

RESULTS

Results of Australia's Health
Panel survey on
recommendations and
regulation of smartphone apps
for health and wellness

Consumers Health Forum of Australia (2018)
Results of Australia's Health Panel survey on
recommendations and regulation of smartphone
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Contents

What is Australia's Heath Panel?	4
Headlines	4
Background	5
Limitations of the survey	5
Methods	7
Results	7
Who or what would you trust to give you recommendations on apps for your health?	8
Big Tech	9
Peers	10
Health Professionals	12
Non-government Organisations	13
Government	15
Do you think the government should have a scheme where health apps are given a rating for accuracy and effectiveness?	16
Consumer Concerns	18
Digital Divide	18
Over-reliance on apps	18
Where consumers will see the recommendations or warnings	19
Appendices	20
Screenshots of the Survey	20
Text of Survey Questions	22

What is Australia's Heath Panel?

Australia's Health Panel is a recent CHF initiative that helps the consumer voice be heard on the national stage, through timely and high-quality surveys. It is a modern, interactive online platform devoted to harnessing the views of Australians about the state of the nation's health care system.

Healthcare will change rapidly over the next ten years, driven by community expectations and developments in fields such as medical knowledge, genomics and digital health. Insights generated by the Panel will strengthen the community voice, shaping the healthcare we want in the 21st century.

Businesses seeking to better shape products and services ask consumers "what matters to you?" **It should be the same in health care**. The Panel provides a unique, direct channel to ask consumers about the contemporary issues in health and care that matter most to them.

Visit Australia's Health Panel here: https://chf.engageable.net

Headlines

Consumers want support in finding accurate, effective smartphone apps for health and wellness, and they should be subject to an authoritative regulatory system that rates them for efficacy.

As consumers increasingly turn to health apps to aid and monitor their health and treatment, there's clearly a need for people to know whether they can trust the apps, and whether they offer the best health option available and are worth the investment in time and money.

Our survey results highlight the growing public demand for credible and effective oversight of health apps given their accelerating reach into every aspect of health care.

- Respondents trust their GPs most when it comes to recommendations for apps, but also do their own research and look to other sources for information;
- There is a role for the government to play in regulating health and wellness apps, with nearly 90% of respondents to our survey say that either the government should review and rate health apps (58%), or should fund another organisation to do it (31%);
- There is a healthy scepticism towards trusting sources like Google or even recommendations from peers completely; and
- Respondents trust non-government health organisations to provide sound advice.

Background

"I have been using the Headspace app to learn meditation and practice it daily. I have also been using Johnson & Johnson 7-minute workout. I have also used perspective, and Daylio for journaling and mood diary. All have been a huge benefit to me."

The first survey for Australia's Health Panel asked who respondents trusted for recommendations of smartphone apps for health and wellness, and what role the government should play in regulating those apps.

Consumers are using health and wellness apps in greater and greater numbers, and it is already an industry worth billions that is sure to continue to grow. Healthcare must always keep safety and quality at its core, so a key question to ask is are those apps safe, useful, and right for our needs – and who do we trust to tell us whether that's the case?

"Health apps are the way of the future, particularly for those researching their symptoms and/or diagnosis. More patients are being empowered by the knowledge they can now access via the internet."

The smartphone is still a relatively new piece of technology and the ways in which it is used are rapidly changing and evolving. As apps continue to improve we move from health and wellness apps that largely only record information or give small behavioural nudges to apps that claim to be able to diagnose, treat or manage our health, the risks and complexity they present to society and individuals increases.

When those health and wellness apps are such that they start interacting with the more formal health system, further questions are raised such as to whether they should form part of a treatment plan or even be prescribed, or whether they should attract government funding in ways similar to medicines on the Pharmaceutical Benefits Scheme.

"Health apps are the way of the future, particularly for those researching their symptoms and/or diagnosis. More patients are being empowered by the knowledge they can now access via the internet."

Limitations of the survey

It is important to note a number of limitations with this survey. CHF views these findings as indicative rather than authoritative. The results have not been analysed for margin of error or

statistical significance and are intended to identify broad themes, foster discussion rather than provide evidence, and highlight where more rigorous research may be needed.

