3 online focus groups, 6 face-to-face mini focus groups, 1 online mini focus group, 6 in-depth interviews, 1 kinship in-depth interview¹ and 2 online discussion boards² (see Table 1 overleaf). The research was conducted over two rounds:

- **Round 1** – between Wednesday 6 November and Tuesday 12 November 2024, and
- **Round 2** – between Tuesday 21 January and Friday 31 January 2025.

The research methodology was designed to:

- **Ensure inclusion of a range of different perspectives in the community** – including groups who may have unique needs in relation to Health and Medical Research;
- **Provide different formats for participation** to support greater inclusion across the sample – including face-to-face and online options, written and spoken options, and options for interpreters; and
- **Allow coverage of different geographic locations** – including different States and Territories, and metropolitan, regional and remote locations.

The sample size was selected to address the scope of the project objectives, based on similar research processes. This sample size allowed for wide breadth and depth of exploration of views and experiences.

¹ That is, an in-depth interview with 2-3 participants who are related to one another.

² A digital platform where participants can post messages and engage in conversations in response to questions from a moderator over four days.

Table 1: Qualitative Research Design³

		Melbourne (metro) VIC	Sydney (metro) NSW	Devonport (regional) TAS	Townsville (regional) QLD	Port Lincoln (remote) SA	Online WA	Online NT	Online (National)	Total
General public	Aged 18-35 years						1 x OFG	1 x OFG	1 x ODB	2 x OFG 1 x ODB n=28
	Aged 36-69 years	1 x FG		1 x FG					1 x ODB	2 x FG 1 x ODB n=34
	Aged 70+ years		1 x FG		1 x FG					2 x FG n=17
Specified cohorts	Parents/carers					1 x FG			1 x OFG	1 x FG 1 x OFG n=17
	Culturally and Linguistically Diverse people ⁴	1 x MG (women)	1 x MG (men)				1 x IDI (with interpreter)		2 x IDI (with interpreter)	2 x MG 3 x IDI n=17
	First Nations people		1 x MG (women)			1 x MG (men)		1 x KIDI		2 x MG 1 x KIDI n=19
	People with disability ⁵ OR chronic illness ⁶			1 x MG					1 x OMG	1 x MG 1 x OMG n=13
	People with low trust in Health and Medical Research ⁷	1 x IDI							2 x IDI	3 x IDI n=3
	People from a lower socio-economic background ⁸				1 x MG					1 x MG n=10
TOTAL		1 x FG 1 x MG 1 x IDI n=19	1 x FG 2 x MG n=24	1 x FG 1 x MG n=16	1 x FG 1 x MG n=17	1 x FG 1 x MG n=19	1 x OFG 1 x IDI n=8	1 x OFG 1 x KIDI n=9	2 x ODB 1 x OFG 1 x OMG 4 x IDI n=46	n=158 participants

³ FG (focus group), MG (mini-focus group), OFG (online focus group), OMG (online mini-focus group), IDI (in-depth interview), KIDI (kinship paired interview) and ODB (online discussion board).

⁴ Defined for the purposes of the research as people who speak a language other than English at home and/or were born and raised overseas.

⁵ This included people who identified as having one or more physical, sensory and/or cognitive or intellectual disabilities.

⁶ Defined as people that had one or more ongoing conditions (usually lasting for 6 months or longer) that may require ongoing medical attention.

⁷ Based on their self-reported level of trust in Australia's Health and Medical Research as between 0 and 2 on a 0-10 scale, where 0 indicated no trust at all and 10 indicated that they trusted it to a great extent.

⁸ Defined as people with a total household income of less than \$60,000.

Recruitment

Participants were recruited via local ISO-accredited specialist qualitative research recruiters and ORIMA First Nations community interviewers. A screening questionnaire was developed by ORIMA and used by recruiters to ensure all participants were aged 18 or over, and to allocate participants to the most appropriate focus group, interview or discussion board. The screening questionnaire was also used to ensure the recruited sample included a spread of ages, genders, locations, life situations and educational attainment levels where possible. The demographic profile of research participants (refer to Appendix A) shows that people from a range of demographic backgrounds participated in the research.

Participants received the following reimbursement payments in recognition of their time and contribution:

- \$120 for participants in face-to-face full or mini focus groups (1.5 hours);
- \$100 for participants in online focus groups, paired/kinship interviews (1.5 hours), and individual interviews (1 hour); and
- \$80 for participants in online interviews (1 hour) and online discussion boards (4 days).

Focus group and discussion board process

The focus groups, interviews and discussion boards were moderated based on a discussion guide (see Appendix C) which covered the key topics of interest. The emphasis placed on each topic varied between discussions based upon the issues raised by specific audiences and particular points of concern or interest shared.

Before attending the focus groups and interviews, participants completed a **short homework task** (see Appendix D) to encourage them to consider the topic before the discussion and support participation.

The general flow of discussion during the focus groups, interviews, and discussion boards is presented below.



1. Awareness and understanding of Health and Medical Research, including:

- Participant understanding of types of Health and Medical Research, funding, roles and responsibilities, use and impacts; and
- Sources of information about Health and Medical Research.



2. Perceptions of Health and Medical Research, including:

- Perceived levels of effectiveness, trust and appropriateness; and
- Perceived importance of Health and Medical Research.



3. The National Strategy, including;

- Awareness and perceptions of the National Strategy; and
- Desired areas for focus and prioritisation.



4. Community engagement and involvement in the Health and Medical Research sector, including;

- Perceived role of the community and preferences for involvement;
- Motivators, enablers and barriers to engagement; and
- Communications needs and preferences.

Data analysis approach

A **manual, systematic but tailored approach** to qualitative analysis was adopted. The same team of specialist consultants conducted all the moderation, analysis and reporting to ensure the analysis was done with a full appreciation and understanding of the context in which responses were provided (e.g. non-verbal cues, language and tone). The qualitative analysis process was based on grounded theory – whereby hypotheses are formed based on the data collected through observation and interviews/focus groups, allowing insights and patterns to emerge through inductive reasoning.

For each session, extensive verbatim notes and quotes were taken by a note-taker. Regular analysis sessions were run and attended by all consultants involved in the project to **cross-check and validate emerging findings**. These involved indicative thematic analysis of results, which then formed the basis for building on and validating emerging findings and insights. As the research progressed, key themes and findings were iteratively developed and refined, to draw out deeper insights.

Presentation of findings

Qualitative research provides insights on the breadth and depth of participant views on a topic. However, it does not allow for quantifying the size and prevalence of views – as such, the number of participants holding a particular view on individual issues cannot be exactly measured.

Where relevant, the following terms have been used throughout the report to provide a qualitative indication and approximation of the size of the research audience who held particular views:



Most – refers to findings that relate to more than three quarters of the research participants;



Many—refers to findings that relate to more than half of the research participants;



Some—refers to findings that relate to around a third of the research participants; and



A few—refers to findings that relate to less than a quarter of research participants.

The term ‘participant’ is used throughout this report to refer to those who participated in a focus group or interview. When the term ‘participants’ is used without specifying a particular cohort, this term refers to participants across cohorts as findings may have been consistent across the various groups or demographics.

The most common qualitative findings are reported – except in certain situations where only a few have raised particular issues, but these are considered to be important and to have potentially wide-ranging implications/applications.

Participant quotes have also been provided throughout the report to support the main results or findings under discussion – indicated by quotation marks.

Additionally, where relevant, the following qualitative descriptors have been used, primarily to describe participants levels of understanding of Health and Medical Research: limited (i.e. minimal or low level); basic (i.e. moderate, superficial level) and good (i.e. strong, foundational level).

Throughout the report, with respect, we refer to First Nations participants and participants from culturally and linguistically diverse backgrounds. We acknowledge that that these communities are

diverse. While we have spoken with participants from a range of circumstances and locations, we acknowledge that aspects of these findings may not be applicable to the whole population of First Nations and culturally and linguistically diverse peoples in Australia. We also acknowledge differing preferred terminologies for referring to identity and cultural backgrounds. The research findings and recommendations should be considered and adapted to meet the requirements and circumstances of specific individuals and communities as appropriate.

Limitations and considerations

This research was qualitative in nature and therefore aimed to gain insights on the breadth and depth of participants' views and attitudes to Health and Medical Research. The selected sample size was appropriate for the scope and nature of the topic areas being explored. However, given the nature of qualitative research, several limitations should be noted when interpreting the findings:

- Limitations due to the selective sampling of targeted groups in the sample design – beyond the groups targeted in the research design, there are other demographic groups in the wider community that have not been specially targeted by the research (e.g. children and young people under 18 years). Therefore, this means that there may be perspectives and attitudes of groups in the population that are not addressed in this report;
- Limitations in quantifying the size and prevalence of findings – due to the qualitative nature of the research, the findings cannot be quantified or extrapolated to the broader population as the sampling method was not based on a statistically valid quantitative approach; and
- Scope and budget constraints – the project scope and budget determined the size of the research design that was used. The methodology included a mix of face-to-face and online sessions to maximise geographic and audience coverage. However, in some instances, face-to-face research was not able to be conducted (e.g. in very remote locations) and a wide selection of location across Australia.

In addition, participants were informed about the topic of the research prior to participating. While they were only provided with limited details, this may mean that people with a higher baseline interest in the topic self-selected into the research.

Glossary of terms used in this report

- Community: this term is used broadly to refer to the general public in Australia.
- Engagement: when information and knowledge about research is shared to better inform the community on why, how, where and by whom research is conducted.
- Involvement: when community representatives actively work with researchers and research organisations to help shape decisions about health research priorities, policy and practice.
- Participation: where an individual voluntarily takes part in a research project after giving informed consent.

2. Awareness and understanding of Health and Medical Research

This chapter presents findings about participants' awareness and understanding of the Health and Medical Research sector in Australia, including their sources of information about Health and Medical Research.

Overall findings

Overall, the research identified that participants had only a **basic level of understanding of the Health and Medical Research sector** in Australia. Most participants were aware of its existence and knew some high-level details (such as the types of research conducted, who was involved in funding and conducting research, and the overall value and benefit of Health and Medical Research). However, participants had limited detailed understanding about how the sector worked, including how funding decisions were made, how the sector was regulated or governed, and how research findings translated into real-world health outcomes.

“*I know [Health and Medical Research] is done by academics with health and medical specialisation, I think Government and universities also do it. You and I pay for it as well as pharmaceutical companies and Government*” – Participant aged 70+, Sydney

Most participants **did not proactively seek information about the Health and Medical Research sector and how it was funded** unless they felt it was directly relevant to them (e.g. if they or someone they knew was experiencing a health condition). As such, most participants' **understanding of the Health and Medical Research sector was based on information they received passively** (e.g. through news media or word-of-mouth).

“*I have not delved into the area of health and medical research in relation to either funding or areas of active research. I have trusted Government funding to be appropriately allocated and the sector to support relevant areas of research topics*” – Participant aged 36-69 years, Online


Current awareness and understanding of Health and Medical Research

There was **generally good awareness of the Health and Medical Research sector in Australia** among participants, particularly due to recent increased exposure to the sector during the COVID-19 pandemic (specifically in relation to vaccine and treatment development). However, there was **limited detailed understanding** of the Health and Medical Research sector and some **knowledge gaps** in relation to how funding is decided, regulation of the sector and how research directly translates into the healthcare setting.

Overall, there was **better awareness** of the following:

- **The general types of Health and Medical Research conducted** – particularly clinical trials and research to identify causes and treatments for health problems;
 - However, participants had limited awareness and understanding of the full breadth of Health and Medical Research (e.g. basic science and pre-clinical research);

- **Who conducted research** – participants had broad awareness of the different types of people and sources of Health and Medical Research, including the general role of researchers, scientists and medical professionals from universities, hospitals and pharmaceutical companies;
- **Sources of Health and Medical Research funding** – participants had high-level awareness of how Health and Medical Research was funded, including by government, charities, independent philanthropists and pharmaceutical companies;
 - However, most participants had limited awareness of specific funding bodies and schemes (e.g. NHMRC);
- **Who used research data** – participants had good awareness that Health and Medical Research data was used by health professionals to inform the care and advice they provided, by government agencies and policymakers to make decisions about the health care system and funding, by the general public to inform choices about their own health, and by private companies to inform the development of health, medical and pharmaceutical products; and
- **Overall benefits of Health and Medical Research** – including improved healthcare and life-expectancy as well as reduced financial burden on the healthcare system.
 - However, most participants had limited understanding of the full scope and spectrum of the impacts, including broader economic or social impacts.


