

The background of the entire image is a vibrant orange color. Overlaid on this background is a complex, abstract network of thin, light-colored lines connecting various circular nodes. The nodes are of different sizes and colors, including white, light orange, dark orange, and blue, creating a sense of interconnectedness and data flow.

AUSTRALIA SPEAKS!

RESEARCH AUSTRALIA
OPINION POLLING 2017

RESEARCH
AUSTRALIA
CONNECTING • ENGAGING • INFLUENCING

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About Research
Australia

ACKNOWLEDGMENTS

The polling for this
report was generously
conducted by Roy Morgan
Research, a Research
Australia Member.

Roy Morgan
— Research —

As major stakeholders in health and medical research, Australians opinions count.

Research Australia has been asking Australians for their opinions on health and medical research and its role in our society, since 2003. Over the past 14 years, it has been clear Australians consider healthcare and health and medical research as high spending priorities for the Australian Government.

Improving hospitals and healthcare has been number one in all fifteen polls.

This is significant because health and medical research in Australia is heavily dependent on public funding and our contributions to research as taxpayers, research subjects and the providers of data.

Our polling shows that Australians want their health professionals to be engaged in research as they can see this leads to better healthcare for patients.

Ensuring that Australians have access to the best possible healthcare, stemming from the best possible evidence based research, is fundamental to better health; thus embedding research in the health system is a key focus for Research

Australia. One way to achieve this is to ensure that the health professionals who care for us are also involved with research. They see firsthand what we as patients and consumers of health services need in practice. This allows them to conduct research that delivers real improvements in healthcare and where Australians need it most.

Researchers are trusted

In an era of big data, the opportunity to harness the masses of information, including personal health records, through better collection, linkage and access, has the potential to transform our health systems and the way we deliver healthcare. Research Australia is gratified by strong levels of public support in our polling for the use of health data in this way, and for the high levels of trust the public has in researchers to use personal health information responsibly and for community benefit.

Lastly, our polling shows that many Australians have little understanding of just how long and expensive it is to

develop new drugs, medical devices and vaccines. It is incumbent on the health and medical research sector to explain the whole of the research pipeline and Research Australia will be leading the way.

Since our first public opinion poll in 2003, we have asked a variety of questions in different ways and captured the sentiment of the day on specific issues. Some findings have been consistent in both attitude and ranking despite our changing world and we have taken the opportunity to republish some of the results from previous years to add a further dimension to the 2017 results.

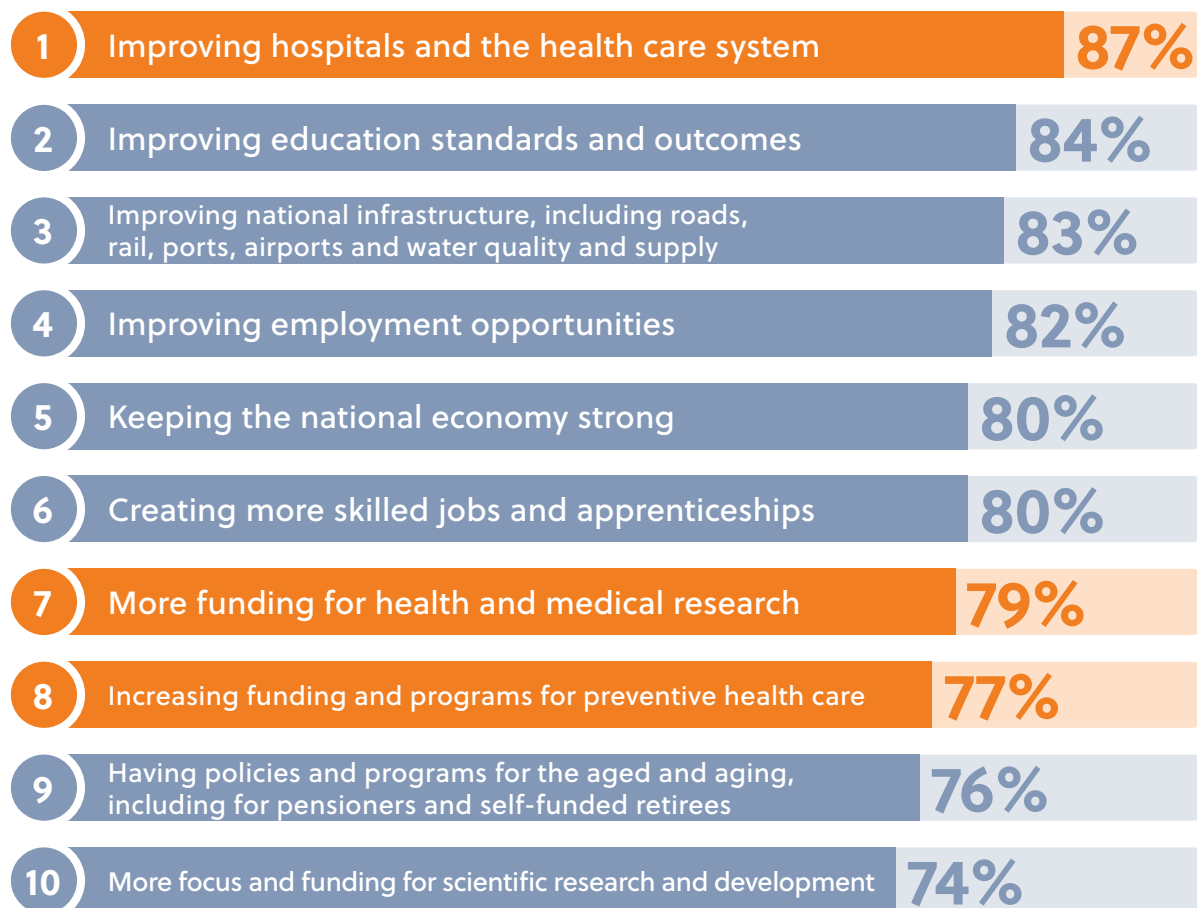
The views of Australians will continue to shape our strategies and priorities into the future and assist us to ensure that a healthy population and healthy economy go hand in hand.



Nadia Levin
Chief Executive Officer
Research Australia

PRIORITIES FOR THE AUSTRALIAN GOVERNMENT

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The scores reflect the proportion of respondents who rated each priority 7 or above out of a ranking of zero ('not important') to 10 ('extremely important'). Respondents were asked to rate 27 priorities in total.

QUESTION:
What priorities do you think the Federal Government should be focusing on over the next 2–3 years.