Future panel surveys will only be available to registered panel members, however as this was the first survey held through Australia's Health Panel it was made publicly available. This increases the risk of 'donkey' responses; however, none were identified in the results.

No paid advertising was undertaken, limiting the pool of respondents for the most part to those that saw it in our newsletters or social media, or in the newsletters and social media of organisations similar to ours that also shared it. This means the respondents are more likely to be aware of health issues, the role of government in the health system, and have a relatively high level of health literacy. Our results should not necessarily be construed as representative of the Australian population.

We deliberately decided not to try and separate apps into categories and left the definition broad and open to interpretation by respondents. This helped generate results but does mean that some people will have responded thinking about very different types of apps than their peers.

It is also important to note when interpreting the results of who people trust to give them recommendations on apps for health and wellness that the context and timeframes in which those interactions occur is dramatically different. The time a consumer spends with a GP is significantly shorter than they might spend in a peer support group or searching with Google. To fully investigate not just who, but where and when consumers want or expect recommendations would require further research.

Methods

Australia's Health Panel is a growing group of consumers who respond to regular surveys on health issues. The project is run by the Consumers Health Forum of Australia, and surveys are delivered using a licensed version of the $\underline{\mathsf{Engageable}}^{\mathsf{M}}$ software.

Future surveys will be closed to the public and only available to registered members of the Panel, however as this was the first survey it was opened to the public to maximise participation and increase Panel membership.

This survey was open to responses from 6 July 2018 – 31 July 2018 and received approximately 260 responses in total, of which not all were complete and were discarded from analysis.

The survey was divided into three sections which are summarised in the table below. Screenshots of the survey and the full text used within is available in the appendix of this document.

Question	Format	Results & Analysis
Who or what would you trust to give you recommendations on apps for your health?	 Likert scale, from 1-5 9 platforms, professions or organisations were rated 	 n = 243 Results were counted and expressed as a percentage of the total responses
Do you think the government should have a scheme where health apps are given a rating for accuracy and effectiveness?	 4 multiple choice options and 1 'other' Also included questions to gather respondents' emails if they wished to be notified of results 	 n = 216 Results were counted and expressed as a percentage of the total responses
Any final comments or thoughts you'd like to add?	Free text response	Not formally analysed but used to improve understanding and provide context to the analysis

Table 1 - Summary of survey questions and results gathered

Results

This section details the results of this survey which are subject to the limitations outlined above.

Who or what would you trust to give you recommendations on apps for your health?

To compare how trusted each 'recommender' is, the score given by each respondent was added together to give a total score. The below figure, 'Comparison of Totals', has that sum on the y-axis, with the least trusted overall scoring slightly less than 600 (Google Search) and the highest scoring nearly 950 (GPs).

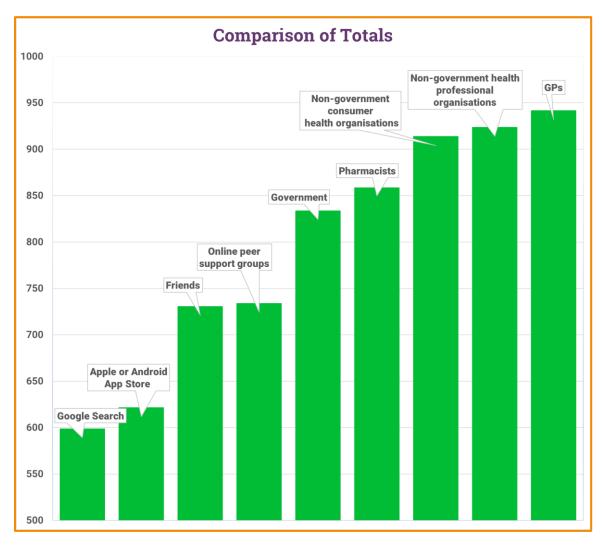


Figure 1 - Totals for each 'recommender' arrived at by adding together all scores a recommender received. n = 213