 *“I know [Health and Medical Research] is about trying to find cures, increase longevity, and better manage health and diseases” – Participant aged 70+, Townsville*

The research identified **limited awareness and understanding** of the following:

- **How funding decisions were made** – including the decision-making process behind funding allocations and who made the decisions. Many participants assumed there was an existing funding strategy in place but were not aware of specifics. A few participants with direct experience with the sector, personally or through family/friends, had some awareness of grants processes;

 *“I don’t know too much about how research works and the funding, but I hope it’s going to the right place” — First Nations participant, NT*

- **How the sector was regulated and governed** – most participants assumed and expected the sector to have oversight and direction, but had limited understanding of who was involved or how it occurred; and

 *“I think the Governemnt regulates it... there will be someone regulating it otherwise we’d be cloning more sheep in Australia” – Participant with disability or chronic illness, Devonport*

- **How research findings translated to impacts for health consumers** – specifically, the processes that led to new research findings being adopted by health professionals to directly impact health care.

Current information sources

The research found that most participants were **not proactively seeking information about the Health and Medical Research sector or funding priorities**. Instead, participants received this information passively, and the research found it was typically about specific health conditions or research projects,

rather than about the sector as a whole. Current sources of information about Health and Medical Research were:

- **News media** – particularly in relation to high profile charities and coverage of promotional events (e.g. the ‘FightMND Big Freeze’, Breast Cancer awareness) and during the COVID-19 pandemic;


 *“I find out information through things popping up on Facebook or on the news about breakthroughs they have made” – Participant aged 18-35 years, WA*

- **Word-of-mouth** – from friends/family;
- **Hospitals and health professionals** – particularly about participation in clinical trials;
- **Personal experience being a research participant** – taking part in research projects or trials related to health; and
- **Work and university** – for those in relevant fields.

Most participants reported that they were only prompted to actively seek information about Health and Medical Research when it was relevant to their own or their family’s health, and could enable them to better understand, manage and/or advocate for their health effectively. Among those who had sought information about Health and Medical Research, participants reported that it was **difficult to find, understand and/or engage with the information**. They reported there was no clear central source of information as it was conducted by different researchers, which made searching time-consuming as it often involved accessing multiple sources. Additionally, they reported that information related to Health and Medical Research often used technical language, jargon and/or required a level of scientific literacy to understand.

When searching for information related to their **personal health**, participants reported using the following information sources:

- **Search engines** (e.g. Google) – they reported looking for official or reputable websites (such as government websites), or using the top results or AI overviews;

 *“I have not researched about health and medical research... generally I just look online or Google things if I ever notice something wrong with myself” – Participant aged 18-35 years, Online*

- **Official websites** – including direct from federal and/or State and Territory government, hospitals, patient advocacy groups and charities (e.g. Cancer Council) and international organisations (e.g. World Health Organisation);
- **Health professionals** – including General Practitioners (GPs), pharmacists and specialists; and

 *“I researched different treatment options for [my condition] ... I found information through my doctor, Government health websites, Cancer Council Australia, and trusted medical sources online” – Participant aged 36-69 years, Online*

- **Social media** – specifically through groups and pages for specific health conditions, particularly when information was not easily available through official sources.

“You trust the research, but you can’t access the system and that causes distrust” – Participant aged 36-69 years, Melbourne

“Health and medical research is opaque, unless you’re specifically looking for something, the average person will know close to nothing other than old wives tales. If there is something people learn, its from the shows on Channel 7. It would be great for reliable health information websites to be better advertised so the public doesn't fumble through less reliable info first” – Participant aged 18-35 years, NT

When assessing the **credibility of information** (about their personal health or Health and Medical Research), most participants reported that they primarily considered the **source of information** and/or **cross-checked across multiple sources**.

“I decide if a source is credible by cross matching the information I’m looking into and asking my friends, or checking if it’s accredited from a university or doctor” — Participant with disability or chronic illness, Devonport

Trusted sources among participants included:

- **Qualified health professionals;**
- **Government** (such as federal or State and Territory Health departments);
- **Health-related advocacy organisations** (e.g. Cancer Council Australia); and
- Those with relevant **lived experience of the condition** – a few participants reported particularly relying on others with lived experience as a source of information, or recommendations for where to look for further information when information from formal sources was not effective, readily available or easy to find.

“It’s easier to trust information if it comes from someone with lived experience... a real person who has gone through the thing you are looking into” — Participant with lower trust, SA

Key implications and considerations

- As the general community is unlikely to proactively seek information about Health and Medical Research, there is an opportunity to **actively communicate** to maximise the likelihood of community engagement and involvement in it.
- The research suggests communicating about the sector **through various channels to reach the wider population**, including news and social media. Trusted sources of information about this topic included health professionals, peak bodies and lived experience ambassadors, which could be leveraged to support this communication.
- To support engagement, information needs to be **easy to find** (e.g. available through a central directory) **and understand** (e.g. not use technical terms).

3. Perceptions of the Health and Medical Research sector in Australia

This chapter discusses participants' perceptions of the Health and Medical Research sector in Australia, including their levels of trust in Health and Medical Research and perceived effectiveness of the Health and Medical Research sector.

Overall findings

Unsurprisingly, the research found that participants placed a high priority on their health and wellbeing as well as that of their friends and family. They also recognised the importance of Health and Medical Research in supporting the health and wellbeing of Australians.

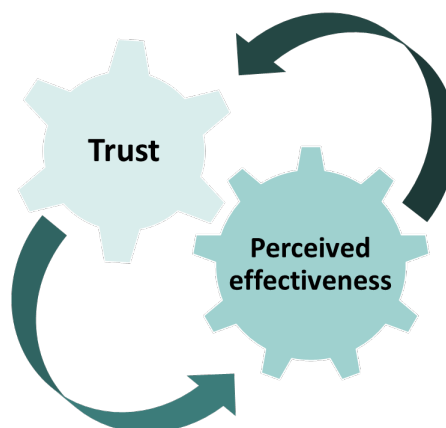
Perceptions of the sector were generally positive among participants, with most feeling the Health and Medical Research sector in Australia was trustworthy and had contributed to health advancements and achievements. However, there were also several (less widely held) negative perceptions, and lower trust in specific types of organisations within the sector.

“ *“I have been living most of my life in another country and I can say that Australia is doing really well. I think the overall success of the research can be seen in the general health of the citizens and with that in mind, Australia is doing well” – Participant aged 18-35 years, WA*

Factors impacting trust and perceived effectiveness of Health and Medical Research


The research found that there was a relationship between perceived trust and perceived effectiveness of Health and Medical Research in Australia (Figure 1). These perceptions influenced one another and were impacted by similar factors. For example, having positive perceptions of the overall effectiveness of Health and Medical Research enhanced trust in the decisions and management of the sector. When participants had limited awareness or understanding about the sector, high levels of trust typically resulted in positive assumptions about the effectiveness of the sector, and vice versa.

Figure 1: Trust and perceived effectiveness mutually reinforced/influenced one another




The research identified the following factors which impacted on participants' perceived **effectiveness** of, and **trust** in, the Health and Medical Research sector (Figure 2):

- **The perceived impact of Health and Medical Research** – participants were more likely to consider Health and Medical Research to be trustworthy and effective if they felt it had a positive impact, including both in terms of the breadth of impact (i.e. how many people and who it impacted) and the degree of impact on individual health (i.e. how much it improved quality of life or life expectancy). In assessing this, participants considered their own direct experiences with receiving healthcare, treatments or health advice as well as the associated health outcomes (e.g. access to new or effective treatments);

 *"The [Health and Medical Research] sector is effective. There's been so much improvement in things... like my friend has a diabetic pad [glucose sensor] in her arm that checks her blood glucose level, that wasn't there 15 years ago"* – Participant aged 36-69 years, Devonport

- The **purpose and motivations** of those funding or conducting research – participants were more likely to consider Health and Medical Research to be trustworthy and effective if they felt those funding or conducting research were motivated by community interests rather than political, career or commercial interests;
- The **timeliness** of research – that is, how quickly research resulted in outcomes for the general public (such as medicines, treatments, health advice or breakthroughs). Participants were more likely to consider Health and Medical Research to be trustworthy and effective if they felt research was efficient, but took time to follow appropriate processes to avoid concerns about ethics or safety;
- The **transparency** of Health and Medical Research – participants were more likely to consider Health and Medical Research to be trustworthy and effective if they felt it was easy to access and understand information about outputs and outcomes from research projects and Health and Medical Research funding;

 *"Knowing who's funded the research means there's more trust... I tend to trust organisations directly working with the affected population"* – Participant aged 18-35 years, NT

- **Alignment** of research priorities **with the needs of the community** – participants were more likely to consider Health and Medical Research to be trustworthy and effective if they felt it addressed real-world issues or groups of people who experienced poorer health outcomes; and
- **Perceived regulation of ethics and quality** – participants were more likely to consider Health and Medical Research to be trustworthy and effective if they felt research was subject to rigorous testing and quality control processes (i.e. to ensure the safety of research participants and of treatments, medicines or health advice before release to the general public) and processes to ensure quality accreditation and education of health researchers.


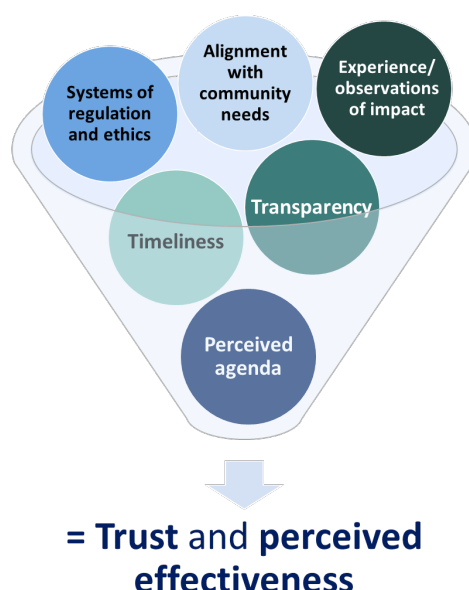
 *"We have high ethical and moral frameworks underpinning the research work done in this country. I also think there is excellent auditing and validation processes in Australian research"* – Participant aged 36-69 years, Online

Figure2: Factors impacting trust in, and perceived effectiveness of, the Health and Medical Research sector



Perceptions of Health and Medical Research in Australia

Given participants had only basic knowledge of Health and Medical Research and the Health and Medical Research sector, participants **were primarily basing their assessment of the above factors on their personal experiences with the health care system** (i.e. whether they/their family/friends had access to effective care); and/or **what they had seen or heard through news coverage about Health and Medical Research or via word-of-mouth** (e.g. about new treatments/breakthroughs). The research found that most participants were otherwise “filling in the gaps” in their knowledge of Health and Medical Research based on assumptions and speculation.

“It’s hard to know how effective [Health and Medical Research sector] is, it’s not something you look into... I sometimes hear about it on the news” – Parent/carer, Port Lincoln

Based on consideration of the range of factors outlined in the previous section, participants reported the following perceptions of Health and Medical Research:

Factor:	Community perceptions:
Impact of Health and Medical Research	<p>Most participants felt that overall Health and Medical Research in Australia was impactful – due to the sector’s:</p> <ul style="list-style-type: none"> ✓ Perceived contribution to long-term health improvements – most felt Health and Medical Research contributed to greater life expectancy, improved treatments for common diseases, and a reduction of preventable diseases; and ✓ Pioneering, “world-leading” achievements in certain areas – e.g. cancer research, vaccine development. <p>However, some participants felt that Health and Medical Research was occasionally:</p>