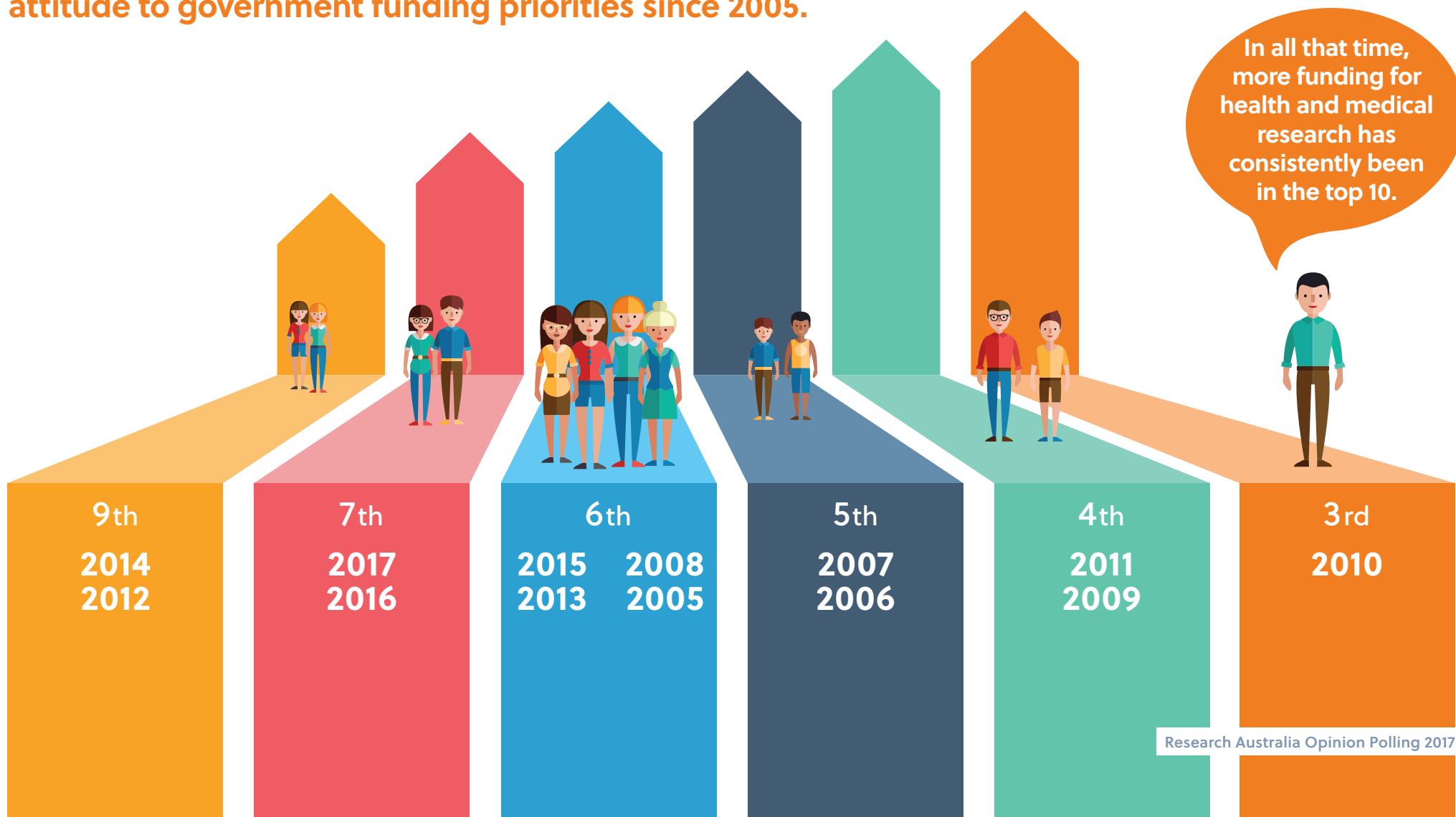
Improving hospitals and the healthcare system remains the top priority, as it has since the first Opinion Polling in 2003.



PRIORITIES FOR THE AUSTRALIAN GOVERNMENT

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Research Australia has been undertaking annual opinion polling since 2003, and testing the public attitude to government funding priorities since 2005.





ECONOMIC IMPORTANCE OF HEALTH AND MEDICAL RESEARCH

86% agreed with the proposition 'Health and medical research is important to the health and economy of the country, and providing adequate government funding is very important'.

► Only 6% thought we should leave it to other countries as they were likely to be better at it.

QUESTION:

Which best sums up your view about government spending on health and medical research in Australia?

WHO SHOULD BE MOST RESPONSIBLE FOR FUNDING

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More people nominated the Australian Government than any other body, with private investment coming in second. It's this combination of public and private investment which can position Australia as a global leaders in the health and medical research sector.

Commonwealth Government



Private business investment by Australian companies



State & Territory Governments



Donations & grants from corporates & corporate foundations



Donations & grants from individuals, community groups & trusts



Local Governments



Private business investment by foreign companies

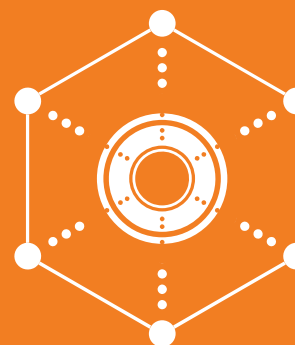


QUESTION:

Which of the following people, groups and organisations should be **MOST** responsible for funding health and medical research in Australia?

Most responsible

Next most responsible



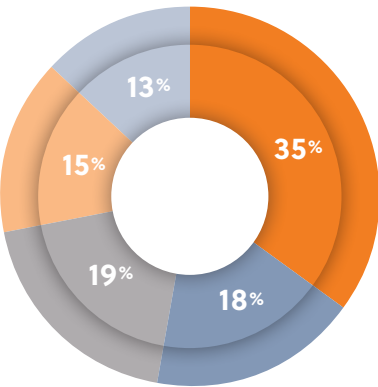
The Australian Government often uses its funding for health and medical research to influence and encourage broader investment.

For example, the Biomedical Translation Fund uses matching Commonwealth Government funding to encourage private sector investment in promising Australian medicines, biotechnologies and medical devices.

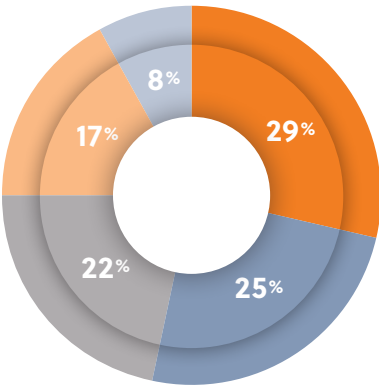
IMPORTANCE OF PRIVATE DONATIONS

While private donations from individuals did not rate highly as primary sources of funding for health and medical research in the responses to the above question, **we know from our previous opinion polls that Australians take donations for health and medical research very seriously.**

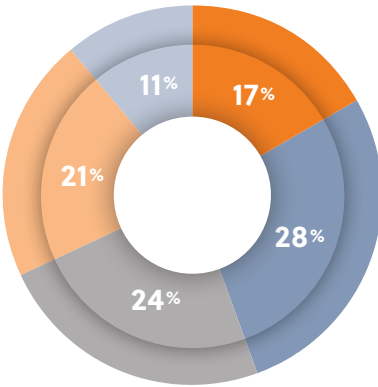
The last time we asked about donations (2015) 48% reported that they had made at least one donation to health and medical research in the previous 12 months. The percentage of people reporting that they donated between \$101 and \$500 per year increased from 14% in 2008 to 27% in 2015.



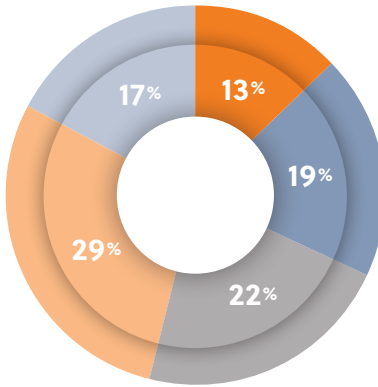
Personal experience with an illness or disease affecting me, a family member or a friend.



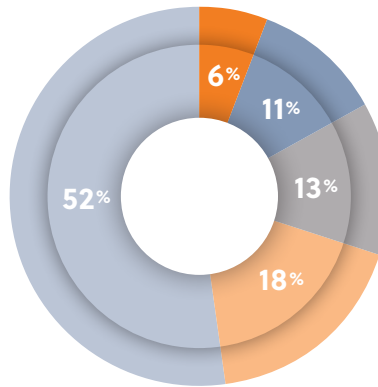
I think donating is important.



I consider it an investment in my and my family's future health.



Supporting a friend or colleague who is raising money.



I was asked to donate, and there was no other particular reason.

Greatest influence Major influence Moderate influence Some influence Least influence

QUESTION (2013):
Please rank the reasons for donating to health and medical research.

AUSTRALIANS SHARE STRONG SUPPORT FOR THE MEDICAL RESEARCH FUTURE FUND

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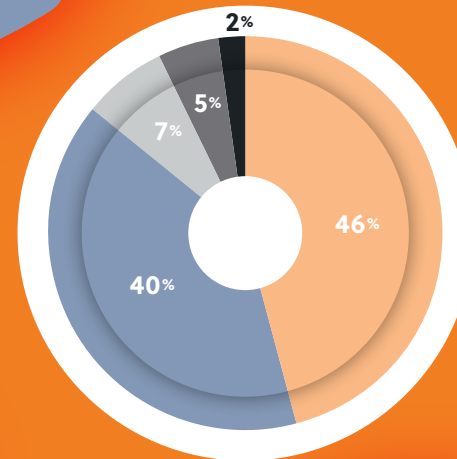
Established in 2015 by the Australian Government, the Medical Research Future Fund (MRFF) is distributing its first funding for medical research in 2017, and over the next four financial years it is forecast to provide more than \$1.3 billion.