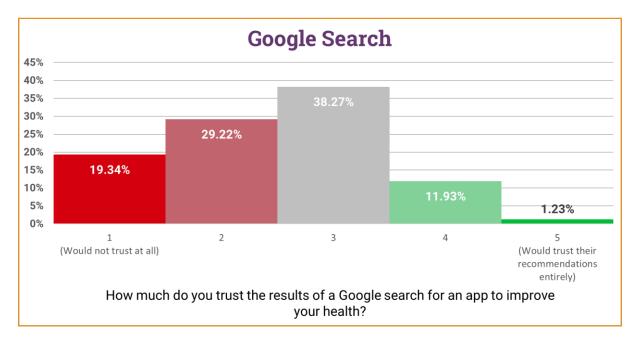


Figure 2- Google search recommendation results. n = 213

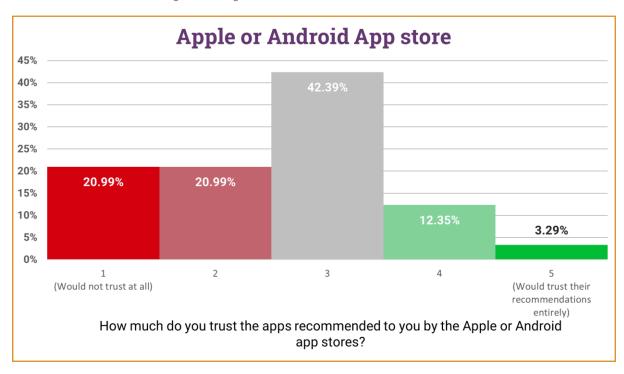


Figure 3 - App store recommendation results. n = 213

Of the options presented to panel members, **Big Tech are the least trusted** with only approximately 15% of respondents rating them a 4 or a 5 and receiving the highest percentage of 1 or 2 votes. There is also a high percentage of 3 votes. This indicates that panel members do not view these sources as reliable sources on their own to find relevant and high-quality apps.

It should also be noted that some respondents rated these methods guite highly and have more trust for doing research on their own rather than relying on the opinions of others, including GPs. This view was in the minority however.

The survey did not ask why this was their opinion, however some of the comments given in the third part of the survey may provide some further insight.

"It would be great to be able to know the difference between a quality app and a gimmick. Currently the app stores are full of gimmick apps with little to no validation to claims."

"We look to Doctor Google for help as we have little faith in our doctors."

"I look at recommendations from all sources then make an informed decision."

Peers

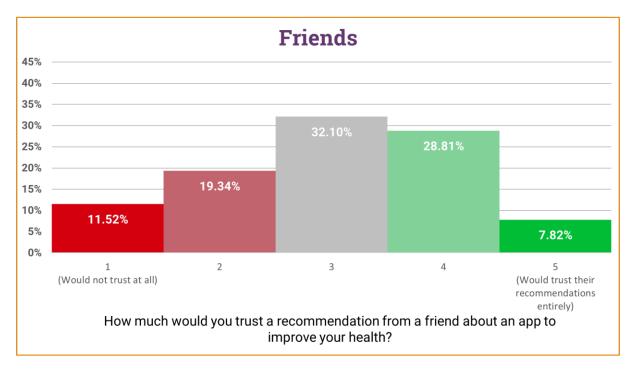


Figure 4 - Friend recommendation results. n = 213

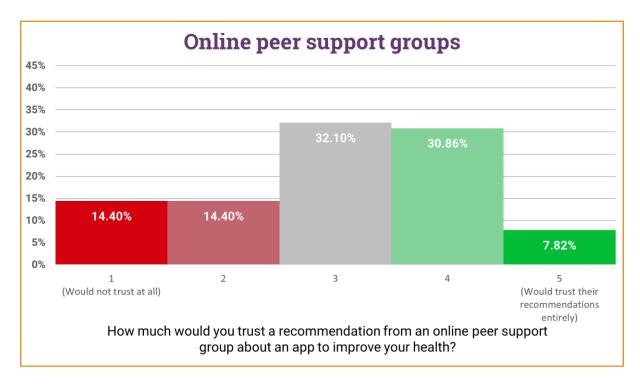


Figure 5 - Online peer support groups recommendation results. n = 213

These results indicate that **consumers trust their peers to give good recommendations on health and wellness apps to an extent, but not completely**. Most respondents were neutral or positive in trusting these sources, with a significant drop between the scores of 4 or 5, where 5 meant 'Would trust their recommendations entirely'.