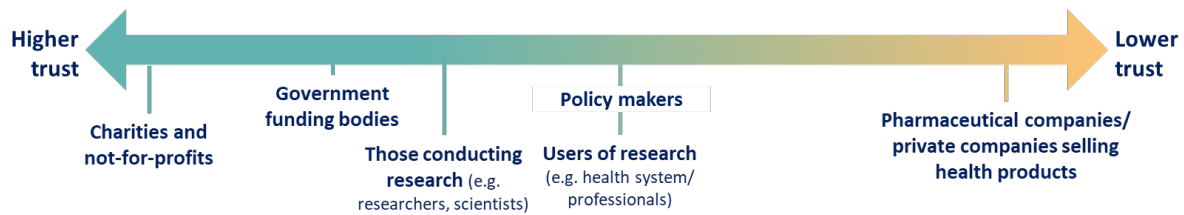
	<ul style="list-style-type: none"> × Over-stated/“over-hyped” – i.e. discoveries “misrepresented”/“exaggerated” in media (e.g. “miracle” cures), which fostered scepticism; and × Underfunded – a few felt that government funding for Health and Medical Research was lower than for other areas (e.g. Defence), which limited the impact it could have. <p>“[Health and Medical Research] in Australia is very effective compared to other countries, just look at the average lifespan in Australia compared to elsewhere” – Participant with disability or chronic illness, Devonport</p> <p>“[Australia's Health and Medical Research sector] is really effective. We're world leaders and that was proven during COVID – we had all the groundwork already in place for the vaccine” – Participant aged 36-69 years, Melbourne</p>
Purpose and motivations	<p>Participants reported having mixed perceptions about the motivations of different parts of the Health and Medical Research sector – they felt positively about decision makers, funders and researchers who were motivated by community interest (e.g. charity organisations). However, participants felt negatively about those who they felt were motivated by commercial interest (e.g. pharmaceutical companies) or by a political agenda (e.g. politicians).</p> <p>“I feel like things don't get researched unless there's money in it for someone” – Participant from lower socio-economic background, Townsville</p>
Timeliness	<p>Many participants felt that Health and Medical Research was generally appropriate and timely. However, some felt that Health and Medical Research was slow to progress (e.g. with lengthy timelines and delays in the delivery of new treatments). Some others felt that the rapid development of COVID-19 vaccines was too fast compared with other vaccines, which raised concerns for a few about safety.</p> <p>“I don't think the long time it takes to do research is appropriate, especially with [conditions] that do actually have a time limit or are impacting people significantly in the moment. I think it should probably be a bit quicker” – Participant with lower trust, Online</p>
Transparency	<p>Overall, perceived transparency of the sector was limited. Participants reported that there was limited communication about the Health and Medical Research sector and/or feeling information was too complex, technical or challenging to understand and engage with.</p> <p>“There's not enough information available, when you look online, the information is jumbled and hard to gather” – First Nations participant, Port Lincoln</p>

<p>Alignment with community needs</p>	<p>Overall, most participants felt that Health and Medical Research was well-aligned with community needs, by being appropriately focused on common health conditions.</p> <p>In some circumstances, participants reported feeling that Health and Medical Research could be biased and/or inequitable – that is, they felt there were gaps in Health and Medical Research, particularly for:</p> <ul style="list-style-type: none"> • Certain topic areas – e.g. women’s health, psychosocial wellbeing, conditions with low prevalence, and “less publicised” health conditions. A few participants felt there was “disproportionate” funding for high-profile conditions (e.g. that were publicised using celebrity endorsement). • Certain population groups, including: <ul style="list-style-type: none"> ○ First Nations people – participants cited poorer health outcomes for this cohort (despite being heavily researched) as an indicator that Health and Medical Research was not equitable; and ○ Regional and rural communities – participants felt that this cohort had less access to research than people living in metropolitan areas and that research conclusions did not consider the context of these cohorts (e.g. recommendations about frequent health care visits which would be challenging due to the limited access in some communities). <p><i>“I have seen lots of articles on how historically, women have often been excluded from medical research, which has resulted in a lack of understanding about women's health and their biology. I understand that only within the last 50 years have we been catching up to this lack of research” – Participant aged 18-35 years, Online</i></p> <p><i>“As Aboriginals, we’re the most researched people in the world... but how long has Close the Gap been there for, have they closed the gap yet?” – First Nations participant, Sydney</i></p>
<p>Regulation of ethics and quality</p>	<p>While most participants reported they were unaware of who regulated Health and Medical Research or how it was regulated, they felt that Health and Medical Research was ethical and safe – as they perceived or assumed the sector had robust regulatory standards to reduce harm and negative outcomes from research, particularly in comparison to other countries.</p> <p><i>“I believe that medical research in Australia is much more regulated and transparent. My trust is all based on blind faith” – Participant aged 36-69 years, Online</i></p>

Trust in the Health and Medical Research sector

Overall, many participants had a high level of trust in Health and Medical Research despite having limited awareness or understanding of how decisions were made. However, participants reported that levels of **trust varied across the Health and Medical Research sector** (see Figure 3) and, for a few, trust **varied in response to particular events**.

Figure 3: Reported levels of trust across the Health and Medical Research sector



As outlined in Figure 3, participants reported:

- **Higher levels of trust in:**
 - **Charities, not-for-profits, and philanthropic funders** – as they were perceived to have a community welfare-focused agenda;
 - **Government funding bodies** – due to their perceived community-focused nature;
 - However, a few felt there was a risk of political agendas influencing public funding, which limited their trust.
 - **Researchers and scientists conducting research** – as they were perceived to be subject to rigorous regulation and reviewed by their peers, and generally were felt to have an altruistic agenda.
 - However, a few participants reported feeling sceptical of the motivations of “career researchers” who they felt were likely to prioritise their own self-interests.



“I generally trust the sector, including charities and Government, but my trust in pharmaceutical companies is low” – Participant from a culturally and linguistically diverse background, Melbourne

- **Moderate or mixed levels of trust in:**
 - **Those who utilised and disseminated Health and Medical Research data** (e.g. health care providers and professionals) – participants reported that their levels of trust differed by individual health professionals. For example, many reported encountering some professionals that they felt were not effectively or appropriately informed about Health and Medical Research or selectively used Health and Medical Research; and
 - **Policy makers** – while some participants were confident that they used research data and evidence to inform decision making, a few felt that policy decisions were not necessarily always consumer-centred or oriented towards “real world” experiences.



“Policy makers are too far removed from reality... they’re the guys in the glass building and they’re not the ones experiencing the healthcare, so I don’t trust them” – Participant with disability or chronic illness, Devonport

- **Lower levels of trust in pharmaceutical companies and private companies** selling health products – primarily due to perceptions of commercial priorities and interests.
 - However, a few participants reported they were more likely to trust in the efficiency and quality of private companies due to their commercial motivations to create a competitive product.

“Overall I have a high level of trust... If I was to place them on a scale from most to least [trustworthy] it would be: bequests, community fundraising, philanthropists, government, private companies, then big pharma. Trust in these sources is determined by what their agenda might be; with the most trustworthy perceived to have no agenda” – Participant aged 36-69 years, Online

For those with lower trust in health, government or research systems, their experiences during the COVID-19 pandemic confirmed or exacerbated their distrust due to concerns about private companies influencing the vaccine agenda, receiving conflicting information about Health and Medical Research, or having negative experiences with public health mandates and advice.

“Since COVID, I think my trust has decreased. In 2020 I woke up and questioned what was forced on me... because to go to certain places I [needed the vaccine]. The more vaccinations, the more dollars that got handed out” – Participant with disability or chronic illness, Online

Key implications and considerations

- Health and Medical Research and information about the sector was **important to, and valued by, participants** – there was a clear perception that it was important and worthwhile investing in and communicating with the public about Health and Medical Research.
- Communications and initiatives which focus on the six factors which were found to impact on trust and effectiveness (see page 15) are likely to **support positive attitudes and perceptions** towards Health and Medical Research.
- There are **opportunities to reinforce or enhance trust in Health and Medical Research** by reinforcing and enhancing perceptions of the effectiveness of Health and Medical Research funding (e.g. by communicating the impact of funding) and vices versa (e.g. transparency about funding is likely to increase perceptions of effectiveness of the sector).

4. Findings about community involvement in Health and Medical Research

This chapter discusses participants' perceptions of the role of the community in the Health and Medical Research sector and in helping shape decisions about research priorities. This includes motivators, barriers and preferences for community involvement in Health and Medical Research.

Overall findings

Overall, most participants felt the community should have opportunities to be involved with Health and Medical Research. They felt that incorporating community perspectives in priority setting could help to ensure that funding was aligned with the current needs and challenges faced by communities. However, participants also emphasised that community input should be balanced with other factors (such as objective health data and expert advice) to inform a holistic assessment of priorities and mitigate the risk of individual biases.

Participants were more interested in being personally involved in Health and Medical Research if they had personal experience with specific health conditions, or if they had strong positive perceptions about the value of personally contributing.

Overall, the research found that lighter-touch involvement opportunities (e.g. sharing data, completing surveys) had the broadest appeal, due to their perceived convenience.

“*The general public should be involved in deciding the priorities because people will feel more connected and listened to when their problems are addressed. At the end they are the real stakeholders and it's for the betterment of these people. The authorities should be aware of the problems of the general public so that they can find the appropriate solutions*” – Participant aged 18-35 years, Online

Perceptions of community involvement in Health and Medical Research

Participants strongly valued community involvement in Health and Medical Research as they felt it would ensure that research and funding priorities effectively addressed real world problems. While most participants expected that it was primarily the role of experts to set funding priorities given their access to professional knowledge, statistics and large data sets, they identified that the community had a role in providing experts with their input to help inform decision making.

Participants identified a range of **benefits** to **community involvement in Health and Medical Research**. These included:

- **Personal benefits for individuals involved in Health and Medical Research** – such as:
 - Feeling a sense of **agency and empowerment** from voicing their perspectives; and
 - **Increased knowledge** about Health and Medical Research and increased **scientific literacy** via learning from the process of being involved as well as being able to share the knowledge with others.

“The impact of involving community [in setting Health and Medical Research funding priorities] is that it makes you feel that you are more involved in having a say... otherwise you’re leaving all these decisions to people 5,000km away, who see you as a statistic, but you don’t get to feel heard or understood” — Participant aged 18-35 years, NT

- **Benefits to the research** – including:
 - Improving the **relevance of the research**, by ensuring that funding is aligned with the current needs and challenges of communities and those with lived experience; and
 - Enhancing the **quality of the research** by ensuring research is informed by the knowledge and experience of those with lived experience.
- **Benefits to the Health and Medical Research sector** – including:
 - **Increased community trust** — participants felt that inviting community involvement increased transparency and confidence in Health and Medical Research; and
 - **Increased public awareness and interest in Health and Medical Research** — participants felt that involvement in the sector would improve understanding and engagement with research across a broad range of the community, in turn supporting broader health literacy and sector accountability.

“You would pay more attention to [Health and Medical Research] because you’re so involved, and talk about it more and get the information out” — Participant aged 36-69 years, Devonport

- **Benefits to the wider Australian community** – including by supporting higher quality and more relevant research.

Participants reported the following potential **challenges or drawbacks of community involvement**:

- **Potential bias and subjectivity** — participants felt that the influence of emotion, media coverage or personal experience on community perspectives may skew funding decisions towards high-profile but less impactful areas;
- **Challenges representing the broad community** — specifically, that a small number of engaged voices may not accurately reflect the views of the broader community they represent;
- **Balancing varied and diverse perspectives** — participants felt that public opinions would reflect a wide range of different health needs, which would be difficult to reconcile into clear overall priorities; and

“If you’re touched by a particular illness then you would think that specific area will need to be researched... so [priorities] will be so different for everyone... the people with the expertise and qualifications should be making the decisions [about what to research]” — Participant aged 70+, Sydney

- **Limited scientific expertise of community** — specifically, that the community would not have the technical knowledge to identify how research could be best used and prioritised.

“I don’t think that general public [should] be involved in deciding overall priorities in Australia’s health and medical research sector. We have trained people in these roles for a reason. I don’t have the knowledge or information to make these decisions” — Participant aged 36-69 years, Online

Motivators and barriers to community involvement in Health and Medical Research

Despite positive perceptions of community involvement in priority setting, most participants had not actively considered being involved in the Health and Medical Research sector prior to the research. They were also not aware of opportunities to do so. The research found that **motivators** to get involved included:

- **Personal relevance and impact** – participants with lived experience (personally or through a friend or family member) of a particular condition, treatment or healthcare need, were more interested in being involved. They had a desire to advocate and share knowledge to improve outcomes for themselves or others like them;

“My friend passed away from leukaemia, in this instance I would be interested and involved in helping the research towards this effort without compensation” – Participant aged 18-35 years, Online

- **Perceiving that personal involvement would be valued or useful** – specifically, feeling that they had a useful and/or unique perspective that they could contribute as well as feeling that they would be heard and would contribute to making a positive difference. Participants who had previous positive experiences with similar activities were more interested as a result.

“Seeing direct evidence that my or the public's involvement in activities is actually being listened to would be a great motivator for even more people to get involved as knowing that your opinion is being heard and matters is what everyone wants to feel” – Participant aged 36-69 years, Online

“I want a better outcome for my people, and I want to break the cycle, close the gap. I could advocate for them, speak on their behalf and provide a better understanding, like to explain things to the other Indigenous people” – First Nations participant, NT

Participants reported the following **enablers** to involvement in Health and Medical Research – i.e. things that would make it easier for them to be involved:

- **“Easy” or convenient options to be involved** – specifically, having options that were time flexible, did not require a large time commitment, and were easy to access (e.g. online or at a nearby location);

“Involvement would have to be online because we are all busy people. If I’m time poor then I want it to be more easily accessible... maintaining that variety of options is important to maintain a reflective group across the population” – Participant with disability or chronic illness, Online

- **Positive incentive or personal benefit** – including receiving a monetary incentive for their time, gaining relevant knowledge (e.g. related to their own health or how to manage a health condition), or personal enjoyment; and
- **Feeling their information and data would be protected** – including being able to remain anonymous, or feeling confident their privacy and confidentiality would be upheld.