As might be expected of a population that thinks the Commonwealth Government should be most responsible for funding health and medical research, and that it should fund more health and medical research, the MRFF is popular.

Support was just as strong last year when we asked a similar question.

QUESTION:

After an explanation was provided, the respondents were asked: Do you support or oppose the MRFF proposal?



Who are the MRFF's strongest supporters?

61% of those aged 65 and over strongly support the MRFF

Support is strong across all of Australia's states and territories.



WHY AUSTRALIANS SUPPORT HEALTH AND MEDICAL RESEARCH

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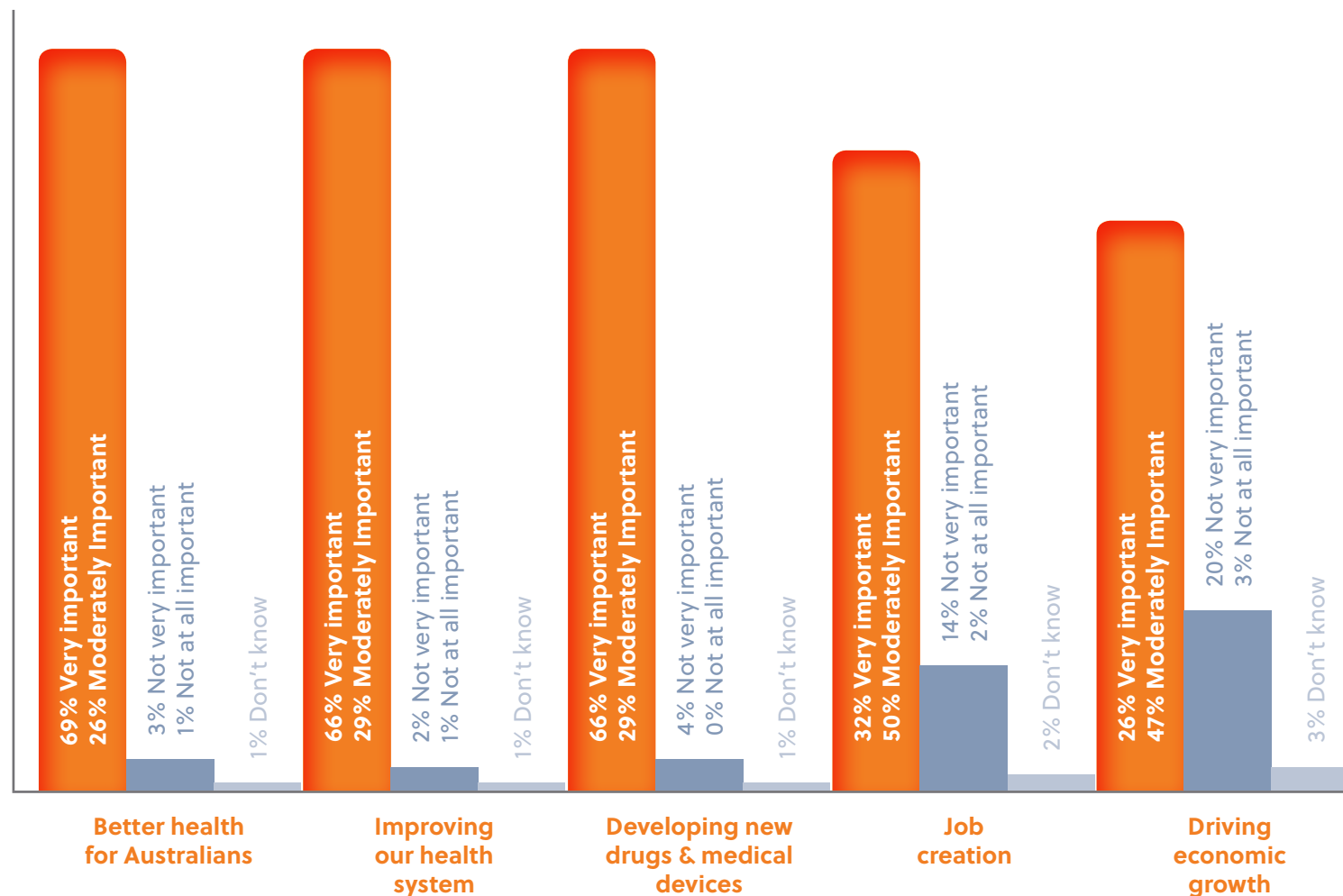
Benefits:

- Better health
- Job Creation
- Improving our health system
- Developing new drugs and medical devices

Australians understand health and medical research is important to job creation and economic growth. While the results are not quite as high, a combined 82% believe that health and medical research is very or moderately important for job creation, and 73% believe it drives economic growth.

QUESTION:

Health and medical research is conducted in Australia in hospitals, universities and specialist medical research institutes, by government organisations, and by private companies, both large and small. Please rate how important you think health and medical research is for the following.



WHAT IS RESEARCH TRANSLATION?

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In Research Australia's 2016 opinion poll, people told us that the best thing we could do to improve our healthcare system was to ensure that healthcare is based on the best and most recent research. Achieving this requires 'research translation', the process of **using research discoveries to develop new products and new ways of doing things**. While we know that people understand the link between research and a better health system, we were curious to know if the public was familiar with the term, as it can be ambiguous or confusing. Even

researchers sometimes disagree about what it means.

When we asked people to tell us what research translation means, **56% of respondents identified the correct response**. This suggests that governments, scientists, researchers and health professionals need to take care to explain what they are talking about when they mention '**research translation**'. When we explained the term, the following were identified as the benefits of translating health and medical research.

What is research translation?

56%

Using research to develop new products and ways of doing things.

36%

Explaining research in language that non-scientists can understand.

6% None of the above.

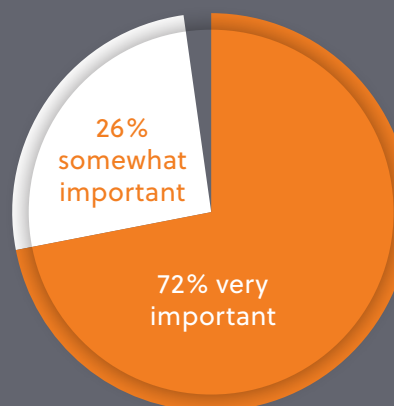
2% Translating research in different languages.

Research Australia Opinion Polling 2017

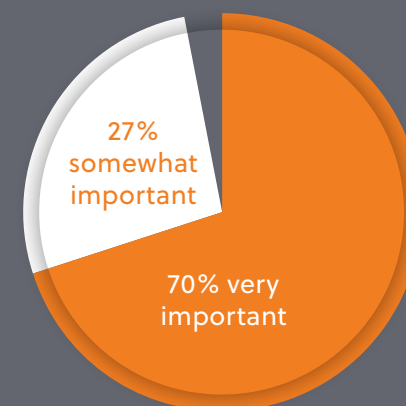
QUESTION:

Here are some possible benefits of research translation in the area of health and medical research. For each possible benefit, please say how important it is to you.

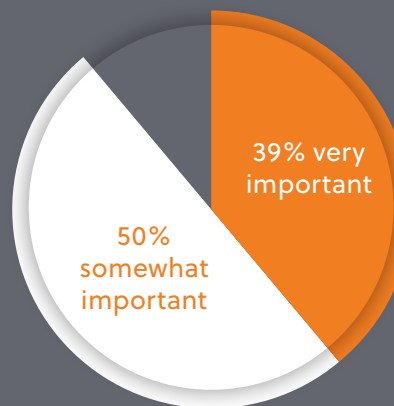
Perceived benefits of translating Health and Medical Research



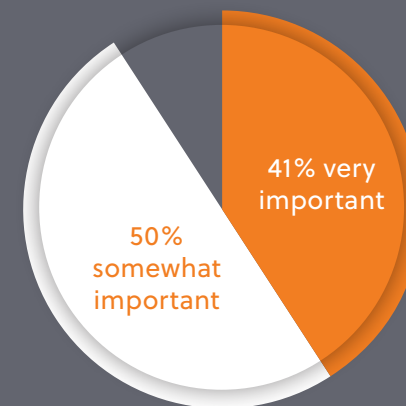
Best and most recent research used in our health system



More efficient health system



More jobs through the development & manufacture of new drugs & medical devices in Australia



Exports of new drugs and medical devices developed & manufactured in Australia

OVERWHELMING SUPPORT FOR EMBEDDING RESEARCH IN THE HEALTH SYSTEM

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Research translation is best achieved when health professionals are involved in research. We wanted to know if Australians supported the idea of the health professionals who care for them being engaged in research.