Peers are clearly a trusted avenue for receiving advice on health and wellness apps but are not enough on their own.

"Irrespective of who recommended an app I would still do my own research."

"If I instigate a search for health information on the internet and am familiar with the sources of the information, I'm much more likely to trust them than I would a friend who tells me about a miracle cure she'd heard about from another friend. Lots of times people like to give health care advice anecdotally or even with no knowledge of the issue at all."

"I have not yet seen an app that has been helpful, nor have I heard of an app from any of the specialised support groups I belong to being recommended."

"As many doctors don't understand my complex and little-known chronic illnesses I do not trust their recommendations very highly, but I do like my GP. I trust friends with similar/the same illnesses/disabilities more than I do most doctors."

Health Professionals

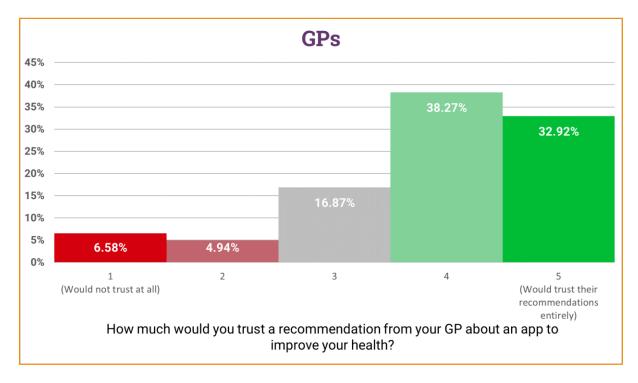


Figure 6 - General Practitioner recommendation results. n = 213

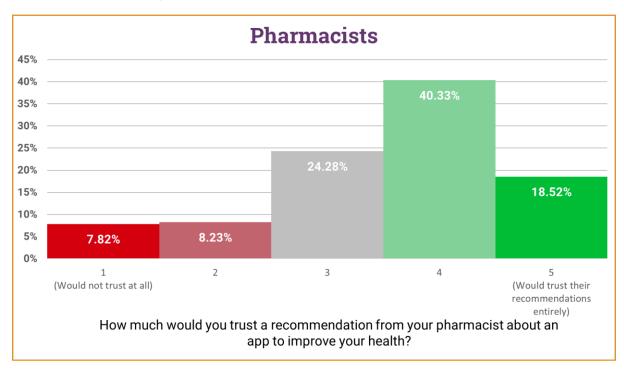


Figure 7 - Pharmacist recommendation results. n = 213

Consumers trust General Practitioners and Pharmacists to give good recommendations on health and wellness apps, with GPs holding the most trust. The high number of '5' scores for GPs indicates a willingness to rely on their advice as a 'final word' on the matter.

This finding lends weight to the call for the clinical usefulness of health and wellness apps to be rigorously evaluated and the results widely disseminated to health professionals, as this high level of consumer trust provides a clear way to get the right apps in the hands of the right consumers. However, if that trust is broken by recommending poor apps or is taken advantage of by snake oil merchants then this method of improving health outcomes would be unnecessarily squandered.

"Any advice given by other than a certified GP should be strictly checked for accuracy."

"There are so many contradictions floating around on what or how to improve one's health. E.g. eggs are good now but were bad not that long ago. Eating fat is not as bad as once thought, etc. There needs to be a trustworthy panel that provides advice through such a proposed app. Perhaps a mix of Doctors and a Panel of others made up of a pharmacist, nutritionist, hospital researchers etc."

Non-government organisations

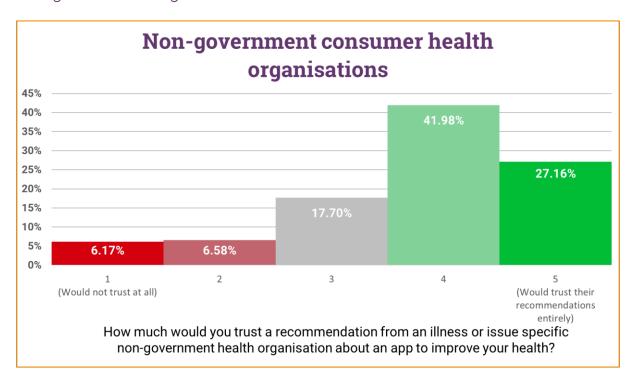


Figure 8 - NGO consumer health recommendation results

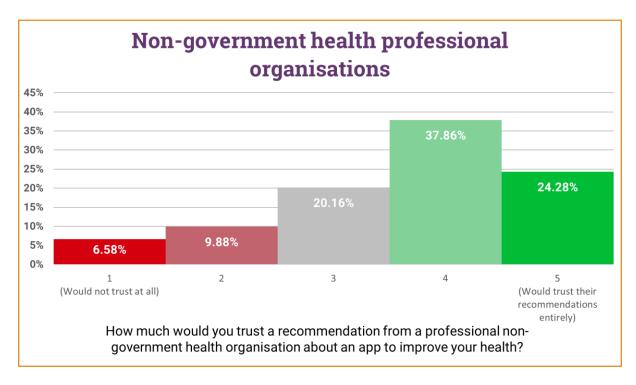


Figure 9 - NGO professional health recommendation results

While not as high as the trust in GPs and Pharmacists, respondents viewed non-government organisations as potential trusted sources of good recommendations for health and wellness apps.

This indicates that these organisations have a role to play in advising on the safety and quality of health and wellness apps and would need to be involved in the development of a successful system for assuring safety and quality in health and wellness apps.

"A credible organisation could vet apps, suggest the better ones, warn against others, and hopefully even give some help in learning how to successfully search for accurate current and relevant information."

"Use existing trusted organisations ... to provide independent information to clinicians and the community and as a reference for anyone developing innovative access to that (quality) information."

"An organisation that is independent of the pharmaceutical industry should assess apps for their evidence base and the accuracy of the information provided on the app."

"I think there's a great opportunity for government funded (possibly NGO or social enterprise created) free apps which allow for the benefits of app technology without the risks of your data being on sold to lawyers and the like."

Government

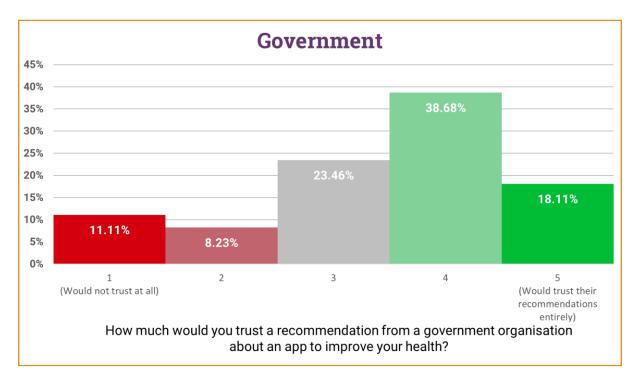


Figure 10 - Government recommendation results

While these results show a clear issue with the base level of trust afforded in Government, **the response was generally positive with Government trusted more highly than friends or peer support groups** (see figure 1). These generally positive results indicate that consumers see a role for government in this area.

Some consumers raised as an example an initiative of the United Kingdom's National Health Service (NHS), the NHS Apps Library¹ as an example that Australia could look toward as an example to learn from.

"The government, through the TGA or elsewhere, should be taking a much greater interest in health supports, as opposed to just drugs and medical devices. Using the advertising council to regulate scams and unsupported so called "therapies" is not an adequate safeguard."

"The Department of Health needs to be a source for sound, evidence-based information.

Important for public health."

"There should be some govt regulations like there is for medicines. Knowing anyone can develop these apps is scary."

-

¹ NHS Apps Library. Accessible at https://apps.beta.nhs.uk/

"Health Apps can assist people to manage health conditions and I believe some rating of them is important. The government has some role in assessing and providing guidance, but other 'specialist' organisations or bodies (like the Cancer Council, Nutrition Australia) have a role also."

Do you think the government should have a scheme where health apps are given a rating for accuracy and effectiveness?

Following the question asking respondents to rate who they would trust, the next question asked respondents if they thought the government should have a scheme where health apps are given a rating for accuracy and effectiveness. 5 answers were possible;

- Yes, the government should review and rate health smartphone apps for accuracy and effectiveness
- No, but the government should fund another organisation to rate health smartphone
- No, things are fine as they are now
- No, the government should not regulate health smartphone apps at all
- Other

Only one respondent answered 'Other' and did not provide an alternative.

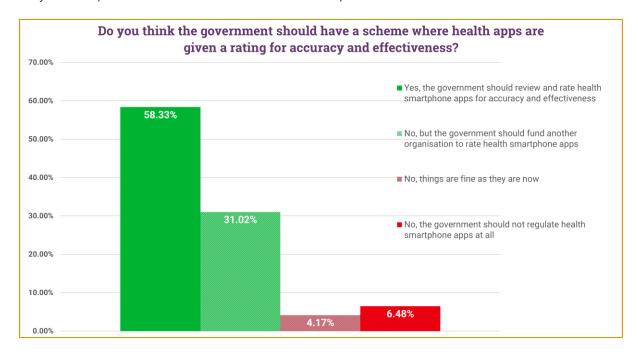


Figure 11 - Results to whether the government should have a scheme where health apps are given a rating for accuracy and effectiveness? n = 216

The results are overwhelmingly in favour of the government playing some role in rating health and wellness apps for accuracy and effectiveness, with nearly 90% of respondents saying they should be involved. The majority responded that the government should do the reviewing and rating (approximately 60%) and 31% thought the government should fund another organisation to do the rating and reviewing.

Approximately 10% of respondents indicated they did not think the government should change their role in this area.

Given the potential bias of respondents to this first Panel survey stemming from them being closer to the health system and its regulation than the 'average' consumer, these results should be taken with a grain of salt and clarified with a more in-depth study to confirm the results.

"Health apps often have pharmaceutical companies funding them to promote their products which is not always apparent."

"So many new apps are coming into the market that it's very hard to keep up with them, the gov should classify them. Most of them cost money and a lot of people can't afford to pay for it, you don't want to spend money on an app that doesn't work for you."

A centralised, regulated, clinically robust rating system for health apps is long overdue. Stringent review criteria must be developed that apps must comply with. Apps must demonstrate clinical testing and results of the testing prior to the App being recommended by the Government."

"To me, 'review and rate' does not equal 'regulate'. I think it would be okay for the Government to provide a review/rating/opinion on a health app, but I do NOT think they should be able to control/regulate what is available."

"I can see many advantages in health apps which may take some of the time and responsibility off carers. However, if the apps fail to do what they are supposed to do the consequences can be dire for both the carer and the person they are caring for.

Against this background I'm in favour of more rigorous quality assurance."

Consumer Concerns

In moving to regulate or assess the safety and quality of health and wellness apps and then recommend them to consumers, concerns were raised by respondents that will, among other issues, need to be considered as any effort to provide better recommendations or regulations for health and wellness apps moves forward. Not all concerns raised have been included in this section.

Digital divide

Not all Australians have access to the internet or smartphones², and those without access are more likely than those with it to achieve lower health outcomes, partially due to the increased likelihood of coming from a lower socioeconomic status or being older.

Any high-level digital health program must take this into account.

"Whatever 'rating system' is used needs to be well thought out and consistently applied.

Particular consideration should be given within reviews for diverse or vulnerable populations and how they may experience the app. Reviews should be by panel rather than individual."

"Healthcare for marginalised and vulnerable groups is inequitable in Australia. You do not get the same access to healthcare nor do you get the same service to healthcare if you do not speak English, are from a culturally and linguistically diverse background, are gender diverse or have different abilities."

"My biggest concern is a lot of older Australians do not have a smartphone as they are too expensive. I myself do not have a smartphone but I do have an iPad and laptop. A lot of older Australians are not computer literate."

"Based on my experience more than 30% do not have/are unable to fully utilise smartphone apps. Much education is needed in this respect."

Over-reliance on apps

The gold standard in healthcare will likely always be face to face interaction with professionals. Some respondents warned against the possible over-reliance on apps as a solution to health problems, and on the potential to place too much responsibility onto the patient to look after themselves.

"I have concerns that digital health apps are pushing the responsibility of getting well onto patients, rather than providers. There needs to be clear recommendations- on where health apps can be useful, and where seeking other forms of support are necessary. Health apps need to be part of a framework that offers different solutions, and support people in finding those."

"I do not believe that any one should be able to self-assess their medical problems. The Government health services specialise in this field as do Doctors and Specialists."

Where consumers will see the recommendations or warnings

Most health and wellness apps have not been developed specifically for the Australian health system, and both the Apple and Android app stores are largely regulated to American standards. Consideration would need to be given to how any scheme for recommending or regulating health and wellness apps would ensure that consumers received the right information and the right time to make an informed decision.

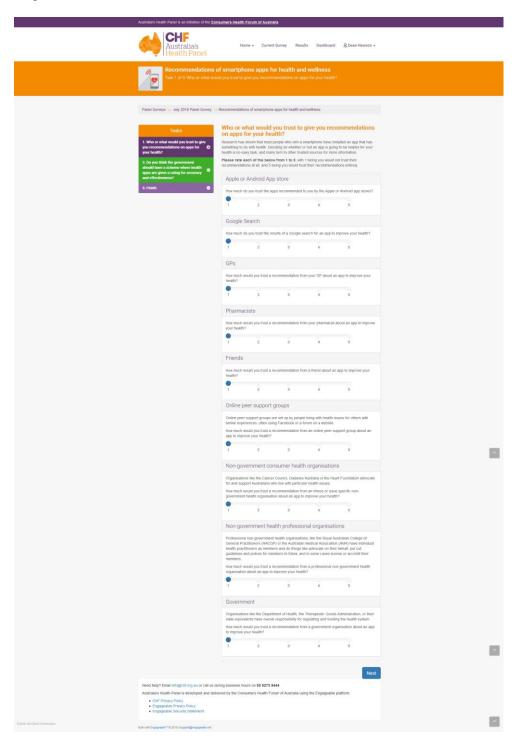
"I'm inclined to think this would be an enormous and impossible task, as apps change all the time, new apps appear, even if they are accurate they can be misinterpreted or used incorrectly, even if they were correct initially over time they'll become out of date etc. I think it would be more valuable to have some sort of global warning on them, or on the app store, or some sort of public education on how to be savvy when accessing health information online in general."

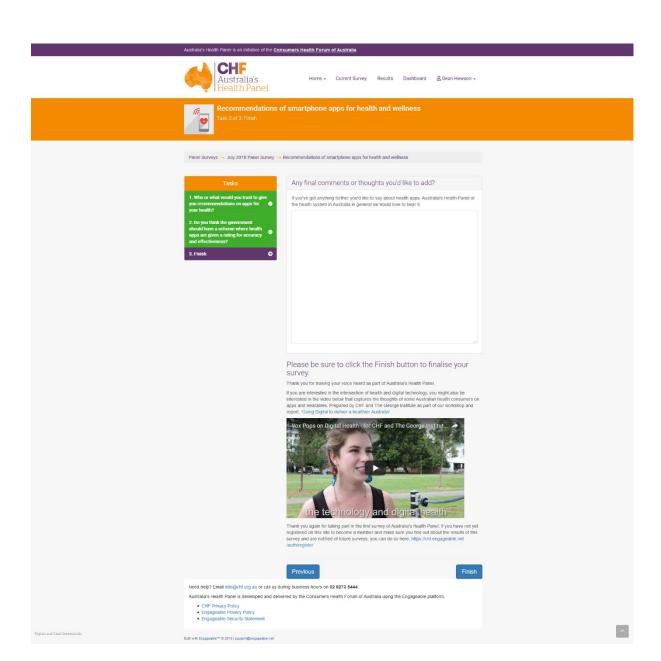
"How would it be ensured the recommendations are followed correctly and in full? How would children be prevented from sourcing what could be detrimental material?"

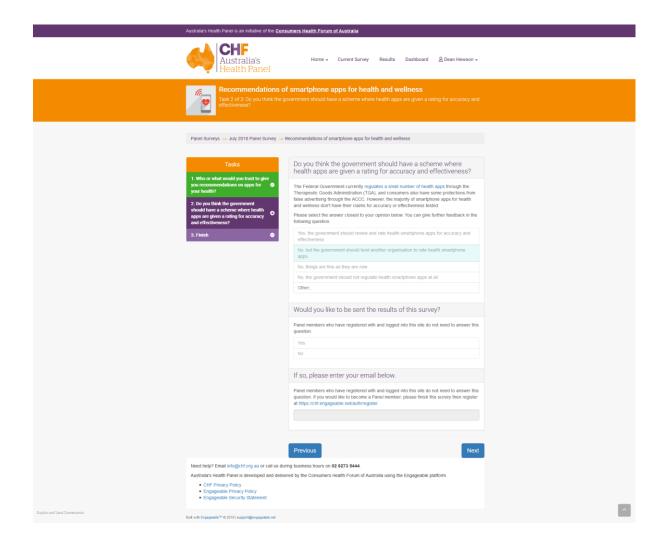
Appendices

Screenshots of the Survey

Screenshots of the survey to demonstrate the format respondents saw. Images taken on 20 August 2018.







Text of Survey Questions

Who or what would you trust to give you recommendations on apps for your health?

Research has shown that most people who own a smartphone have installed an app that has something to do with health. Deciding on whether an app is going to be helpful for your health is no easy task, and many turn to other trusted sources for more information.

Please rate each of the below from 1 to 5, with 1 being you would not trust their recommendations at all, and 5 being you would trust their recommendations entirely.

Apple or Android App store

How much do you trust the apps recommended to you by the Apple or Android app stores?

Google Search

How much do you trust the results of a Google search for an app to improve your health?

GPs

How much would you trust a recommendation from your GP about an app to improve your health?

Pharmacists

How much would you trust a recommendation from your pharmacist about an app to improve your health?

Friends

How much would you trust a recommendation from a friend about an app to improve your health?

Online peer support groups

Online peer support groups are set up by people living with health issues for others with similar experiences, often using Facebook or a forum on a website.

How much would you trust a recommendation from an online peer support group about an app to improve your health?

Non-government consumer health organisations

Organisations like the Cancer Council, Diabetes Australia or the Heart Foundation advocate for and support Australians who live with health issues.

How much would you trust a recommendation from an illness or issue specific non-government health organisation about an app to improve your health?

Non-government health professional organisations

Professional non-government health organisations, like the Royal Australian College of General Practitioners (RACGP) or the Australian Medical Association (AMA) have individual health practitioners as members and do things like advocate on their behalf, put out guidelines and polices for members to follow, and in some cases license or accredit their members.

How much would you trust a recommendation from a professional non-government health organisation about an app to improve your health?

Government

Organisations like the Department of Health, the Therapeutic Goods Administration, or their state equivalents have overall responsibility for regulating and funding the health system.

How much would you trust a recommendation from a government organisation about an app to improve your health?

Do you think the government should have a scheme where health apps are given a rating for accuracy and effectiveness?

The Federal Government currently regulates a small number of health apps through the Therapeutic Goods Administration (TGA), and consumers also have some protections from false advertising through the ACCC. However, most smartphone apps for health and wellness don't have their claims for accuracy or effectiveness tested.

Please select the answer closest to your opinion below. You can give further feedback in the following question.

Yes, the government should review and rate health smartphone apps for accuracy and effectiveness

No, but the government should fund another organisation to rate health smartphone apps

No, things are fine as they are now

No, the government should not regulate health smartphone apps at all

Other

Would you like to be sent the results of this survey?

Panel members who have registered with and logged into this site do not need to answer this question.

If so, please enter your email below.

Panel members who have registered with and logged into this site do not need to answer this question. If you would like to become a Panel member, please finish this survey then register at https://chf.engageable.net/auth/register.