Participants reported the following **barriers to involvement** in Health and Medical Research:

- **Not being aware of opportunities** – particularly of opportunities in specific areas of health that aligned with their interests or experiences;
- **Time constraints** and/or **competing priorities** – specifically, being “too busy” and/or feeling that participation was not a priority for them;

“I would be less likely to be involved if it was too often or too arduous... anything more than once every couple of months is too much for me” – Participant aged 36-69 years, Devonport

- **Overly complex information or involvement options** – including the use of jargon or complex medical language in communications related to involvement, and limited accessible information for those with limited English literacy;
- **Limited confidence** – specifically, feeling there would be a need for specialised knowledge or a high level of scientific literacy to be involved, or not understanding the value or benefit they could contribute;
- **Negative past experiences** – with the health system, research, researchers or similar consultation processes. A few participants reported having experiences on non-health related community advisory committees that were culturally unsafe or inappropriate, or reported feeling they were “judged” by others regarding their personal health beliefs, which increased their hesitancy about being involved in similar processes in the future;

“I was involved in another advisory body and it was such a negative experience, I had to walk out after a couple of days. I was the only Aboriginal person there and they wouldn’t even listen to me... there was no cultural safety. So I probably wouldn’t do that again” – First Nations participant, Sydney

- **Limited physical access** – particularly for those living remotely who felt they would need to travel to metropolitan areas to participate;

“Distance is a barrier, research might be done in Melbourne or in South Australia and I’m here” – Participant aged 70+, Townsville

- **Being uncomfortable discussing their personal health conditions** – particularly if they felt there was a social stigma about a condition they had (e.g. mental health and sexual health conditions) or they were part of a community that had established social norms about not discussing health (e.g. among older and First Nations men); and

“There’s stigma attached to health... being a male, in general I don’t like to voice what I’m going through” – First Nations participant, Port Lincoln

- **Feeling that contributions would not be valued or listened to** – specifically, that involvement was “tokenistic” or that their perspectives were not taken seriously by researchers and funding bodies.

Preference for community involvement

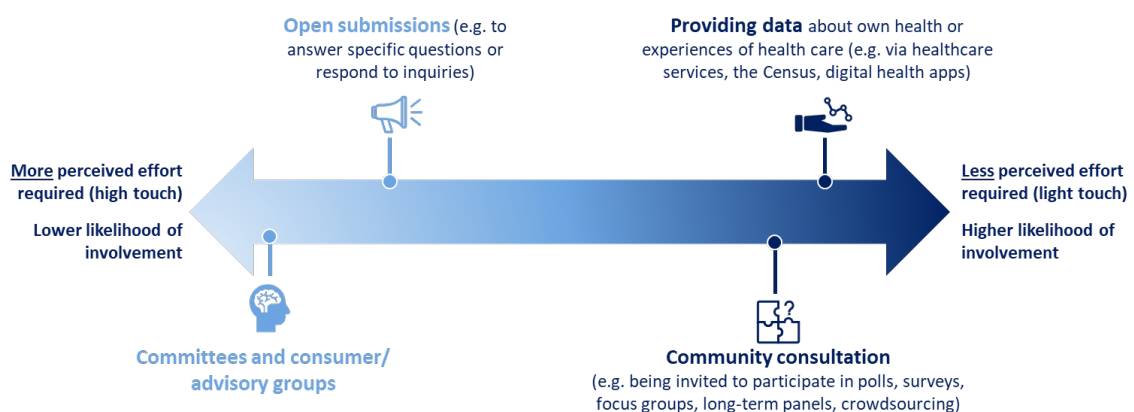
The research explored a range of potential avenues for community involvement in Health and Medical Research priority setting and funding decisions. While levels of interest in involvement varied, most

participants had greater interest in contributing via activities that were simple and had a low time commitment.

When prompted with a larger list of potential engagement activities (see Appendix B), most participants reported they were more likely to be involved in the Health and Medical Research sector by **providing access to their health data and information** (e.g. via healthcare services, the Census, or digital health apps) or by participating in **simple community consultation activities** such as polls, surveys, panels, focus groups or crowdsourcing (see 4). These activities were of particular interest as they were perceived to have a short, achievable time commitment and could be completed flexibly; and they required less specialised knowledge, experience or scientific literacy. This level of involvement was felt to be appropriate for the general public as they were small, but meaningful opportunities to be involved that could be balanced with other inputs to enhance the relevance and positive impact of Health and Medical Research.

“I would definitely give health data, it’s easy and the GPs have the data. By the time the researcher gets it, it’ll be anonymous... it’s a great idea and if I can help future generations I definitely would” – Participant aged 70+, Townsville

Figure 4: Types of community involvement in Health and Medical Research



Only a few participants reported they would be interested in activities requiring a greater time commitment, level of input or knowledge such as participating in a group or committee, workshop or public submission process. These participants tended to have stronger motivators for being involved in Health and Medical Research such as being personally impacted or knowing someone personally impacted by a health condition, or representing an underrepresented cultural background or community (including those living in regional or remote areas, those from a First Nations community, or from a culturally and linguistically diverse background). These participants were more likely to identify the value of their perspectives and appreciate the opportunity to have a say.

“[I would feel motivated] if someone in our family was impacted by direct experience” — Participant from a culturally and linguistically diverse background, Melbourne

The research identified **additional considerations** for supporting involvement with specific cohorts, including:

- For people with **lived experience and their carers**:

- Acknowledging and respecting the expertise of people with lived experience and their carers; and
- Ensuring that opportunities are physically and sensorily accessible, and can accommodate a range of abilities and accessibility needs.
- For people from **culturally and linguistically diverse backgrounds**:
 - For consultations (e.g. questionnaires, polls), participants reported needing information in simple English, or options for translated content or interpreter support when activities were targeted towards specific language groups; and
 - Employing cultural sensitivity for both the audience and condition-specific contexts (e.g. research related to sexual health).
- For **First Nations peoples**:
 - Ensure activities implement culturally safe and appropriate practices, and take a localised approach in their design (e.g. engage local, respected community Elders and leaders and avoid overly formal language/use locally appropriate terminology);
 - Minimise consultation fatigue by being strategic about when and why engagement occurs;
 - Prioritise reciprocity for all engagements with communities and ensure accessibility of information (e.g. provide options for verbal/audio presentation as well as simple, plain English written versions); and
 - Adopt meaningful co-design and co-led processes.

Key implications and considerations

- There is an opportunity to **increase community awareness** of opportunities to be involved in Health and Medical Research and increase perceptions of the value and relevance of this involvement.
- The **barriers and enablers** outlined in this chapter should be considered in the development of community involvement activities to maximise the ease and accessibility of involvement.
- The research suggests that there is a need to **tailor involvement opportunities**, and communications about these, to the needs and interests of certain cohorts – for example, more general information and opportunities for the broad community, and more targeted and directed information and opportunities for those with lived experience or stronger motivators.

5. Findings about the National Strategy

This chapter discusses participants' interest and ideas in relation to the National Health and Medical Research Strategy, including priorities to be considered in its development.

Overall findings

Overall, there was **limited awareness** that the National Strategy was being developed. **Most participants supported the general concept**, however there were some concerns based on their limited understanding. The research found that effective communication about the National Strategy could minimise concerns and potential negative perceptions.

“[The National Strategy] has the possibility of providing clarity and direction, reduction of duplication of effort and to allow researchers to learn from each other to make advances more quickly... but it might reduce the flexibility to respond to new emerging risks or research methods” – Participant aged 36-69 years, Online

Given the challenge of reflecting the diversity of individual needs and preferences in one national strategy, participants reported that the National Strategy should include a framework of key principles that inform the selection of priorities and funding decisions to support trust and transparency in the sector.

Perceptions of having the National Strategy

The research identified **that most participants held positive perceptions** about the concept of the National Strategy. Participants felt that introducing the National Strategy would be beneficial for Health and Medical Research in Australia, particularly in terms of:

- **Improving efficiency** – by reducing duplication of research and funding efforts by setting an overarching direction;
- **Providing a consistent, long-term focus** – by having a defined and unified set of principles to set the direction, providing a clearer and more long-term focus;
- **Improving equity** – between different areas of research and cohorts currently experiencing poorer health outcomes by introducing a strategic approach to enhance focus on specific issues;

“Closing the gaps with regards to more disadvantaged communities such as regional communities, disability communities and culturally diverse communities. I think this is important because it is important that everybody receives the most optimal level of healthcare possible. I think that at the moment, these groups are not getting the same level of healthcare and access to healthcare as they should be” — Participant aged 18-35 years, Online


- **Increased collaboration** – between key stakeholders in the sector by setting a shared direction and promoting the sharing of ideas to maximise positive outcomes; and
- **Greater accountability and transparency** – of the Health and Medical Research sector, particularly by having a clear set of publicly available priorities against which the progress of Health and Medical Research can be assessed.

“The benefit [of having a national strategy] is that we have a baseline to look back on in the future. For example, we can point to this document in ten years' time and say, 'this is what we


started off saying we wanted to achieve, and this is how well we have gone about achieving those aims.’ It will help keep us accountable and make more of a difference with the research we are doing” — Participant from a culturally and linguistically diverse background background, Sydney

However, despite having positive perceptions, many participants also reported having **questions or concerns** about the National Strategy which could **develop into negative perceptions if not appropriately addressed**. These included questions and concerns about:

- The potential for the National Strategy to be too **inflexible**:
 - To address unforeseen future needs or challenges (e.g. emerging health emergencies); and
 - To meet the diversity of needs across Australia (e.g. specific regional-level needs that may not be relevant to the broader population and reflected in national priorities).

 *“The strategy should be flexible and prioritise what the Australian people need” — Participant with lower trust, Melbourne*

- **Potential for politicisation** – participants were concerned that priorities could be influenced by the changing priorities of successive governments. Participants felt this could reduce the ability of the National Strategy to have long-term impacts and/or lead to suspicions of it being a “performative” gesture by the Government to appear to be acting in relation to Health and Medical Research without a genuine commitment to improve;

 *“Having a national strategy is a great idea, however.... how can you ensure that the people making the Strategy are doing it for the best reasons possible and not just for political reasons, or personal reasons?” — Participant aged 36-69 years, Online*

- **Poor integration with existing strategies and funding** – specifically:
 - Scepticism that the National Strategy was redundant or a superficial rebranding of existing efforts, based on the assumption that a strategy already existed; and
 - Concern that the priorities for the National Strategy would override existing funding priorities and lead to defunding of ongoing research.

 *“The strategy sounds like a different dress on the same pig” — First Nations participant, Sydney*

- **Concern about how research funding was being prioritised currently** – for some participants the need for the introduction of the National Strategy implied there was a “problem” with existing research and funding, undermining trust in the sector.


Community priorities for the National Strategy

While most participants identified the value of community input into Health and Medical Research priority-setting, they also understood the challenges of addressing the diversity of individual needs and preferences and the potential risk for individual bias to skew priorities from critical areas. As such, most participants felt there was a need for a balanced and neutral approach to deciding priorities for the National Strategy.