QUESTION:

Some healthcare professionals (doctors, physiotherapists, nurses etc.) and some hospitals and other healthcare providers are involved in research as well as providing patient care, while others are focused solely on providing patient care. Which of the two statements best reflects your view?

Health professionals, research and quality care

84% Believes health professionals who see patients and also undertake research provide the best care to patients, because they are more aware of new developments and the latest practices

16% Believes health professionals who see patients but don't also undertake research provide the best care to patients, because they have more experience with patients

Translating research findings quickly and efficiently into changes in clinical practice is one of the keys to improving patient management, reducing adverse events and readmissions, and reducing wasted spending on unnecessary tests and treatments.

Ultimately, embedding research in Australia's health system can deliver safer, more effective, evidence-based, efficient health care.

TISSUE AND BLOOD SAMPLES FOR RESEARCH

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Translation of research doesn't just need health professionals to get involved. Most health and medical research is dependent on the participation of patients and the public. Blood and tissue samples taken during medical procedures can be vital sources of information for research.

The good news is that many of us are supportive of our blood and tissue samples being stored in a biobank and used for research purposes.

QUESTION:

Some patients allow a blood or tissue sample that is removed during surgery or a medical procedure to be stored for future research. This is known as tissue banking or biobanking. If asked, would you allow your tissue to be placed in a biobank and used in research studies?

Support is highest among older Australians, with **61% of those aged 65 and over** definitely prepared to allow samples to be biobanked for research.

Allow samples to be biobanked?

51% Definitely yes
42% Probably yes
5% Probably no
2% Definitely no

The results are consistent with questions we asked about biobanking and research in 2014.

To capitalise on this willingness of Australians to contribute to biobanks, **we need a greater public investment in biobanking**, to create a more coherent and effective national network with better access for researchers from across Australia.

HEALTH CONSUMER DATA AND RESEARCH

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Information about us is collected each time we go to the doctor, a hospital, the dentist, physiotherapists and other health professionals. Some of this information is then provided to government agencies.

Another way we can all get involved in research is by allowing our health data to be used for research purposes. We asked about the level of support for the use of medical records for a range of different purposes.

There is strong support for the use of health records for research, with 93% of Australians either strongly or somewhat supporting it and only 7% opposed.

In response to a similar question in 2016, 91% indicated they were willing for their health data to be used for research purposes.

It is essential to engage people along the whole of the research pipeline about the transformative power of data and analytics.

Research Australia can promote new opportunities for consumers to share their de-identified data, for the health system to collect data, and for researchers to efficiently access and use the data.

48% Strongly support
45% Somewhat support

The use of patients' medical records by health and medical researchers for research purposes



70% Strongly support
28% Somewhat support

To monitor the outbreaks of new diseases



66% Strongly support
32% Somewhat support

To plan health services – for example, where new hospitals or more doctors are needed



60% Strongly support
37% Somewhat support

To monitor the effectiveness of our health services



46% Strongly support
46% Somewhat support

To pay a health professional or hospital for services provided to you



QUESTION:

a) Please indicate if you support government agencies collecting data about you for these purposes.

b) Do you support or oppose the use of patients' medical records by health and medical researchers for research purposes?

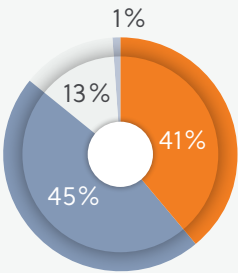
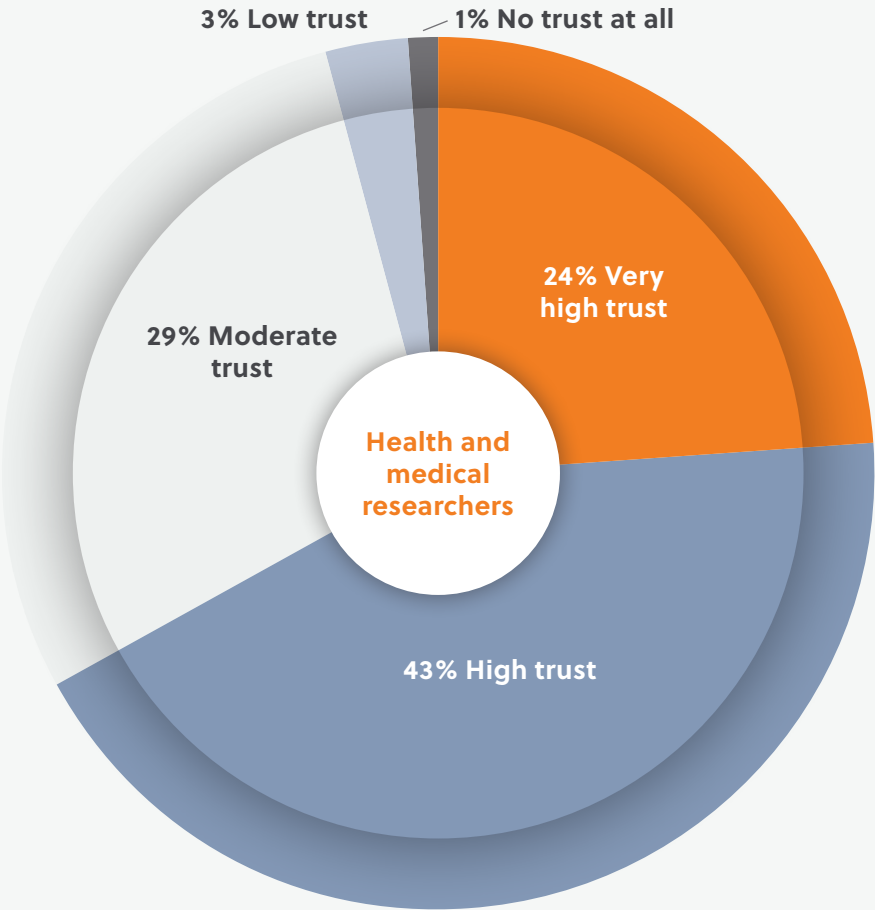


RESEARCHERS ARE TRUSTED

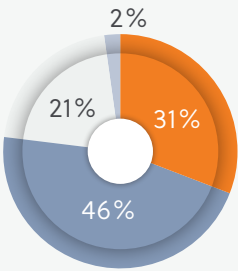
Strong support for the use of personal health information for research purposes suggests the Australian community trusts researchers to use personal health information responsibly. We asked people specifically about their level of trust.

The results show researchers are trusted almost as much as the health professionals we rely on to treat us.

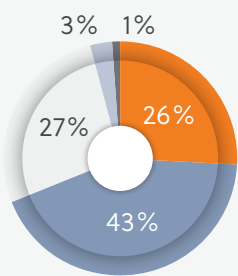
QUESTION:
Please rate each of the following, in terms of how much trust you would have in them to have access to personal health information and to use it responsibly.



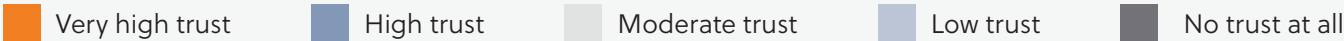
A doctor providing treatment to you



A nurse providing treatment to you



A physiotherapist, occupational therapist or other health professional providing treatment



SUPPORT FOR CLINICAL TRIALS

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Clinical trials are a critical part of the translation of new medicines, therapies and practices into healthcare. These can also benefit patients, providing access to new treatments that are otherwise not yet available. Research Australia has been undertaking polling about clinical trials since 2004, and public support for clinical trials has remained strong over this period.

This public support makes Australia a great place to conduct clinical trials, along with our strong regulatory framework, world class medical and research facilities and educated and expert research and healthcare workforce.

Research Australia advocates for a sustainable and strong clinical trials environment driving evidence-based change in the health system and new commercial opportunities.

QUESTION:

Clinical trials are used to test the effectiveness of new medical treatments and drugs before they are commercially available. If you required treatment and were asked to participate in a clinical trial of a new medical treatment would you agree to be involved?

In 2017, we asked a series of questions about clinical trials, including your willingness to participate in a clinical trial if they needed treatment.



56% indicated they would definitely or probably do so.



A further 38% indicated they would need further information.



Only 4% would probably or definitely refuse.

WHY PARTICIPATE IN A CLINICAL TRIAL?

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We were curious about what motivates people who told us they would definitely or probably participate in a clinical trial to do so. Here is what they told us. While self-interest is a strong motivation, so is the common good and a sense of altruism.

These findings are broadly the same as the last time we asked these questions in 2015.

QUESTION:

Here are some possible reasons people may have for agreeing to take part in a clinical trial. For each reason, please say how important it is to you in deciding to participate in a clinical trial.

Other options were "not very important" and 'not at all important'.

Reason for participating

Clinical trials are necessary to develop new treatments

80% Very important

19% Somewhat important

There may be a chance it will save or extend my life

74% Very important

22% Somewhat important

Australia has a well-regulated and ethical process for clinical trials

68% Very important

29% Somewhat important

I trust that my doctor would recommend participation in my best interest

63% Very important

32% Somewhat important

It would give me access to new treatments not yet generally available

59% Very important

36% Somewhat important

I want to help those who have health problems, even if it might not help me

53% Very important

40% Somewhat important

WHAT MIGHT DISCOURAGE YOU FROM PARTICIPATING IN CLINICAL TRIALS?

17

We were also curious about what might discourage people who had indicated they were willing to participate in a clinical trial or had indicated they would need more information.

QUESTION:

Here are some possible reasons people may have for not being sure about whether to take part in a clinical trial. For each reason, please say how important it is to you in deciding whether to take part in a clinical trial. (Respondents who indicated they were willing or needed more information)

Other options were "not very important" and 'not at all important'.

Reason for not participating

It would depend on what other treatment options are



It would depend on how sick I was



I'd want a guarantee about the security and confidentiality of my personal health information



I'd want to know if I would get any payment



We, as the sector responsible for clinical trials, must continue to address consumer concerns about confidentiality and the security of data.

For the 4% who earlier indicated they definitely or probably wouldn't participate in a clinical trial, the major concern was clinical trials' experimental nature, with 92% of this small group indicating this was a very or somewhat important consideration.

Other, less significant, factors were a lack of understanding about clinical trials, a concern that it may not be of benefit, a lack of trust in the organisations running clinical trials, the time and effort required and concerns about the security and confidentiality of their information.

HEALTHY VOLUNTEERS AND CLINICAL TRIALS

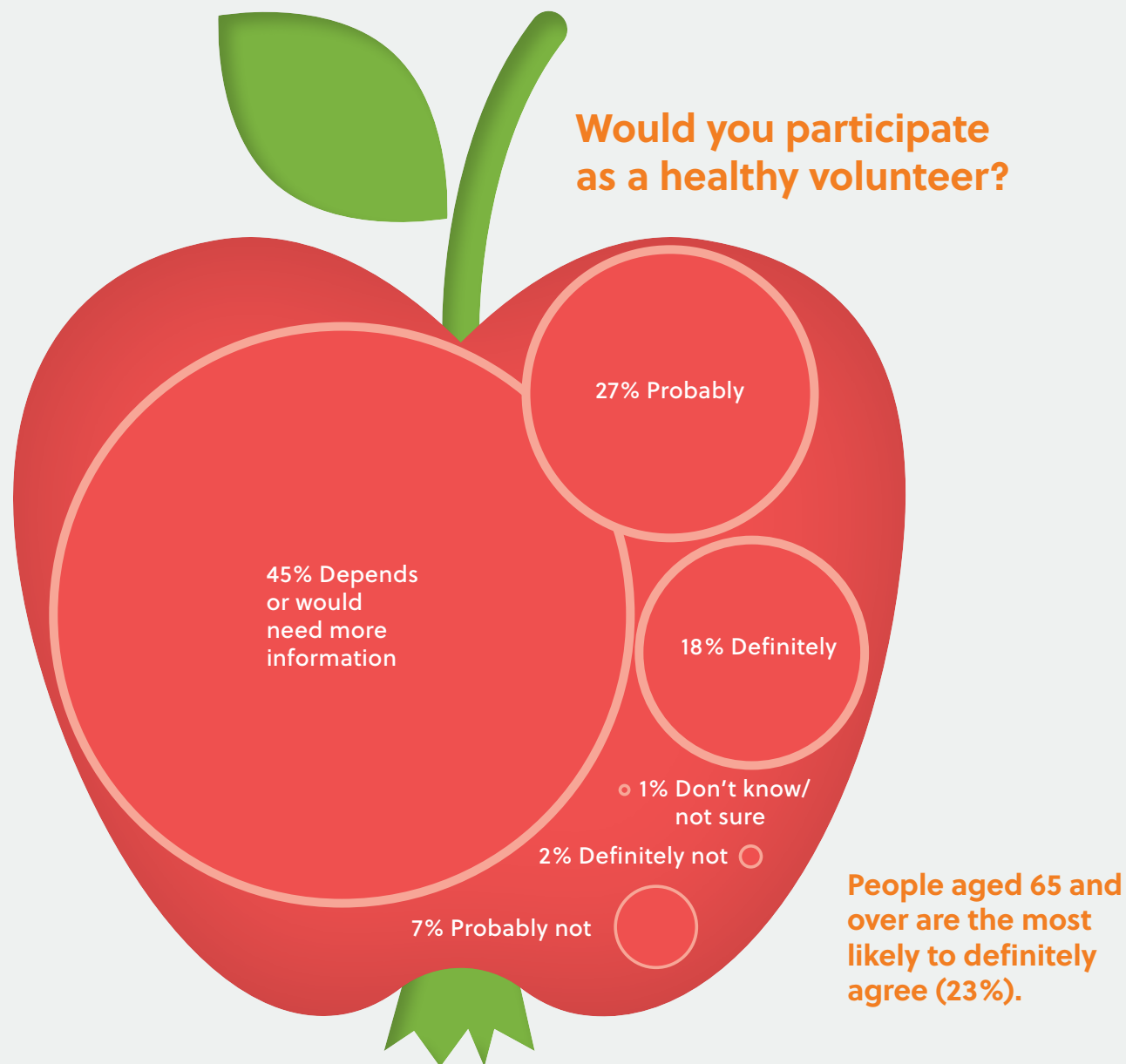
18

While most of us associate clinical trials with people who are sick and need treatment, **in the early stages, clinical trials need to recruit healthy volunteers.** We were interested to know if people who told us they would be willing to participate in a clinical trial if they needed treatment, would also be willing to participate if they didn't need treatment.

Understandably, fewer people would be willing to participate if they were healthy than if they needed treatment, but the number willing to do so is still significant and indicative of a strong sense of altruism in the Australian community.

QUESTION:

In early stage clinical trials, new medical treatments and drugs are given to healthy volunteers to ensure the new treatments and drugs are safe. Would you agree to participate in a clinical trial if you were asked to do so and you DID NOT require treatment?