Most participants felt the National Strategy should include a **framework of key principles that inform the selection of priorities and funding decisions** to **support trust and transparency** in the sector. As

shown in Figure 5, participants identified several key considerations which they felt should underpin the selection of funding priorities, including:

- **Prevalence of a health condition or issue** – participants felt the National Strategy should prioritise conditions that were more prevalent among the total population or among at-risk groups or people experiencing disadvantage;

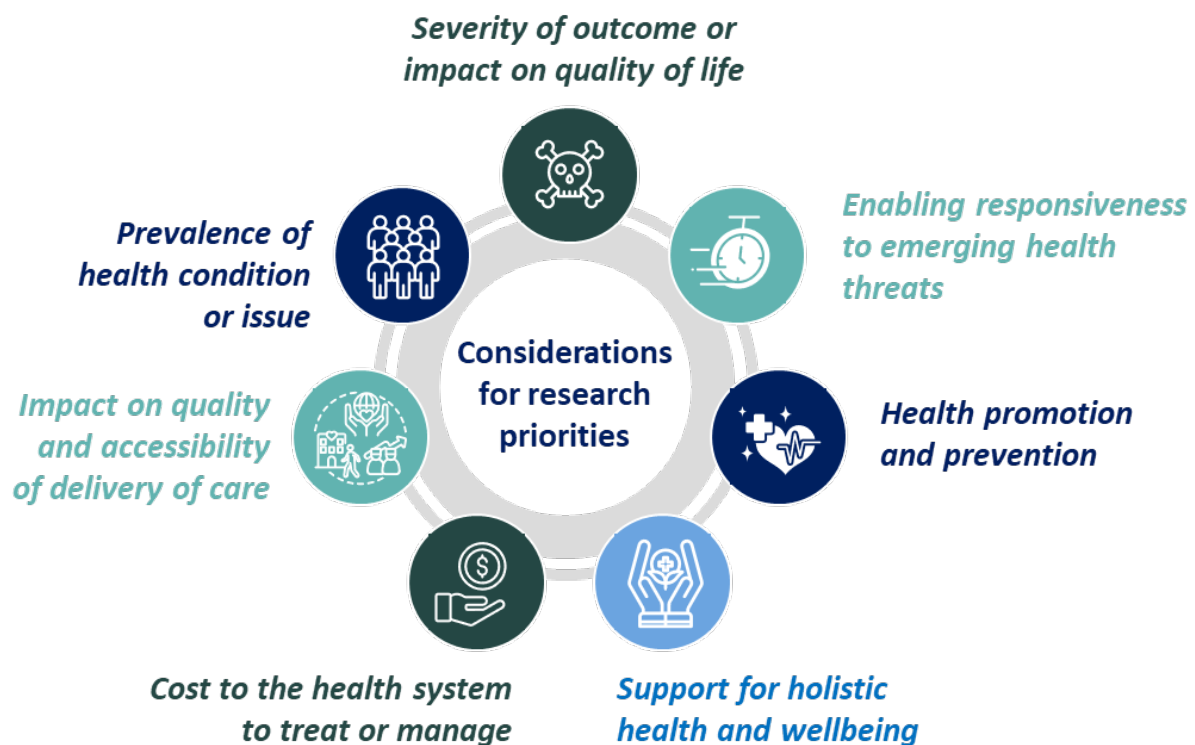
 *“In my view, having this strategy will be beneficial to health in Australia... to better focus on where we put our resources... like for issues that stand out in certain locations. In Darwin there are lots of mental health issues... there’s not enough recognition of that concern”* — Participant aged 18-35 years, NT

- **Impact on quality and accessibility of delivery of care** – participants felt the National Strategy should prioritise research which could have tangible impacts on quality, accessibility and affordability of healthcare;
- **Severity of outcome or impact on quality of life** – participants felt the National Strategy should prioritise conditions with serious negative impacts (e.g. high number of years of life lost, and/or ability to be involved in work, study and other activities leading to a fuller life), including rare or chronic illnesses;

 *“I believe it is very important to consider the impacts on quality of life, because at the end of the day, one’s quality of life is a huge part of what healthcare should be trying to improve”* – Participant aged 18-35 years, Online

- **Cost to the health system to treat or manage** – participants felt the National Strategy should prioritise conditions and issues that had a high burden on the health care system;
- **Enabling responsiveness to emerging health threats** – participants felt the National Strategy should support the Health and Medical Research sector to adapt quickly to pandemics or other health emergencies to support community health;
- **Health promotion and prevention** – participants felt the National Strategy should prioritise research that supports people to live healthier, better lives through health education and consideration of innovations that enhance health and reduce the likelihood of illness; and
- **Support for holistic health and wellbeing** – participants felt the National Strategy should prioritise research that considered the social determinants of health in health promotion and management, and explored non-pharmaceutical options for supporting health and wellbeing.

Figure 5: Considerations for setting funding research funding priorities



While the research identified diversity in the specific areas and priorities of interest among participants, the following were consistently raised as cohorts and topic areas of importance and concern:

- **Women and women's health** – to address a current perceived gap in health research, including under-representation of women in research about a range of health conditions as well as perceived gaps in research for specific conditions (such as menopause and endometriosis);

“Women's health needs to be researched more, a lot of research is done on males... even research done on mice is done on male mice, so from the bottom up there's a gap” – Participant from lower socio-economic background, Townsville

- **Aged care and healthy ageing** – to address the needs of an ageing population and perceived gaps in research to understand how to support quality of life in older age, as well as at end of life;

“I don't think they do much research on old people, I guess we're not of much use” – Participant aged 70+, Townsville

- **First Nations health** – to address a perceived limited efficacy of research in contributing to positive health outcomes for this cohort, including supporting pathways into research for First Nations people;
- **Regional, rural and remote health** – to address health issues and conditions specific to, and more prevalent in, regional areas and to ensure treatment and management approaches are tailored to the needs of people living in these areas;

- **Childhood health and early prevention** – to contribute to “upstream”, longer term benefits to health outcomes;

“Children and youth health should be prioritised... look at the preventative stuff, including mental health... anything can be prevented at a young age and that’s better for down the track” – Participant aged 36-69 years, Devonport

- **Chronic illness and disease management and prevention** – to address a perceived increased prevalence of chronic conditions in the population, the negative impacts on lives and costs of ongoing treatment and management;
- **Mental health** – to address the perceived prevalence of mental ill-health and limitations to existing treatment and management options, including interest in research that considers social determinants and preventative strategies;

“Both my kids have serious mental health issues so I’m personally affected by that.. I think mental health needs to be researched more” – Participant aged 36-69 years, Melbourne

- **Cancer research** – continuing to fund and support cancer research to find new treatments, promote cancer prevention and improve existing treatments given the perceived high prevalence and impact of cancers;
- **Healthcare accessibility and affordability** – conducting research to improve affordability, effectiveness and equity of access; and
- **Disease prevention and healthy lifestyle** – research to proactively support health, including in relation to diet, exercise, sleep, and alcohol and drug use.

“A priority should be having balanced research... research that will look at [alternative treatments] not just what tablet I can take. There needs to be balance. Right now they only think big pharma and what medicine will heal this” – Participant with lower trust, SA

In addition, participants felt that the National Strategy should consider how to leverage **technological advances** to maximise the efficiency and positive outcomes from research. This included using big data to identify health trends and provide better information to experts to make informed decisions as well as new technologies (e.g. artificial intelligence) to support diagnostics and treatment.

“All conditions are important but they need to look at the data being used to inform [Health and Medical Research] and plan for future health issues by using our data” – Participant aged 70+, Sydney

Key implications and considerations

- There is **perceived value in the National Strategy** and sharing information about it is likely to support trust and transparency in the sector.
- The introduction of the National Strategy may raise **questions and concerns that will need to be addressed** when communicating about the National Strategy.
- The research identified a **range of priorities and principles** that participants would like to see reflected in the National Strategy which should be considered in its development.

6. Communications about Health and Medical Research

This chapter discusses opportunities to support engagement with Health and Medical Research through communications activities about Health and Medical Research in Australia and the National Strategy. This includes findings about benefits to communicating, the potential role and objectives of communications and considerations for its delivery.

Overall findings

The research identified **benefits and value to communicating** with the general public about the National Strategy and Health and Medical Research in Australia. It found that strengthening communication would likely support increased public engagement and involvement in the sector, enhanced awareness and understanding of Health and Medical Research, improved health literacy and broader trust and acceptance of the Health and Medical Research sector.

The research identified several considerations to maximise the effectiveness of communications as well as potential challenges that should be considered when communicating. Participants felt it was particularly important to consider strategies to address communities' diverse interests within Health and Medical Research and to ensure communications were accessible to people with varying levels of health literacy.



"I want to know the next steps and how we are benefiting from the improvements, not in major detail but I want them to be more proactive in publicising what is happening... because lots of people have lost a bit of trust since COVID... especially since the vaccination rollout which has hurt my trust a little" – Parent/carer, Online

Benefits to communicating about Health and Medical Research

The research found that effective communication with the general community about Health and Medical Research in Australia, including about the National Strategy, could lead to the following benefits:

- **Direct benefits**, including:

- **Increased likelihood of public engagement and involvement in Health and Medical Research** – by raising awareness and understanding of the sector and highlighting opportunities for the community to be involved;



"If people are more knowledgeable, they may potentially have an opportunity to have input in what research the funding goes towards" – Participant aged 18-35 years, Online

- **Increased likelihood of acceptance and trust of, and support for, the sector** – specifically, participants felt that increasing transparency and accountability through clear and consistent communication could strengthen the overall credibility of Health and Medical Research. This was felt to be particularly important in the context of reduced trust following the COVID-19 pandemic (see Chapter 3); and



"The impact is people will be more aware of general research and trust improves" – Participant from a culturally and linguistically diverse background, Melbourne

- **Increased health and scientific literacy** – participants felt that communications about Health and Medical Research would support them to better understand basic health and scientific principles.
- **Indirect benefits/longer-term flow-on benefits:**
 - **Positive health attitudes and behaviours** – participants felt that effective communications about Health and Medical Research could increase people’s understanding and consideration of their own health and ways to support it, making them more likely to adopt positive health behaviours;

“It would be nice to hear about what’s going on [in Health and Medical Research] and be better informed. If I saw diabetes is high, I’d know I don’t want to go down that path and I might change my lifestyle” – First Nations participant, NT

- **Increased resilience to mis/disinformation** – participants were concerned about the prevalence of incorrect information about health and research. Improving community understanding of Health and Medical Research, and access to credible Health and Medical Research information, may reduce susceptibility and the spread of health-related mis- and dis-information; and
- **Positive residual emotions** – communicating about Health and Medical Research was likely to “reassure” the general public and make them feel “hopeful”, by supporting the perception that Health and Medical Research was a priority for governments and that funding decisions were made appropriately.

“I want to hear about [Health and Medical Research], it gives me hope for a better community” – Participant from lower socio-economic background, Townsville

Communications objectives

To guide development of communications about Health and Medical Research, the research identified the following overall communications aims:

- **Raise awareness** of the Health and Medical Research sector and the National Strategy;
- **Build acceptance and support** for the Health and Medical Research sector and the National Strategy; and
- **Encourage engagement and involvement** in Health and Medical Research.

Specifically, the research found that communications should seek to achieve the following outcomes:

- **Knowledge outcomes** – increased awareness and understanding of:
 - The National Strategy;
 - The basics of Health and Medical Research (i.e. who, what, when, where, why and how);
 - How research priorities are set; and
 - Opportunities for the public to be involved in Health and Medical Research.
- **Attitudinal outcomes** – supporting the community to feel:
 - That Health and Medical Research and the National Strategy is important;
 - Reassured that the sector and Health and Medical Research is effective;

- Confident that priorities and funding meet community needs;
- Trust in Health and Medical Research, the National Strategy and the sector; and
- Empowered to be engaged and involved in Health and Medical Research.
- **Behavioural outcomes** – encouraging the general public to be:
 - Involved in Health and Medical Research; and
 - Engaged with information about Health and Medical Research in Australia.

Information and communication needs

To support achievement of the communications objectives, the research identified key information needs among participants related to Health and Medical Research overall; the National Strategy; and opportunities for community involvement in Health and Medical Research.

In relation to the **Health and Medical Research sector overall**, the research identified that participants needed information about:

- **Outcomes and impacts of research in Australia** – demonstrating the size and extent of the impact of research funding in Australia using examples that the community can easily understand and engage with (such as case studies, success stories and statistics). Participants were particularly interested in information about Health and Medical Research that identified links to how the research may impact everyday people;
- **Factors influencing funding decisions** – clear explanations of why certain research was funded, including when there was community and stakeholder involvement;

“It would be beneficial to know more about where money is going... to see where the research is focused in Australia and how the funding is split. It would provide comfort to know that the Government is being held accountable” – Parent/carer, Online

- **Where and how to stay up-to-date about Health and Medical Research** – such as what opportunities exist to subscribe to newsletters, follow official channels on social media, or visit dedicated government websites to receive updates about Health and Medical Research projects and progress; and
- **Where to access more detailed information about Health and Medical Research** – such as where to find information about who conducts and funds research; timelines and phases for research and the rationale for these; and ethical regulations guiding Health and Medical Research.