DEVELOPING NEW DRUGS

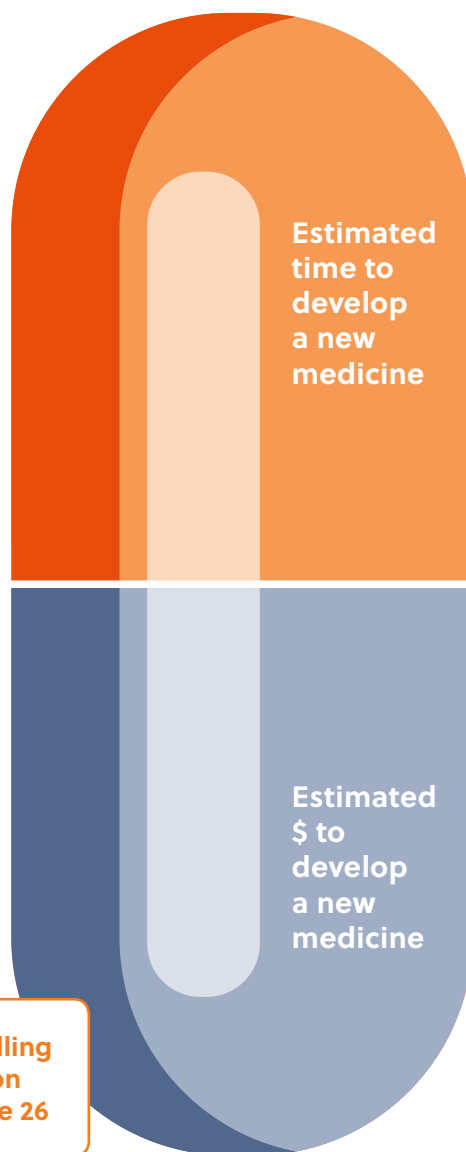
19

Another factor in the translation of research discoveries into healthcare is the time and money required. In the case of medicines, it is estimated to take between 10 and 15 years to bring a new vaccine or medicine to market. We wanted to know what the level of understanding of this is in the broader community.

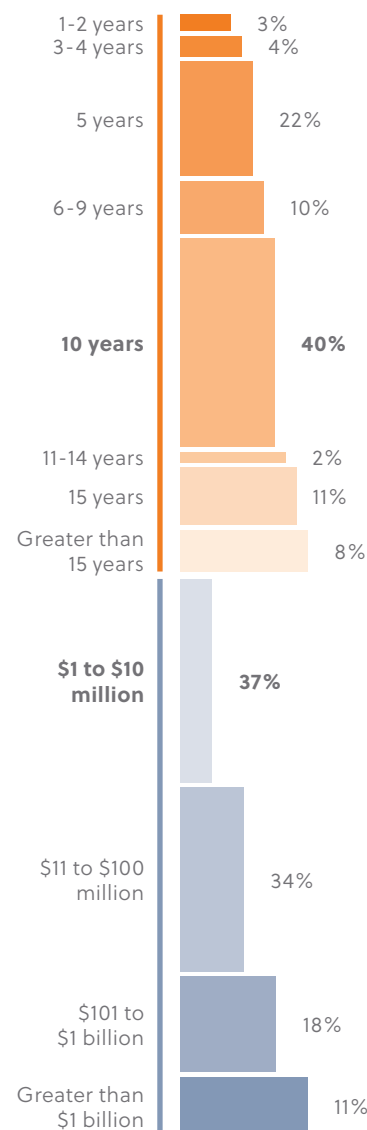
Why ask people how much it costs or how long it takes?

It's not important that people know the actual cost of developing a medicine – what does matter is that they understand that it is a long and expensive process. This helps to shape the public's expectations about when that research 'breakthrough' they hear about might become a new medicine, and why some drugs, particularly for small patient groups, are so expensive. It's not just about the cost of manufacturing the pills in that bottle – it is all the years of research and development that led to it and all the new approaches that were tried and *didn't work*.

With the initial research phase, often publicly funded in our universities and research institutes taking so long, sustained public funding is essential. And with the majority of the development costs for a new medicine or vaccine borne by private pharmaceutical companies in the later stages, private sector investment is equally important.



See polling question on page 26



Time taken

We asked people to estimate the time required in years. Responses varied widely, with around half (53%) making an estimate within the range of 10 to 15 years.

Dollars required

Not only does it take a long time to bring a new vaccine or medicine to market, but it takes a lot of money, estimated on average to be \$3.5 billion.

This is a staggering amount of money and one that most of us have trouble imagining. Not surprisingly, estimates of the cost of developing a new medicine varied enormously.

THE INTERNET AND OUR HEALTH

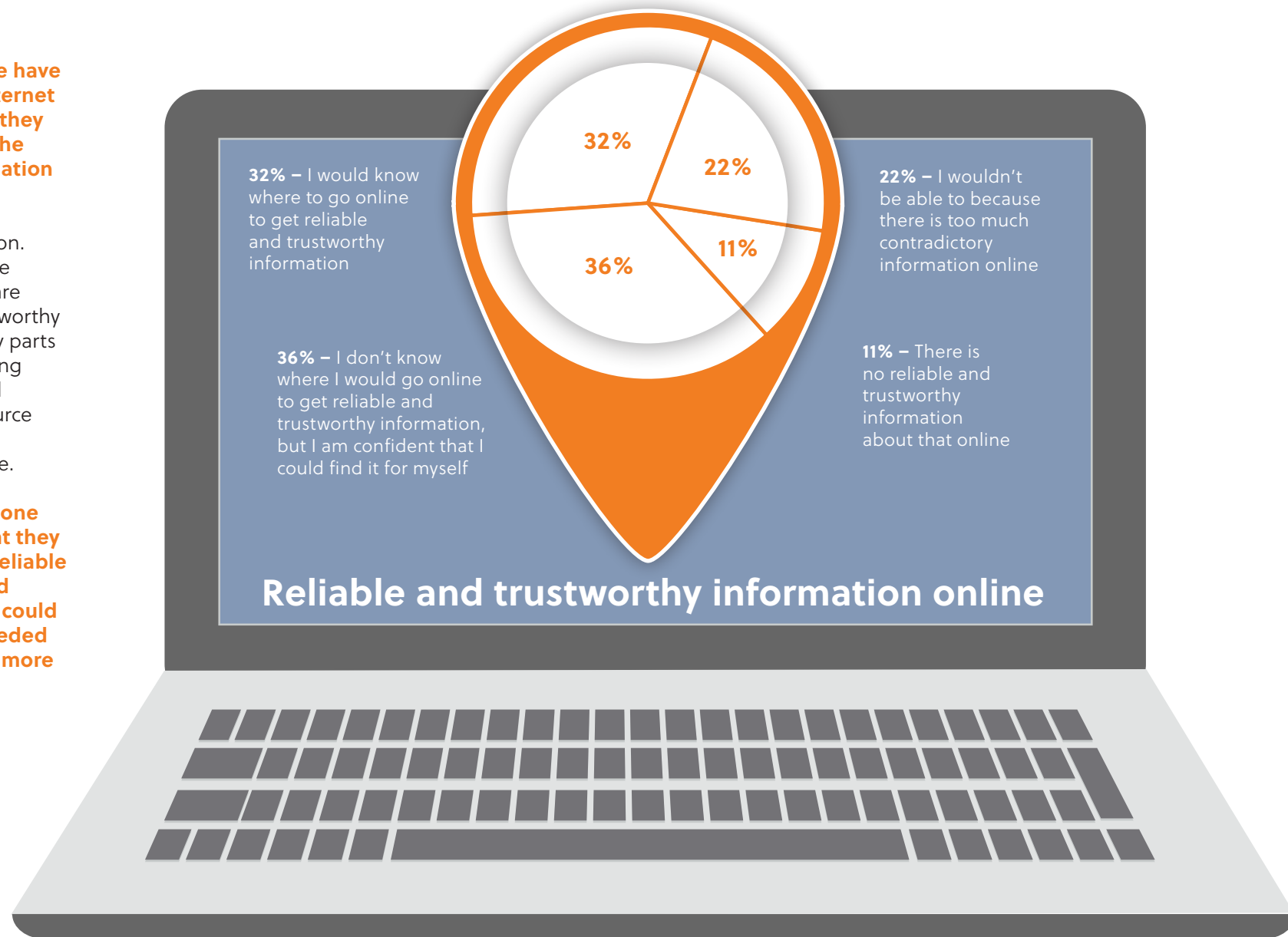
20

Over our last few annual polls we have explored how people use the internet to check their symptoms before they see a doctor, and how they use the internet to obtain further information after a consultation.

We know they want more information. We checked in again this year on the question of how confident people are that they can find reliable and trustworthy information online. As with so many parts of our lives, when it comes to learning more about our health and medical conditions the internet can be a source of useful information, not so useful information and complete nonsense.

Overall the news is good. About one third of people are confident that they know where to go online to get reliable and trustworthy information, and another third are confident they could find good information if they needed it. The remaining third are much more sceptical and/or pessimistic.

See polling question on page 26



USING THE INTERNET FOR OUR HEALTH

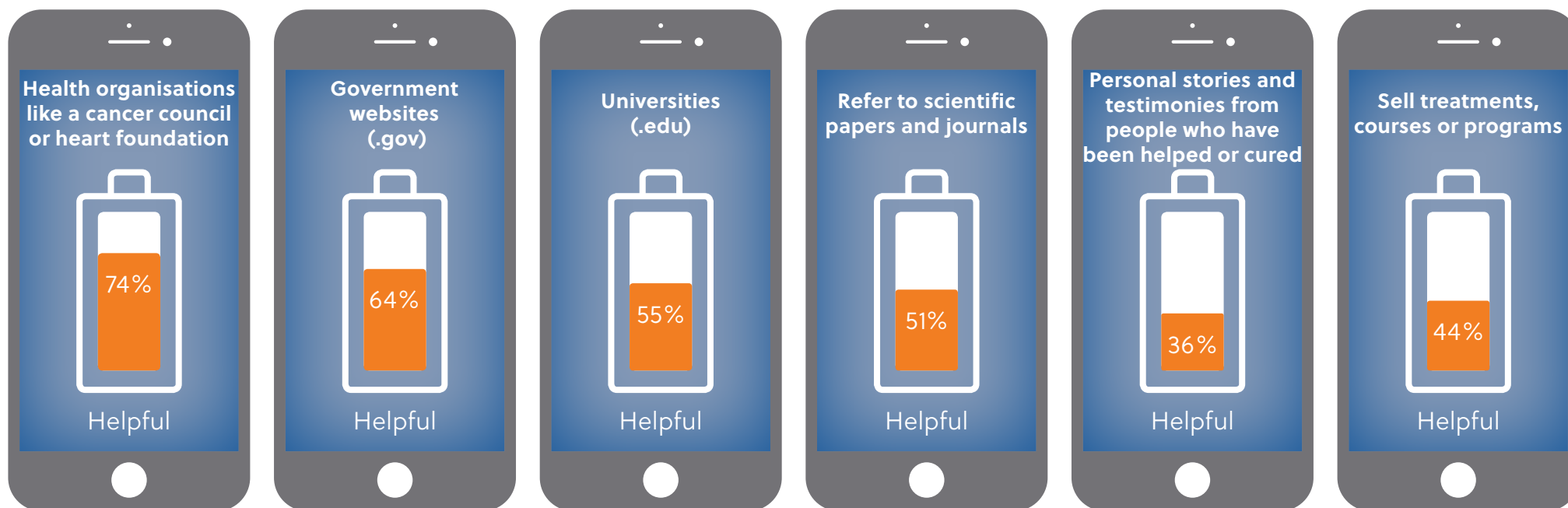
21

In 2015 we asked people a related question about which kinds of websites they found helpful.

78% reported using the internet to obtain health information in the previous 12 months. The following is what they told us about the types of websites they found helpful.

Research Australia is promoting stronger links between researchers, consumers and healthcare providers to enable faster uptake of evidence based practice. Better and more reliable information for consumers, including online, is an essential component.

See polling question on page 26



THE MY HEALTH RECORD AND RESEARCH

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My Health Record is a relatively new tool that means your important health information like allergies, current conditions and treatments, medicine details, pathology reports and diagnostic imaging reports can be digitally stored in one place. **Healthcare providers like doctors, specialists and hospital staff can see these details online from anywhere at any time when they need to, such as in an accident or emergency.**

The Australian Digital Health Agency has reported that at around the same time Research Australia's polling was being conducted, over 4.8 million people (around 20% of the Australian population) had a My Health Record. The Opinion Polling supports this with **24% of respondents reporting they had a My Health Record**. 10% also reported having created a My Health Record for a dependent child/children. Perhaps more importantly, only **59% of people were aware** of the My Health Record, suggesting that there is more work to be done to raise awareness. Also, less than half the people who are aware of the My Health Record have created one, so awareness is not the only barrier.

Why would researchers be interested in the My Health Record?

While it is still in its infancy, the My Health Record promises to be a very important database of health information that can be used for a range of research including identifying trends in population health over time, the emergence of new diseases, monitoring the effectiveness of new medicines, and understanding regional differences in health care.

History tells us that human health has made huge advances when medicine intersects with mathematics and data. Research Australia continues to advocate for health records to be made more readily available for research.

This is part of Research Australia's role in encouraging the policy settings for efficiently shared, linked and secured data.

See polling question on page 26



METHODOLOGY

23

Research Overview

Statement of Compliance with International Standards:	This research project was carried out in compliance with ISO 9001 & ISO 20252
Client Name:	Research Australia
Research Service Provider Name(s):	Roy Morgan Research Ltd
Sub-contractor used:	None
Process sub-contracted:	None
Research Objectives:	This research was conducted to trend attitudes towards medical and health issues in Australia.

Quantitative Research

Target Group:	Australians 18 years and older
Proposed Sample Size:	1000
Actual Sample Size:	1011
Reason for Difference in Proposed to Actual Sample Size:	Slight over-recruitment in some age/gender/location cells due to some respondents having begun but not completed the online survey when the quota target was met (i.e. they are permitted to finish). This over-recruitment was subsequently corrected during the weighting process (see below)
Fieldwork Period:	3rd May to 10th May 2017
Sampling Method:	Members of Roy Morgan Research's Proprietary Online Panel, 18 years and older, living in Australia, were emailed an invitation to participate in the survey.
Data Collection Method:	Online survey (CAWI – Computer Assisted Web Interviewing)
Response Rate:	9.0%
Weighting Process:	Weighted proportional to population by age, sex and area, and projected to Australian 18+ population estimates
Estimation/Imputation Procedure:	No estimation/imputation processes used
Representatively of the Sample Population:	Sample is broadly representative of Australia's population by sex, age and area
Maximum Sampling Tolerance:	±3.0%
Incentive Type:	Points redeemable for cash

OPINION POLL 2017 QUESTIONS

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AUSTRALIANS' TOP 10 PRIORITIES FOR THE FEDERAL GOVERNMENT (PAGE 3)

Q: Firstly, please think about what priorities you think the Federal Government should be focusing on over the next 2–3 years. As you read through the following list of issues, please rate how important you personally think each issue is, as a priority for the Federal Government to be focusing on over the next 2–3 years.

Please use a 0 to 10 scale, where a 0 means that it is not important up to a 10 that means it is extremely important or a critical priority for the Federal Government to be focusing on over the next 2–3 years.

ECONOMIC IMPORTANCE OF HEALTH AND MEDICAL RESEARCH (PAGE 5)

Q: What best sums up your view about the Medical Research Future Fund? (Choose one)

1. The Medical Research Future Fund provides valuable and necessary government grants to support health and medical research and innovation
2. The Medical Research Future Fund is an unnecessary use of taxpayer money that would be better off spent elsewhere or saved
3. I don't know enough about the Medical Research Future Fund to answer

WHO SHOULD BE MOST RESPONSIBLE FOR FUNDING HEALTH AND MEDICAL RESEARCH IN AUSTRALIA (PAGE 5)

Q: Which of the following people, groups and organisations should be MOST responsible for funding health and medical research in Australia? And which should be the NEXT MOST responsible? Mark one response in each column.

	MOST RESPONSIBLE	NEXT-MOST RESPONSIBLE
The Commonwealth Government	1	1
State and Territory Governments	2	2
Local Governments	3	3
Private business investment by Australian companies	4	4
Private business investment by foreign companies	5	5
Donations and grants from individuals, community groups and trusts	6	6
Donations and grants from corporates and corporate foundations	7	7

SUPPORT FOR THE MEDICAL RESEARCH FUTURE FUND (PAGE 8)

Q: In 2015 the Federal Government established the Medical Research Future Fund which will build to \$20 billion over time and use only the investment earnings to fund health and medical research. The aim is for the investment earnings of the Medical Research Future Fund to provide \$1 billion per year for health and medical research by 2021. Do you support or oppose this proposal?