In relation to the **National Strategy**, the research identified that participants needed information about:

- **Its purpose** – including why it was being introduced;

“I’m definitely open to learning more about the National Strategy. I’d like to know more about the key goals of the Strategy and how they align with societal needs and how it will benefit the community in the short and long term” – Participant aged 36-69 years, Online

“I want to know about the constraints of the Strategy. There will need to be transparency on what it is and how it works” – Parent/carer, Port Lincoln

- **Its scope** – including who it relates to within the sector, and the aspects of Health and Medical Research it does and does not influence;
- **How the National Strategy differed** from previous approaches;

“I want to know who does this National Strategy affect? How is it different from other health strategies that have previously been implemented?” – Participant aged 18-35 years, Online

- **Duration of the National Strategy and level of commitment** – specifically, how long the National Strategy will be in place, and the extent of political support and buy-in from the private sector;
- **Potential tangible benefits of the National Strategy** – particularly how it is likely to positively impact individual health and well-being;
- **How the National Strategy has been developed** – to provide transparent information about the consultation processes and who has contributed to it; and
- **Progress of the National Strategy and Health and Medical Research priorities** – participants expected that over time, they would receive feedback on key milestones, changes to priorities and assessment of progress in relation to the National Strategy.

“Information about the Strategy in plain terms that explains the aspirations of the Strategy would be good as a general communication. It would also be useful to receive more specific information about how the Strategy relates to my specific health conditions” – Participant aged 36-69 years, Online

In relation to opportunities to be **involved in Health and Medical Research**, the research identified that participants needed information about:

- **The value of being involved** – including information about how public involvement contributes to Health and Medical Research and improves health outcomes (e.g. the value of specific perspectives, knowledge and skills) as well as the personal direct and indirect benefits of involvement;

“I need to know if there are any personal benefits to be being involved, what they’ll do with the data and information and if it’s genuine research” – Parent/carer, Port Lincoln

- **How the community can be involved** – such as the types of activities (e.g. surveys, consumer advisory groups), what input the community can provide (e.g. priority setting, research design) and when the community can be involved; and
- **Where and how to find out about opportunities to be involved in Health and Medical Research** – e.g. which websites or pages to visit/follow, or where to sign up to receive alerts about opportunities to be involved in Health and Medical Research, including those relevant to their areas of interest.

Communications considerations

The research identified several key considerations to support the development of effective communications about Health and Medical Research and the National Strategy, including about preferred channels, timing, sources, tone and delivery.

Preferred information channels

The research identified a clear need for "push" communications (i.e. information that people do not need to search for) as most participants were not actively seeking information on this topic without being prompted. Participants reported the following preferred channels:

- **News media** – such as stories on TV, radio and/or online news coverage, current affairs programs, talk-back radio and other news programs, including with researchers/research institutes;
- **Social media pages and ads** – via Federal and State/Territory Government, peak bodies, specific interest/community groups and/or research institutions on social media;
- **Health clinics/GPs** – e.g. via posters, brochures and QR codes in clinics; and
- **Community organisations** (see "Tailored channels and communication needs" below).



"I'd want to hear about [Health and Medical Research] through the media, a letter in the post, my GP, social media or moderated proper websites" – Participant aged 36-69 years, Melbourne

Timing

In relation to **timing** of communications about the **National Strategy**, many participants expected to receive communications in the lead up to its release and implementation. The research suggested that the introduction of the National Strategy could present an **opportunity to enhance overall awareness and attention on the Health and Medical Research sector more broadly**, using the announcement as a platform to establish and strengthen community engagement with Health and Medical Research.

Participants were interested in **ongoing** communications over time **about the progress of Health and Medical Research** (e.g. every few months), particularly when there were important and relevant progressions or breakthroughs. The research identified that the National Strategy could be leveraged for this purpose by providing high-level updates on progress against the National Strategy's priorities.



"I don't want to go for two years without hearing anything about it, you need regular check-ins with the community about what they are studying and how it affects us" – First Nations participant, Port Lincoln

Source

The research suggested that the **Australian Government Department of Health and Aged Care should be the primary source** of high-level information about the Health and Medical Research sector and the National Strategy. Most participants felt that the Department was an appropriate and credible source of information on this topic and believed it should take responsibility for sharing information, given its role in developing and implementing the National Strategy.



"I would like to know more about the National Strategy directly from the Department of Health as I feel that Department would be responsible for its implementation and management" – Participant aged 36-69 years, Online

Tone

To support achievement of the communications objectives, the research suggested that communications should adopt a tone that is:

- **“Hopeful”** and **“positive”** – participants felt that Health and Medical Research had direct positive impacts on lives and that this should be reinforced; and
- **“Neutral”, “educative”** and **“informative”** – specifically, presenting information in a clear, direct manner without being overly persuasive or promotional to avoid perceptions of “politicisation”.



“It comes down to hope and trust... communications should help me to feel more supported as well as more confident in how my taxpayer money is being spent” – Parent/carer, Online

Considerations for delivery

To support effective communication about Health and Medical Research and the National Strategy, the research identified the following key learnings in relation to the development and delivery of communications:

- **Provide simple, high-level information** to achieve cut-through and engagement, with **options to access more detailed information** (e.g. through a website or “opt in” process for emails or newsletters);
- Use **clear, simple language** and **accessible formatting** to ensure information is easy to understand and engage with for all literacy levels and abilities – for example, participants suggested using short sentences, dot points, clear headings, infographics, supporting icons/visual elements and/or using a range of formats (including written, visual and audio formats) to support accessibility for different needs and preferred engagement types across the community;



“The information about the Strategy needs to be made widely available to the public. The impacts of the Strategy and the statistics need to be in simple English for people who don’t understand difficult words” — Participant from a culturally and linguistically diverse background, Melbourne

- Consider providing options for **key communications to be available in multiple languages** to support reach and engagement among diverse communities and ensure inclusivity of key information about Health and Medical Research;
- Provide a **clear, central directory of information** that consolidates key Health and Medical Research updates and provides links to other relevant sources of information to increase ease of finding information; and
- Where relevant, **tailor Health and Medical Research communications by health topic or community group** to support cut-through and relevance. Consider providing options to filter detailed information about Health and Medical Research on websites or customise updates and alerts by specific topic areas to make it easier for individuals to find relevant information.



“The information needs to be from one source... it’s important to share findings with the public because we don’t usually get to see that” — Participant with disability or chronic illness, Devonport

Tailored communication needs

The research found that some cohorts had unique information and engagement needs, and preferred channels for accessing information. Tailored communications could be used to effectively reach and engage these audiences.

For people with **lived experience and their carers** the research identified unique:

- **Information needs** – including:
 - Opportunities to be involved in Health and Medical Research that were directly relevant to the individual's lived experiences; and
 - New treatments or research related to their specific conditions or experience.
- **Communications channels** – specifically, health professionals with knowledge of their specific condition; patient advocacy groups; condition-specific organisations; and/or condition specific social media groups (including informal social groups and pages).

For people from **culturally and linguistically diverse backgrounds**, the research identified unique:

- **Communications needs** – including the need for plain language information, with key information available in multiple languages; and
- **Communications channels** – including language-specific media (such as SBS, and language specific TV or radio channels); and community and faith-based groups.



“I mostly receive my information by watching the news, like the Greek program on SBS, which is very helpful, so if that can be used to make sure information is accessible to everyone” — Participant from a culturally and linguistically diverse background, WA

For **First Nations peoples**, the research identified unique:

- **Information needs** – including:
 - Opportunities to be involved that were relevant to the health and priorities of local First Nations communities; and
 - Information and updates specifically related to Closing the Gap (CTG) targets and health outcomes for First Nations peoples.
- **Communications channels** – specifically, Aboriginal Medical Services (AMS); Aboriginal Community-Controlled Health Organisations (ACCHOs); Aboriginal Community-Controlled Organisations (ACCOs); trusted Community Elders; and First Nations specific or locally known and respected health institutions (e.g. Menzies).

Challenges and risk mitigation strategies

The research also identified several potential challenges/risks associated with communications as well as opportunities to assist in mitigating these risks to consider in the design and delivery of communications.

Challenges	Strategies to mitigate
Difficulty communicating across differing levels of health and science literacy – in particular overly complex/technical information could lead to misunderstandings or disengagement.	<ul style="list-style-type: none"> ✓ Ensure simple, plain language (e.g. avoid unnecessary jargon), and provide definitions of key terms and acronyms where needed; and ✓ Adopt different communication formats to support universal access to information, broad appeal and understanding (e.g. visuals, infographics, audio).
Communicating across the diversity of interests – due to the breadth of Health and Medical Research , participants reported differing areas of research interest and relevance.	<ul style="list-style-type: none"> ✓ Use tailored channels to target opportunities strategically; ✓ Organise detailed information by interest areas and provide options for opt-in information on specific areas of interest; and ✓ Prioritise digital content that is known to have higher engagement (i.e. based on analytics).
Difficulty establishing credibility (especially for those with low trust) – including distrust that stemmed from exposure to mis/disinformation and/or past negative experiences with healthcare or government institutions.	<ul style="list-style-type: none"> ✓ Communicate accurate, foundational information about the sector; ✓ Consider monitoring and addressing emerging mis/disinformation; and ✓ Leverage information that increases perceived effectiveness and trust and avoid detractors (see information requirements).
Raising concerns when communicating about the National Strategy – for example, that it would be restrictive, inflexible, politicised or redundant.	<ul style="list-style-type: none"> ✓ Address potential concerns and information gaps in key messaging.

Key implications and considerations

- There is a **clear benefit of, and need for, communications** to raise awareness, build acceptance and support, and encourage engagement and involvement in Health and Medical Research.
- There are **clear and consistent information needs** which can be leveraged in **broad high-level communications**, with **options for more detailed information** for those who want it as well as opportunities to tailor communications to specific audiences.

7. Conclusions and implications

Conclusions

Overall, the research found that there was only **basic awareness of the existence and importance of the Health and Medical Research sector** in Australia among the general community. There was **limited in-depth understanding** of more detailed information about how the sector operates, including how funding decisions are made, how the sector is governed and how research translates into tangible health outcomes. There was **limited active information-seeking** about the Health and Medical Research sector and its funding, with most participants receiving information about the sector passively/incidentally (e.g. through news media or word-of-mouth).

Overall, there were **positive perceptions of the importance and value** of Health and Medical Research among the general community, particularly as health was a high priority for participants. The research found there were positive perceptions of the effectiveness of Health and Medical Research in Australia and a reasonable level of trust in most of the sector. Perceptions of **effectiveness and trust** were influenced by perceived: impacts of Health and Medical Research; purpose and motivations of funders and researchers; timeliness of research; transparency of the sector; alignment of research with community needs; and regulation of ethics and quality.

There was strong perceived value of **community involvement in Health and Medical Research and in setting research priorities** among participants. Participants reported that this involvement had benefits for individuals, the research, the sector and the broader community. However, the research suggested that **in-depth involvement** was primarily likely among those who were highly motivated (e.g. strong personal relevance and perceived ability to provide valuable input). Most participants were interested in **lighter-touch involvement**.

There was **support among participants for having the National Strategy** to strengthen the use of research funding, support positive health outcomes and to streamline research efforts nationally. However, there were also questions or concerns about the role of the National Strategy and how it would work in practice. Participants identified a number of **expectations in relation to principles the National Strategy may adopt** to identify research priorities, including consideration of: prevalence of health conditions; impacts on quality of life; responsiveness to emergencies; preventative and health promotion approaches; quality of, and access to, health care; costs to the health care system; and holistic approaches to health and wellbeing.

The research identified **value to communicating about Health and Medical Research to support engagement**. Key benefits identified by participants included: increasing trust, acceptance and support for the sector; improving health and scientific literacy; and increasing the likelihood of public involvement in Health and Medical Research. The research identified a range communications objectives to guide communication activities about Health and Medical Research and the National Strategy. Participants highlighted the need for simple, high-level information and interesting examples of research findings, with options to explore more detailed information (e.g. on specific areas or topics of interest).

Implications and considerations for Health and Medical Research policies and sector

The findings from this community research raised several implications for consideration in the development of strategies to enable community involvement and engagement in research as well as for the development of the National Strategy.

In relation to **community involvement in Health and Medical Research**:

- Ensure strategies to enable community involvement in Health and Medical Research are designed to **leverage enablers and address barriers** (see Chapter 4) to maximise the likelihood of involvement, including for specific audiences.
- Emphasise the **motivators to involvement** in communications about opportunities (i.e. why involvement may be relevant and the value that community perspectives can bring) to increase interest and empower individuals to be involved.
- Offer and communicate broadly about **‘light-touch’ involvement options** available for the general community (e.g. data sharing or consultation processes) to raise awareness and support achievability of involvement across the breadth of the community.
- Deliver targeted communications about **deeper involvement options** via tailored approaches and channels to those identified as having stronger relevance based on the area of research, to increase the likelihood of uptake of opportunities.
- Ensure opportunities for involvement are **appropriate, accessible, culturally safe and inclusive**, particularly when engaging specific cohorts, to support increased uptake and positive experiences of involvement.