1. Strongly support
2. Somewhat support
3. Somewhat oppose
4. Strongly oppose
5. I do not know/not sure

WHY AUSTRALIANS SUPPORT HEALTH AND MEDICAL RESEARCH (PAGE 9)

Q: Health and medical research is conducted in Australia in hospitals, universities and specialist medical research institutes, by government organisations, and by private companies, both large and small. Please rate how important you think health and medical research is for the following:

1. Better health for Australians
2. Job creation
3. Driving economic growth
4. Improving our health system
5. Developing new drugs and medical devices

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WHAT IS RESEARCH TRANSLATION? (PAGE 10)

Q: In the context of scientific research, 'research translation' is used to describe the process of using research discoveries to develop new products and new ways of doing things.

Here are some possible benefits of research translation in the area of health and medical research. For each possible benefit, please say how important it is to you.

(Very important, somewhat important, not very important, not at all important)

1. Best and most recent research is used in our health system
2. More efficient health system
3. More jobs through the development and manufacture of new drugs and medical devices in Australia
4. Exports of new drugs and medical devices developed and manufactured in Australia

EMBEDDING RESEARCH IN THE HEALTH SYSTEM (PAGE 11)

Q: Some healthcare professionals (doctors, physiotherapists, nurses etc.) and some hospitals and other healthcare providers are involved in research as well as providing patient care, while others are focused solely on providing patient care. Which of the two statements below best reflects your view?

1. Hospitals that also undertake research provide the best care to patients because they attract better qualified staff.
2. Hospitals that don't also undertake research provide the best care to patients because all their resources are directed to looking after patients.

TISSUE AND BLOOD SAMPLES FOR RESEARCH (PAGE 12)

Q: Some patients allow a blood or tissue sample that is removed during surgery or a medical procedure to be stored for future research. This is known as tissue banking or biobanking.

Do you think that a person should have to provide formal consent for their samples to be kept in a biobank and used for research purposes?

1. Definitely yes
2. Probably yes
3. Probably no
4. Definitely no

If asked, would you allow your tissue to be placed in a biobank and used in research studies?

1. Definitely yes
2. Probably yes
3. Probably no
4. Definitely no

SUPPORT FOR HEALTH CONSUMER DATA (PAGE 13)

Q: Information about us is collected each time we go to the doctor, a hospital, the dentist, physiotherapists and other health professionals. Some of this information is then provided to government agencies. The following is a list of some of the purposes for which government agencies might collect health data. Please indicate if you support government agencies collecting data about you for these purposes.

(Strongly support, somewhat support, somewhat oppose, strongly oppose)

1. To pay a health professional or hospital for services provided to you
2. To monitor the outbreaks of new diseases
3. To plan health services, for example where new hospitals or more doctors are needed
4. To monitor the effectiveness of our health services

Q: This information can also be useful to health and medical researchers. For example, it can help in understanding links between different medical conditions, or in assessing the effectiveness of new treatments. Do you support or oppose the use of patients' medical records by health and medical researchers for research purposes?

1. Strongly support
2. Somewhat support
3. Somewhat oppose
4. Strongly oppose

HEALTH RECORDS, RESEARCH AND TRUST (PAGE 14)

Q: Please rate each of the following, in terms of how much trust you would have in them to have access to personal health information and to use it responsibly.

(Very high trust, high trust, moderate trust, low trust, no trust at all)

1. A doctor providing treatment to you
2. A nurse providing treatment to you
3. A physiotherapist, occupational therapist or other health professional providing treatment to you
4. Administrative staff in a public hospital
5. Administrative staff in a private hospital
6. Administrative staff at your doctor's office
7. Health insurance companies
8. Government Health Department staff (arranging payments, comparing performance)
9. Health and medical researchers

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SUPPORT FOR CLINICAL TRIALS (PAGE 15)

Q: Clinical trials are used to test the effectiveness of new medical treatments and drugs before they are commercially available. If you required treatment and were asked to participate in a clinical trial of a new medical treatment would you agree to be involved?

1. Yes, would definitely agree
2. Yes, would probably agree
3. Depends / Would need more information
4. No, would probably disagree
5. No, would definitely disagree
6. Don't know / Not sure

REASONS FOR PARTICIPATING IN CLINICAL TRIALS (PAGE 16)

Q: Here are some possible reasons people may have for agreeing to take part in a clinical trial. For each reason, please say how important it is to you in deciding to participate in a clinical trial. (Very important, somewhat important, not very important, not at all important)

1. Clinical trials are necessary to develop new medical treatments
2. There may be a chance it will save or extend my life
3. I want to help those who have health problems even if it might not help me
4. I trust that my doctor would recommend participation in my best interest
5. It would give me access to new treatments not yet generally available
6. Australia has a well-regulated and ethical process for clinical trials

DISCOURAGEMENT FROM CLINICAL TRIALS (PAGE 17)

Q: Here are some possible reasons people may have for not agreeing to take part in a clinical trial. For each reason, please say how important it is to you in deciding not to participate in a clinical trial. (Very important, somewhat important, not very important, not at all important)

1. I am worried about being used for experimental treatments that are unproven
2. I don't understand enough about clinical trials
3. It may not be of direct benefit to me and may be of more benefit to others
4. I don't trust the organisations running the clinical trials
5. It takes too much time and effort to be involved
6. I am worried about the security and confidentiality of my personal health information

HEALTHY VOLUNTEERS AND CLINICAL TRIALS (PAGE 18)

Q: In early stage clinical trials, new medical treatments and drugs are given to healthy volunteers to ensure the new treatments and drugs are safe. Would you agree to participate in a clinical trial if you were asked to do so and you DID NOT require treatment?

1. Yes, would definitely agree
2. Yes, would probably agree
3. Depends / Would need more information
4. No, would probably disagree
5. No, would definitely disagree
6. Don't know/Not sure

DEVELOPING NEW DRUGS (PAGE 19)

Q: How long do you think it takes, on average, for a new medicine to be available to patients from when the research first commences? If not sure, provide your best guess.

_____ years

Q: How much do you think it costs, on average, for research and development for a new medicine from when the research first commences to when it becomes available to patients?

Please answer in whole numbers, as either millions or billions of Australian dollars. If not sure, please provide your best guess.

_____ \$million OR _____ \$billion
(range 1 to 999) (range 1 to 999)

THE INTERNET AND OUR HEALTH (PAGE 20)

Q: Which best sums up your view about obtaining reliable and trustworthy information online about a medical condition? (Choose one)

1. I would know where to go online to get reliable and trustworthy information.
2. I don't know where I would go online to get reliable and trustworthy information, but I am confident that I could find it for myself.
3. There is no reliable and trustworthy information about that online.
4. I wouldn't be able to because there is too much contradictory information online.

MY HEALTH RECORD AND RESEARCH (PAGE 22)

Q: Have you heard of My Health record?

YES/NO

Q: Have you created a My Health Record for:

1. yourself? YES/NO
2. your child/children?
 1. YES - for one or more of my dependent children
 2. No - for none of my dependent children
 3. Not Applicable – I don't have any dependent children

ABOUT RESEARCH AUSTRALIA

Research Australia is the national alliance representing the entire health and medical research pipeline from the laboratory through to the patient and the marketplace.

Research Australia uses its unique convening power to position health and medical research as a significant driver of a healthy population and contributor to a healthy economy.

OUR VISION

Research Australia envisions a world where Australia unlocks the full potential of its world-leading health and medical research sector to deliver the best possible healthcare and global leadership in health innovation.

OUR GOALS

- Connect** researchers, funders, and consumers to increase investment in health and medical research from all sources.
- Engage** Australia in a conversation about the health benefits and economic value of its investment in health and medical research.
- Influence** government policies that support effective health and medical research and its routine translation into evidence-based practices and better health outcomes.

Publisher

Australia Speaks Opinion Polling 2017
is a publication of Research Australia Ltd
ABN 28 095 324 379
384 Victoria Street, Darlinghurst NSW 2010
Researchaustralia.org
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An abstract graphic on the right side of the image, consisting of a dense network of thin, light-colored lines connecting various circular nodes. The nodes are in shades of orange, white, and dark grey, creating a complex, web-like structure that suggests connectivity and research.

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