In relation to the **National Strategy** and **funding priorities**:

- Consider community expectations in relation to **important factors for setting research priorities** (see Chapter 5) in the development of the National Strategy and/or communications about the National Strategy to support perceived appropriateness and fairness of decision making.
- Consider community expectations in relation to **topic areas and cohorts** felt to be a priority for Health and Medical Research (see Chapter 5) in the development of the National Strategy and/or communications about the National Strategy to increase the likelihood that perceived gaps will be addressed.
- Address identified **questions and concerns** about the National Strategy in communications to support accurate understanding and likelihood of support.

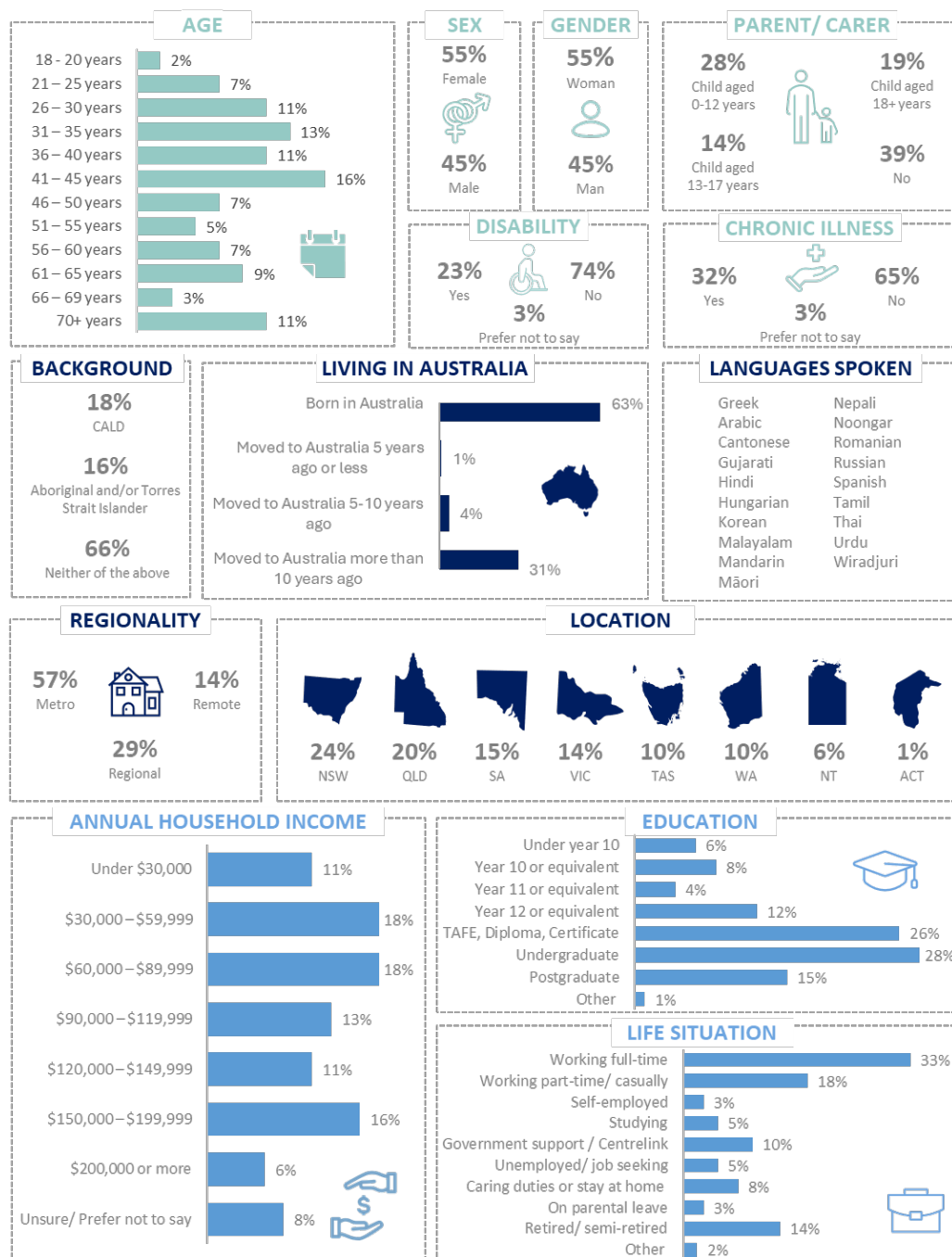
In relation to **communications**:

- Address high-level **information needs** about Health and Medical Research and the National Strategy (Chapter 6), particularly through the use of case studies, statistics and research examples, to maximise likely engagement by addressing current knowledge gaps and interest areas.
- Disseminate information and communications through a range of “push” **channels** (e.g. news media and social media) to enhance the reach of information, including using trusted and tailored channels.

- Adopt **clear, simple language** and **accessible formats** to ensure information is easily understood by people of all English literacy levels and abilities to maximise engagement. Also consider the use of different styles of information; use of infographic and visual elements; and indicate if translated content is available.
- Consider opportunities for providing a **central source or directory for detailed information** about Health and Medical Research that allows deeper exploration, ideally via topics or cohorts of interest.
- Consider using the release of the National Strategy as a **prompt for launching information** about Health and Medical Research and consider providing ongoing high-level communications about Health and Medical Research to maintain or enhance public trust, interest and perceived effectiveness of Health and Medical Research funding.

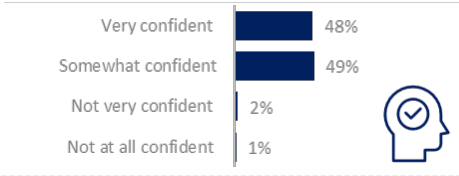
Appendix A: Demographic profile of research participants

Before beginning the focus groups and interviews, participants completed an anonymous demographic questionnaire (paper-based or online, depending on preference)⁹. Data from this questionnaire is included below to provide a summary of the cohort of participants included in the qualitative sample. Percentages may not sum to 100% due to rounding or questions permitting multiple responses. Some participants did not complete a questionnaire. The data below is based on n=152.

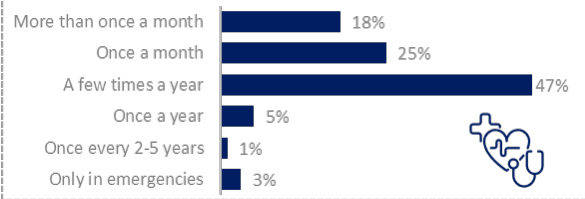


⁹ Note: in this questionnaire, the question related to gender also included the following response options which were not selected by participants: 'Non-binary'; 'I use a different term [please specify]'; and 'Prefer not to answer']

CONFIDENCE UNDERSTANDING INFORMATION GIVEN BY A HEALTH PROFESSIONAL



FREQUENCY OF HEALTHCARE ACCESS

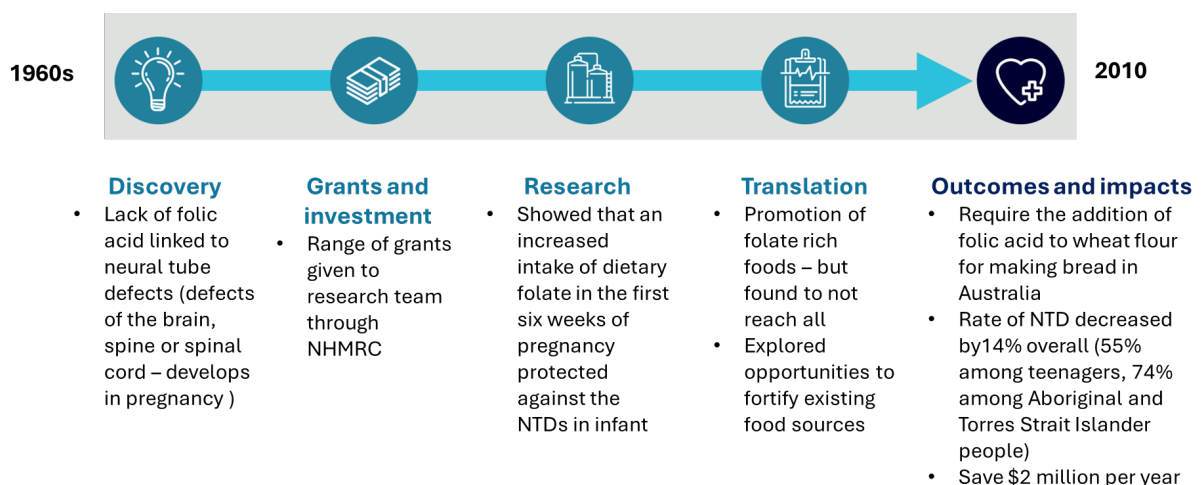


Appendix B: Stimulus used in the research

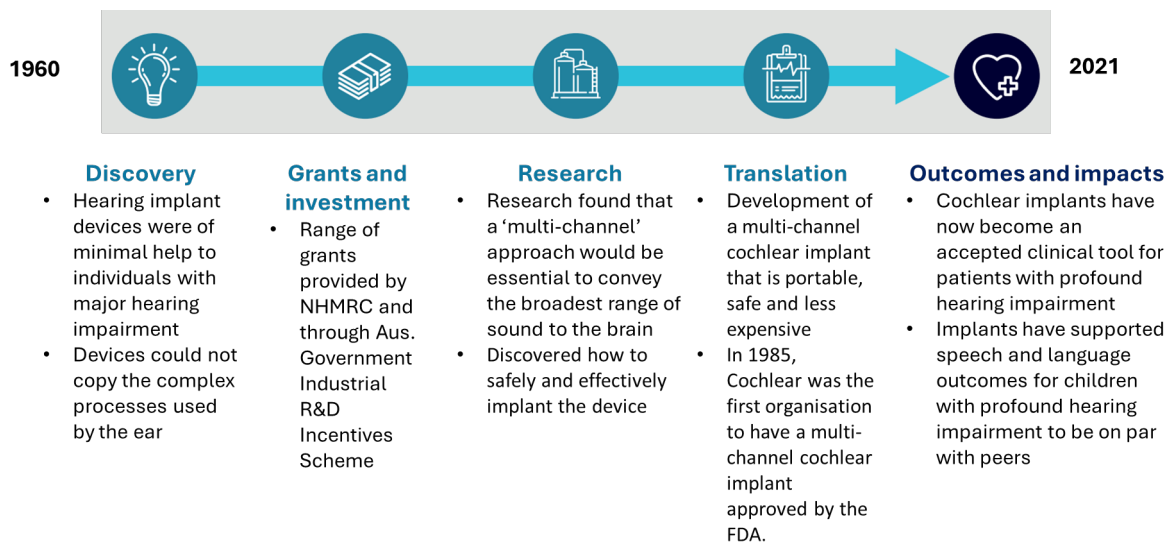
Key information about the Health and Medical Research sector

- **PURPOSE:** Overall, health and medical research helps us learn more about health and how to give better healthcare to people in Australia.
- **WHAT:** Health and medical research is a way of collecting and studying information to better understand health problems or answer health questions. It can involve testing new treatments and medicines, finding ways to prevent illnesses, figuring out what causes diseases, improving how people get health care, and spotting health trends in the community.
- **WHO:** This research is done by scientists and doctors at universities, hospitals, and other research centres, including government organisations and private companies.
- **FUNDING:** Money is needed to support these research projects. Funding can come from the government (like from the Medical Research Future Fund or National Health and Medical Research Council), charities, or private companies. Often, researchers have to apply for grants (money for their projects), and experts decide which projects should get funded based on things like how the research will help the community.
- **ETHICS:** Any research that involves people or uses personal information must follow rules in the National Statement on Ethical Conduct in Human Research. These rules make sure the research is fair, safe, and respectful. There are also laws about privacy and the approval of treatments and medicines.

Health and Medical Research Case Study: Folate and healthy babies



Health and Medical Research Case Study: Cochlear implants



Key information about the Nation Health and Medical Research Strategy

- The Australian Government is creating a plan called the National Health and Medical Research Strategy. This plan will help decide what health and medical research gets done in Australia.
- It will focus on what Australia is already good at in research, fix any gaps, and keep attracting talented researchers and money to the country.
- The plan will relate to everyone involved in research and the people impacted by it — including different levels of government, private companies, charities, universities, and the public.
- The goal is to make sure that money for research goes where it's needed most. This will help new treatments and health supports become available faster, making Australians healthier and improving their lives.

Examples of research sector engagement/involvement

- Patient and consumer advisory groups:** these groups include people with certain health conditions, disabilities, or from different cultural backgrounds. They help choose what research is most important by sharing their experiences and ideas.
- Co-design patient and consumer groups:** these groups work with researchers to help design projects so they meet the needs of the people who will benefit from them.
- Public representation on research committees:** this means everyday people being part of research committees, like those that decide what gets funded or make sure research is ethical (fair and safe).
- Research steering/governance committees:** for example, having a First Nations group help guide research projects.
- Public consultation:** this can happen once or continue over time, and includes things like:
 - Surveys
 - Focus groups (small group discussions)
 - Public submissions (people sending in their opinions or ideas)

- Town hall meetings (community meetings)
- Workshops where people help set research priorities or design projects
- Long-term panels (groups of different people from the community who discuss health priorities over time)
- **Citizen science/participatory research:** this is when people help collect data, do research, or help to make sense of the information collected in projects.
- **Sharing research findings with the public:** this could be actively sharing important health information with the general public or specific groups of people.
- **Crowdsourcing:** using online platforms where the public can suggest and vote on research ideas or health problems they want to see solved.

Case study examples of research sector engagement/involvement

“Val was invited to join a consumer advisory group organised by a national health charity after losing a family member to a related disease. Since then, she has been a passionate advocate for more research on early screening. Based on the feedback from Val and other members of the committee, the charity has been exploring ways to prioritise and support research into early detection.”

“Henry has faced mental health challenges for many years, so when he saw a post on social media about a consultation shaping mental health research priorities, he wanted to be involved. He completed a survey, sharing his thoughts on what he believed should be the main focus of mental health research, drawing from his own experiences. Henry signed up to receive updates on future consultation opportunities so he could take part in more feedback processes in future.”

“Mel is an Aboriginal woman who is retired now, but previously worked in community health, promoting healthy habits in her community. Soon after her retirement, she was invited to join a governance committee that helps to govern health and medical research priorities in her regional area. Mel has been on the committee for two years and uses her position to make sure that the perspectives of Aboriginal and Torres Strait Islander peoples are considered in decision making.”

Appendix C: Research discussion guide

Discussion guide

Community focus groups

Explanatory notes

- This discussion guide provides an idea of the range and coverage of issues that will come out of the research project.
- It is a guide for discussion and will not be used as a script—phrasing, wording and order will be adapted as appropriate for each focus group.
- This guide does not represent a complete list of the issues/questions that will be asked or covered in each focus group or interview. The coverage will be guided by the researchers and informed by participants.
- Questions will be asked around the issues in the guide and will be fully open-ended.
- Some questions are necessary for context-setting and testing for 'group think' effects.
- Some questions are similar because they are trying to get at an issue from a number of angles and will validate responses/views.
- Timings specified are a guide only. Timings are for focus groups and would be adjusted proportionally for interviews.

Background (5 mins)

Introduction: self, note-taker and ORIMA Research.

About the research:

- Research today on behalf of an **Australian Government agency**.
- Talking about health and medical research, and your thoughts and opinions on this topic (it is ok if you don't know much, we will give you more information as we go).

Confidentiality and anonymity:

- Everything said will be **confidential and anonymous**.
- Report will focus on **common themes** - all findings and quotes will be **de-identified**.

Observations and recording:

- Confirm consent for **notetaking and recording**.
- All recording **stored securely** and only accessed by the researchers.
- (If relevant) confirm consent for any **observers**.

Group format:

- The research is **voluntary** and you can **skip any questions** you don't feel comfortable answering or leave the session at any time.
- There are **no right or wrong answers**, and different points of view are encouraged. Please be open and honest.
- Most **questions** will be put to the whole group, sometimes specific people will be called on or each person will be asked for their answer.
- Questions will **not ask about your personal health**, but welcome to share what you feel comfortable as part of explaining your perspectives on the topics discussed.
- The session will take up to **1.5 hours**.

Online considerations:

- IT support if needed.
- Functionality – use of chat function/hands up.

Consent: Confirm verbal consent.

Warm-up questions and context setting (5 mins)

This section is to build inter-group rapport and provide the moderator with context to draw on throughout the discussion.

- a) **Name**
- b) **Life situation** – e.g. studying, working/looking for work, caring responsibilities
- c) **Current sources** of information about health and medicines

Awareness and understanding of health and medical research (15 mins)

This section will establish participants' level of awareness and understanding of the health and medical research sector as well as how they currently engage with it. Participants will be provided with only basic information in the homework task and this section will explore more detailed topics.

Health and medical research

- a) **Word association:** “health and medical research” [participants: write 2-3 words on post-it note + moderator to explore: top-of-mind associations, meaning]
- b) Explore **awareness and understanding** of:
 - **Types** of health and medical research [explore: health areas, translational science spectrum]
 - **Roles and responsibilities** [explore: who conducts, commissions, funds, governs, regulates]
 - **Funding** [explore: who provides, how decided, how it works, duration – check awareness of DoHAC, NHMRC, philanthropic and corporate funding (e.g. pharmaceutical/medical device companies)]
 - **Use** of health and medical research [explore: who uses research, what it informs]
 - **Impacts** of health and medical research:
 - i. For Australia/the community
 - ii. For individuals [explore: perceived personal impact]

Current and past engagement/involvement with health and medical research

- a) Discuss:
 - **Sources of information** about the health and medical research sector, including what is funded [explore: active vs passive information seeking, quality/credibility of information, how this is assessed (refer to homework task as prompt – page 7)]
 - **Experiences engaging** with health and medical research [explore: what, where, when, why – probe for engagement beyond seeking information to directly inform own health (e.g. advisory groups, advocacy, participation)]
 - Key health **areas of interests** for research [refer to homework task as prompt – page 7]

After exploring initial awareness, understanding and engagement, moderator to give participants more information to ensure all participants are ‘on the same page’, including about what health and medical research is, what it covers and how funding structures currently work (see page 5).

Perceptions of health and medical research (20 mins)

This section will identify participants' perceptions of health and medical research and how funding works currently.

- a) Discuss overall perceived **effectiveness** of health and medical research in Australia [explore: whether currently meeting needs (why/why not), change over time, impact of funding/investment on supporting effectiveness]
- b) Explore **perceived levels** of the following for the health and medical research sector:
 - **Trust** [explore: trust in academics/researchers, policy makers, Australian Government, those who use/disseminate data + potential changes over time]
 - **Appropriateness** [explore: priorities, funding, outcomes – including for different cohorts]
- c) Discuss factors which **increase/decrease** trust + appropriateness [explore: past experience, transparency, intentions, accuracy, conflicting information, cultural safety/appropriateness, AI]
- d) Discuss:
 - Perceived **importance** of health and medical research [explore: why, benefits/drawbacks]
 - Key **opportunities/challenges** for health and medical research in Australia
 - Perceived level of **consideration of communities** in health research [explore: who, how, level of effectiveness – probe for consideration of specific cohorts]

Health and medical research strategy (15 mins)

This section will aim to identify participants' interest and ideas in relation to the National Health and Medical Research Strategy.

Moderator to share basic information about the Strategy to enable informed discussion (see page 5).

Awareness and perceptions of Strategy

- a) Explore:
 - Existing **awareness** of Strategy development, if any
 - **Perceptions** of having the Strategy [explore: levels of support, benefits/drawbacks, potential impact]

Priority areas

- a) Explore areas for **focus and prioritisation** for Strategy, including:
 - **Types** of research [explore: what makes an area of research important]
 - **Groups** impacted/involved [explore: community, researchers, specific cohorts]
 - **Ethics and safety** [explore: ethical research, cultural safety, trauma-informed approaches, privacy]
 - **Technology** [explore: big data, AI, digitalisation]
 - **Other** topic areas [explore: other areas based on what participants have raised during the discussion]

Community engagement/involvement in health and medical research sector (25 min)

This section will identify perceptions of the role of the general public in health and medical research, including motivators/barriers to engaging the community and opportunities to increase engagement.

Community engagement/involvement in health and medical research sector

- a) Discuss:
 - Ideal **role of general public** in health and medical research sector, including setting priorities/direction [explore: what, who, when involved, why]
 - Types of **activities** general public could/should have role in [moderator to show example list of types of activities to stimulate discussion (pages 5-6) – explore: which activities are useful, why, who should be involved, how, when, one-off vs ongoing engagement, any suggestions + impact of having community engagement]
 - Potential **benefits/drawbacks** of community being involved in health and medical research [explore: what, for whom (e.g. for individuals, community, research sector), why]
- b) Discuss:
 - **Past/existing experience** engaging/being involved with health and medical research, if any
 - **Personal interest** in being involved in health and medical research sector [explore: why/why not interested, what interested in]

Motivators/barriers to community engagement/involvement

- a) Discuss:
 - **Motivators** to community engagement/involvement in health and medical research [explore: factors driving interest]
 - **Enablers**/what would make the community more likely to engage/be involved [list participants' responses]
 - **Barriers**/what would make the community less likely to engage/be involved [list participants' responses – explore for English literacy, health literacy, service access, resources + cultural differences]
- b) Discuss how to **overcome barriers + other opportunities** to increase engagement/involvement [explore: how to address barriers identified above, potential strategies, the likely impact of these, needs for different cohorts]

Communications

- a) Discuss opportunities to **improve communications** about health and medical research (including the Strategy and about the sector overall), including:
 - Information **needs** [explore: type of information, level of detail + interest in information about funding]
 - **Channels** to use/avoid + preferred **source** [explore: trusted/credible sources]
 - Preferred communication **format** [explore: e.g. written, video, audio, infographic]
 - **Timing** [explore: when, ongoing vs one-off]
 - **Tailored information** requirement for different cohorts

Conclusions (5 mins)

This section provides closure to the discussion and an opportunity to identify what was most salient to participants from the discussion. A subset of these may be asked, depending on time remaining.

- a) Have you learnt **anything new** from today's discussion?
- b) What's the most **important thing** that the Australian Government can do to ensure the best possible outcomes from Australia's health and medical research?
- c) Is there **anything else** you would like to add or that you feel we haven't covered in today's discussion?

Finish

Summarise outcomes:

- We are doing this research on behalf of the **Department of Health and Aged Care**
- The report from this research will be published on the **Department's website**.
- The purpose of this research is to understand what people know and think about health and medical research in Australia. This research will inform the development of **the National Health and Medical Research Strategy**.
- If you're **interested in hearing more** about the Strategy or **contacting someone** from the Department's Strategy team, please visit: <https://www.health.gov.au/our-work/national-health-and-medical-research-strategy>

Thank participants and explain process for **thankyou payment**

Appendix D: Research homework task

Homework task

The focus group or interview you participate in will be about **health and medical research** in Australia.

What is health and medical research?

Health and medical research is a way of collecting and studying information to better understand health problems or answer health questions. It can include:

- Testing new treatments and medicines
- Investigating ways to prevent people from getting sick
- Figuring out what causes illness
- Learning how to make health care better for people
- Looking for health patterns in communities

This research can be conducted by researchers at universities and other research centres.

We will tell you more about the topic during the session – don't worry if you don't know much about it.

Before our session, we would like you to consider and answer the following questions. We will ask questions about these topics during our discussion. Please complete and provide **email confirmation** when you have finished.

1. Have you looked for any information about health and medical research in the last five years?
 - a. Yes – please specify what information you looked for: _____
 - b. No
2. Where did you look for this information?
 - a. News articles
 - b. Social media
 - c. Podcasts/webinars
 - d. Documentaries/TV programs
 - e. Research journals
 - f. Government health websites
 - g. Other health websites (e.g. Cancer Council Australia, Diabetes Australia)
 - h. Public Health newsletters (e.g. agencies like WHO, CDC)
 - i. Pamphlets/brochures/letters (e.g. provided by a health service, GP, pharmacist)
 - j. Community forums
 - k. Conversations with a health practitioner (e.g. my GP)
 - l. Other source – please specify: _____
 - m. I have not looked for information about health or medicines in the last year.
3. What are the top 3 things you think health and medical research in Australia should focus on (e.g. health areas, community groups of interest, ways of researching)?
 1. _____
 2. _____
 3. _____

4. What are the most important considerations when deciding what to focus on in health and medical research (select up to 3)?
- a. How much it can improve people's quality of life
 - b. How many people are affected by the health problem
 - c. Whether there are gaps in current treatments or solutions
 - d. The financial cost of the health problem to society
 - e. How much it affects at-risk groups or people experiencing disadvantage
 - f. What the community needs and thinks is important
 - g. New discoveries in science and technology
 - h. How much money is available for the research
 - i. The chance to stop illness from happening in the future
 - j. How likely the research is to succeed
 - k. Other – please specify: