



information  
and privacy  
commission  
new south wales

# Attitudes of the NSW Community to Privacy 2017

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## Background

In April 2017, the NSW Privacy Commissioner initiated an independent survey of the NSW community's views of privacy and current topical issues in privacy.

This survey was carried out as part of the statutory responsibilities of the Privacy Commissioner.<sup>1</sup> The survey was intended to provide a broad and indicative sense of the public's view of how privacy is regarded in developing areas such as data analytics and what may be necessary to address to ensure that reforms based on data innovations have the trust of the community. This is necessary as it is known that a lack of trust in the perceived protection of the privacy of individuals can have unintended consequences, such as the provision of inaccurate or incomplete information or even a choice not to use a service or product.

The main survey areas were data use and attitudes to the sharing of personal and health information. Within these main groupings, the topics were belief in de-identification of personal and health information, the sensitivity of different types of information, and perceptions of the extent to which privacy issues are taken seriously.<sup>2</sup> This summary draws upon the main findings of the survey report (attached).

## Key Points

- › Nearly two thirds (63%) of survey respondents do not think, do not know or are undecided if those in authority generally, are taking privacy seriously. This indicates a significant lack of trust in the community at a time when the use of and reliance upon data is significant and growing.
- › 60% of survey respondents do not believe, or are not sure, that data collected about them can be fully de-identified. This suggests significant uncertainty relating to the use of data, particularly uses that rely on de-identified data.
- › Where data cannot be fully de-identified, the support of survey respondents for their information being used for a purpose other than that for which the information was originally given, declined markedly.
- › Survey respondents cared about the uses to which their personal information (eg names, contact details, date of birth, images) could be put. There was less agreement to personal information being disclosed that would re-identify individuals, than for health information. In the circumstance of providing personal information for research purposes, only 39% agreed (13% strongly and 26% slightly agreed) compared to 58% for health information (26% strongly agree and 32% slightly agree).
- › The survey results suggest that young people care about their privacy. Younger survey respondents appear to care about their privacy differently and many in this age group are still forming their views. Older citizens were more likely to have a definite view.
- › Privacy was not just seen as good for the individual but also for society as a whole. This view was more associated with women and the older age group than those aged 18-34 years.

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<sup>1</sup> Under the *Privacy and Personal Information Protection Act, 1998* section 36 (2)(f) and (j).

<sup>2</sup> Mixed mode methodology using 350 computer assisted telephone interviews and 150 via an online survey for households without a landline phone. The sample was representatively stratified by location (metro/regional) and age. Data was collected between 24 April and 3 May by trained interviewers. Analysis was undertaken by SPSS+ computer software.

## Results<sup>3</sup>

### Confidence in de-identification of data and its use

Frequently data analytics, Big Data and Open Data rely on de-identification as a means to make personal/health information non-identifiable and able to be disclosed or used for purposes other than those for which the information was provided originally. The views of the public were sought on this process.

Less than half (40%) of respondents believed that data collected about them could be fully de-identified. 60% did not believe or were not sure if it was possible to fully de-identify their data (a quarter was not sure (25%) and 35% did not believe in full de-identification).

Those aged 18–34 years (43%) and those 55 years plus (42%) were firmer in their views that data collected about them could be fully de-identified so their identity would not be apparent to anyone. But nearly one-third (30%) of younger respondents were not sure while only 18% of the older age group were not sure. The highest proportion of people (42%) who felt it was not possible to fully de-identify data were aged 35–54 years.

### Health information

If identity could be apparent, respondents were asked when they would agree to their health information being disclosed. There was not strong agreement for any use of health information when identity could be apparent. Majority agreement was reached when 'slightly agree' responses are added to 'strongly agree' responses. Agreement was then highest (58%) for using potentially identifiable health information for research purposes followed by disclosure for 'planning and delivering government services' (56%); 'help government agencies develop new policies' (55%) and 'help monitor the quality of government services' (54%).

The majority did not support use of their health information when identity would be apparent for monitoring of services or products usage (34%) or for consultation purposes (32%) (even when 'strongly agree' and 'slightly agree' response categories are combined).

Younger respondents were more significantly more likely to be undecided about the use of their health information particularly in comparison to those aged 55 plus regardless of the purpose. Younger people were most undecided when it came to their health information that could identify them, being used for research purposes or for consulting with the public.

All age groups were far more likely to think it inappropriate that health information be used for other services if there was a chance they could be identified.

### Personal information

There was noticeably less agreement for sharing personal information (for example, name, address, date of birth, images) for whatever purpose with the vast majority of respondents not agreeing with this practice generally.

Of all of the purposes posed for disclosing personal information, research purposes had the greatest support. 13% 'strongly agree' with disclosure for a research purpose and disclosing 'as part of consulting with the public' had the lowest strong agreement (5%). When respondents who 'slightly agree' are included just less than four in ten agreeing (39%), agree (either strongly or slightly), with the use of potentially identifiable personal information for research purposes.

More than 60% do not agree to the use of their personal information for monitoring the individuals' use of services and products or as part of consulting with the public.

Again, younger people (18 – 34 years) were significantly more undecided about whether they agreed or not, particularly compared to older age group of 55 plus years, regardless of the purposes.

Essentially, agreement to other uses drops markedly for sharing both health and personal information when one's identity can be apparent to others.

<sup>3</sup> This summary is to be read in conjunction with the attached report.



## Consent to re-use of information by government providers as a pre-condition of obtaining services

### Health information

The majority of respondents, almost two thirds, did not agree that they should have to consent to the use of their health information for other purposes, as a condition of receiving a government service. Women, older age groups and people with children were significantly more likely to not agree to this.

Support rose for other uses of their health information if it could be fully de-identified (52%) but fell sharply if there was a chance the individual could be identified. This view was strongest in the age group 35-54 years.

### Personal information

This lack of support for making the provision of personal information for other purposes a condition of receiving service was even more marked for personal information. The pattern seen with health information, where agreement rose if the health information could be fully de-identified, did not emerge with personal information. Overall, 37% agreed with use of their personal information for other purposes as a condition of obtaining the service, but only 26% agreed if the health information was fully identified, and only 12% agreed if there was a chance that the de-identified personal information could identify them. This pattern basically repeated across the three age groups.

Younger people supported personal information being re-used for other purposes as a condition of receiving a service (59%) but this dropped sharply to a lower level (20%) if there was a chance of being identified.

Those who particularly did not support this practice were older (55 years plus) or who did not believe it was possible to fully de-identify their personal data. Those aged 35–54 years demonstrated the least agreement (just 5% agreement) for the re-using of personal information for other purposes as a condition of service.

The difference in agreement (strong and slight agreement responses combined) for health and personal information being shared when re-identification is possible is marked. There is greater agreement for health information being shared for

what can be called for public benefit purposes. In contrast, there is not majority support for personal information being used when re-identification is possible.

**Table 1: Differences in attitudes to using health and personal information originally provided for one purpose for subsequent purpose(s).**

Use for another purpose than original reason for provision	Health Information %*	Personal Information %*
Research purposes	58	39
Planning and delivering Government services	56	36
Helping Government develop new policies	55	37
Helping monitor the quality of Government services	54	36
Monitor use of products and services	34	24
As part of consulting with the public	32	24

*\*strongly and slightly agree*

## Privacy concerns

Of most concern to respondents was information about their family or social life being made public without their permission (38%). The vast majority (80%) felt this practice should be prohibited and 51% felt it was currently prohibited.

Providing government health records to other people (for example, another organisation) was of great concern (36%) also, particularly amongst those without children. 83% felt this practice should be prohibited under legislation (and 73% felt it was currently prohibited).

Younger people were more likely to be most concerned about photos of them being posted on the internet (26%) than about information about their family or social life being made public without permission (24%).

The majority (72%) felt that information about products or services they use being disclosed to others without permission should be prohibited.

### Why these issues were privacy concerns

The reason why these activities were of the most concern (that is, information about family or social life being made public without permission; government health records being made available to secondary users; photos being published on the internet and information about products and services used being disclosed to others without permission) were:

- › ‘Nobody’s business but mine’ as the predominant reason why it was of most concern if government health records were made available to people other than those it was given to originally (72% overall; 77% for women respondents);
- › ‘The information could be used in ways that I don’t know about’ as the primary reason why it was of most concern if photos were published on the internet without permission (61%);
- › ‘The information could be used in ways that I don’t know about’ as the primary reason why it was of most concern regarding information about usage of services and products being disclosed to others without permission (61% overall; 70% males).

The reasons why people were concerned varied by age as well as by the practice posited. For example, the oldest age group (55 years plus) were more likely to think that information about their family or social life should not be made public without their permission, because ‘it was nobody’s business but mine’. This was 80% for this age group but 65% for those between 18-34 years. This latter group was more likely to be concerned because ‘the information could be used in ways that I don’t know about’ (75% v 58% for 55+ group).

These differences were similar if slightly more marked (83% v 63%) for government health records being made available to people other than those to whom it had been initially provided. But older age groups were much more concerned that these health records could be used in ways that they did not know about with 80% of 35-54 year olds reporting this reason as their main area of concern.

The younger age group was more concerned about their information being used in ways they do not

know about irrespective of whether it was government health records, photos of them on the internet without their permission, their social or family life, or service or product usage.

On the question of whom these concerns were expressed (that is, self or family), those aged 18–34 years showed a statistically significant difference of being more concerned for themselves (24%) and less concerned for family (18%). Older age groups 35-54 and 55 plus years, were less likely to be concerned about the effect of privacy breaches upon themselves (9% and 10%) than those 18–34 years and were more concerned about family members (34% for both older groups).

There were some interesting gender differences although not showing as statistically significant. A greater proportion of men were more concerned for other family members such as children than equally concerned for ‘self and family’ (32% v 53%). Almost quarters of women were more concerned (24%) for other family members and six out of ten were equally concerned for both self and family (61%).

The responses indicated that for some, there was concern that privacy was important for the ‘health of society as a whole’ not just for the individual. This view was more often given by as a reason for their concerns by women and the older age group than those aged 18-34 years.

### Remedies for perceived privacy breaches

The recourse most preferred tended to be for legal action against breaches that involved:

- › an internet service provider on-selling information (39%);
- › a public sector employee releasing data to a non-government organisation without consent (42%);
- › a neighbor installing cameras that looked directly into your premises, or someone posting unwanted images of you online (30%).

The exception was a greater preference (37%) for an order requiring neighbours’ cameras or unwanted images posted online, to be taken down or returned. Those who felt financial compensation was an appropriate solution were more likely to be aged 18 – 34 years. For all privacy breaches however, few respondents felt that financial compensation (3–9%) or an order issued to require

the offender to apologise (3-5%) was an ideal solution.

What people (83%) thought most strongly should be prohibited was government health records being made available to another organisation (other than the one to which they were originally provided). Of next greatest concern was information about their family or social life being made public without permission (80%) and photos being published on the internet without permission (76%).

The younger age group was more likely to think that publishing photos of them on the internet was currently prohibited (26%) as compared to older age groups. Older age groups were considerably far more likely to believe that currently there were prohibitions against information about their family or social life being placed on line without permission.

### **How seriously are those in authority are taking privacy?<sup>4</sup>**

Overall, there is a roughly equal proportion of those who think those in authority generally are taking privacy very seriously (10%) compared to those who think they are not taking it very seriously at all (11%).

There were interesting similarities and differences between the younger and older age groups. A little over a third of both older and younger age groups (37% and 36% respectively) thought those in authority are taking privacy very or quite seriously. The difference between these two age groups was that the younger 18 – 34 year olds were more undecided (27%) than those aged 55 plus years (7% undecided).

One quarter (25%) of younger ages felt privacy was not taken seriously at all while nearly half (46%) of those in the older age group of 55 years plus, thought this.

## **Conclusion**

The survey was intended to provide a broad and indicative sense of the public's view of how privacy is regarded in developing areas such as data sharing and data analytics, and to identify what may be necessary to address to ensure that reforms based on data innovations have the trust of the community.

This trust is necessary as it is known that a lack of trust in the perceived protection of the privacy of individuals can have unintended consequences such as the provision of inaccurate or complete information or even a choice not to use a service or product. The majority of survey respondents do not believe or do not know if de-identification is possible or effective. This uncertainty may be compounded by knowledge that other publicly available datasets can be used to re-identify data.

The repurposing of personal and health information provided for one purpose, such as obtaining goods or services, for another purpose is of increasing significance in the age of Big Data and Open Data. These results clearly indicate that the community values the ability to control who may obtain their personal or health information and who may be able to identify them based upon this information. It is additionally apparent that the community has strong views as to what subsequent uses the information they provided for one purpose may be put to without their consent.

Addressing these concerns is necessary and an exciting challenge for all – including the community.

### **For more information**

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<sup>4</sup> The term 'those in authority' was chosen because of its capacity to capture decision makers wherever located in both private, voluntary and public sectors. The aim was to obtain a broad sense of the public's view on this issue.









## Privacy Study

Prepared for the Information and Privacy Commission

May 2017

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## 1. Executive Summary

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### 1.1. Methodology

This research consisted of n=500 computer-assisted telephone interviews (CATI) amongst New South Wales residents aged 18 years and over.

Statistically significant results (at the 95% confidence level) are shown in bold **GREEN** or **RED** when higher or lower than the total respectively.

### 1.2. Research findings

#### 1.2.1. Data

- More than a third do not believe that data can be *fully* de-identified (35%), however this was lowest amongst those aged 18-34 (**27%**).
- Respondents are most likely to AGREE to their health or personal information being disclosed *for research purposes* (health 58%; personal 40%).
- Respondents are most likely to DISAGREE to their health or personal information being disclosed *to monitor your use of particular products or services* (health 50%; personal 62%).
- 18-34 year olds are most likely to think that government providers should be able to make it a condition of obtaining the service that they can use your health (**54%**) or personal (**59%**) information.

#### 1.2.2. Privacy breaches

- *Information about your family or social life being made public without permission* was the activity of most concern (38%) particularly amongst those aged 55+ (**50%**).
- The majority are equally concerned for other family members and themselves (57%) when it comes to possible privacy breaches.
- Those aged 55+ are most likely to think that those in authority are not taking privacy seriously at all (**46%**).



## 2. Methodology

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### 2.1. Background and objectives

The Privacy Commissioner is an independent statutory officer who reports to the NSW Parliament. The functions of the Privacy Commissioner are set down in the Privacy and Personal Information Protection Act, 1998. These include ‘to conduct research, and collect and collate information about any matter relating to the protection of personal information and the privacy of individuals’ and ‘to prepare and publish reports and recommendations about any matter (including developments in technology) that concerns the need for, or the desirability of, legislative, administrative, or other action in the interests of individuals [sections 36(2)(f) and (j) respectively].

In order to ascertain public sentiment and knowledge levels with regards to privacy and information access matters, the NSW Privacy Commissioner commissioned Woolcott Research & Engagement to carry out a NSW-wide survey. Specific objectives of the research included investigating:

- Awareness of activities currently prohibited under privacy legislation;
- Extent of concern about various activities in relation to privacy legislation;
- Belief that data can be *fully* de-identified;
- Sentiment towards the use and disclosure of health and personal information;
- Extent of concern about privacy breaches; and
- Extent to which those in authority are seen to be taking privacy issues seriously.

### 2.2. Research design

This quantitative research was conducted using a mixed mode methodology whereby a total n=500 interviews were carried out, with n=350 conducted via computer-assisted telephone interviews (CATI) and n=150 via an online survey (amongst households without a landline).

The survey was amongst New South Wales residents aged 18 years and over, with quotas set to ensure that a representative sample was achieved by location (metro/ regional) and age group (18-34/ 35-54/ 55+).

Fieldwork was conducted between 24<sup>th</sup> April and 3<sup>rd</sup> May 2017. The phone interviews were carried out by trained CATI interviewers in Woolcott Research & Engagement's in-house phone room and the online component through a reputable, research only panel.

### 2.3. Statistical significance

SPSS+ computer software was used to conduct all analysis including statistical tests of significance. Results that are statistically significant at the 95% confidence level are shown in bold **GREEN** or **RED** when higher or lower than the total respectively.

## Research Findings

### 3. Data Identification

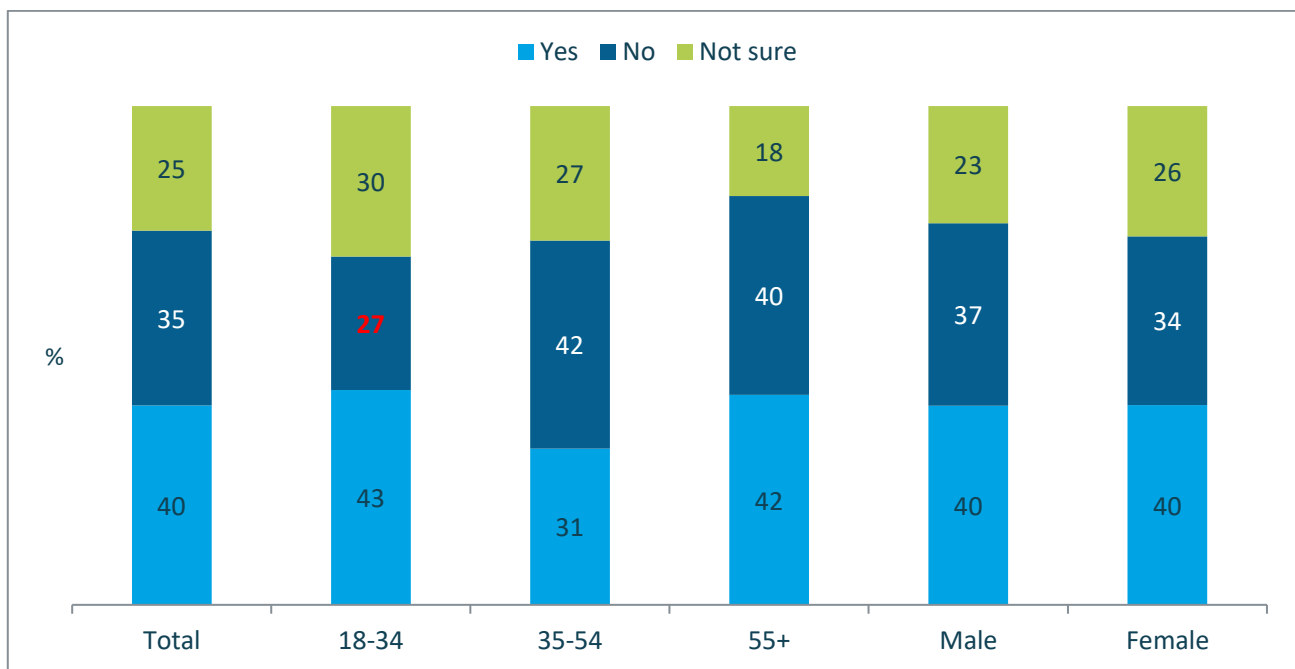
#### 3.1. Belief that data can be *fully* de-identified

Respondents were asked if they believe that data collected about them can be *fully* de-identified, in the sense that their identity would not be apparent to anyone.

Only four out of ten of respondents indicated that yes, they do believe that their data can be *fully* de-identified (40%). A quarter of respondents were unsure if this was the case (25%), while more than a third indicated that no, they do not believe that their data can be *fully* de-identified (35%).

Those answering ‘no’ were significantly less likely to be aged between 18 and 34 (27%).

Figure 1 Belief that data can be fully de-identified



8. Do you believe that data collected about you can be fully de-identified, in the sense that your identity would not be apparent to anyone?  
Total n=500; 18-34 n=202; 35-54 n=115; 55+ n=183; Male n=213; Female n=287



## 3.2. Disclosure of information

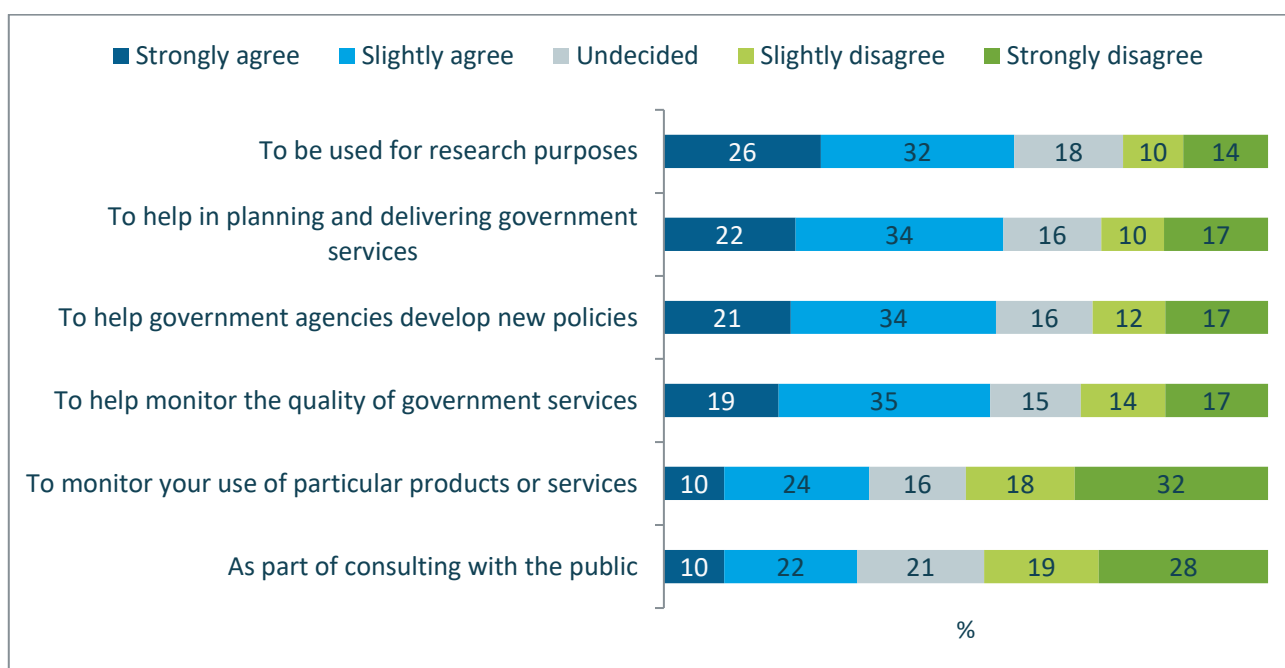
### 3.2.1. Agreement with health information being disclosed

Respondents were asked if they would be prepared to have their or their family’s health information disclosed for different purposes, assuming that the people using the information would be able to identify them.

The highest level of agreement was for health information being disclosed *to be used for research purposes*, with almost three fifths of respondents strongly or slightly agreeing with this (58%). There was also high agreement for health information being disclosed to the government for various uses, including *to help in planning and delivering government services* (56%), *to help government agencies develop new policies* (55%), and *to help monitor the quality of government services* (54%).

The lowest agreement levels related to the disclosure of health information in order *to monitor their use of particular products or services* (34%) and *as part of consulting with the public* (32%).

Figure 2 Agreement with health information being disclosed



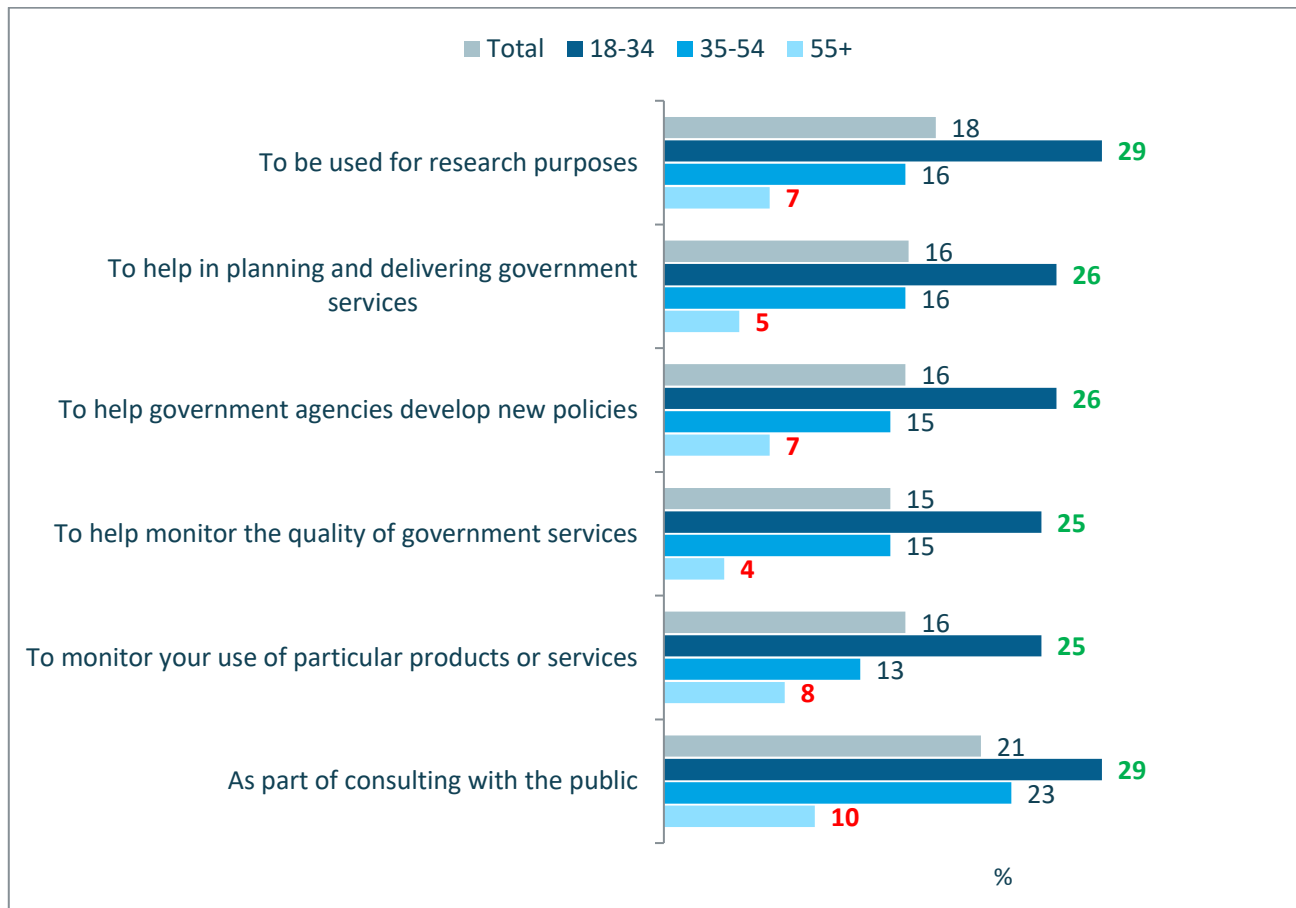
9. I would now like to find out whether you would be prepared to have information about you disclosed for different purposes, assuming that the people using the information would be able to identify you.

Firstly, thinking about you or your family’s health information. Would you agree or disagree with your information being used for each of the following purposes...

Total n=500

As seen below in Figure 3, younger respondents aged 18-34 years were significantly more likely to be undecided about the use of their health information, particularly compared to those aged 55+.

Figure 3 Undecided about health information being disclosed



9. I would now like to find out whether you would be prepared to have information about you disclosed for different purposes, assuming that the people using the information would be able to identify you.

Firstly, thinking about you or your family's health information. Would you agree or disagree with your information being used for each of the following purposes...

Total n=500

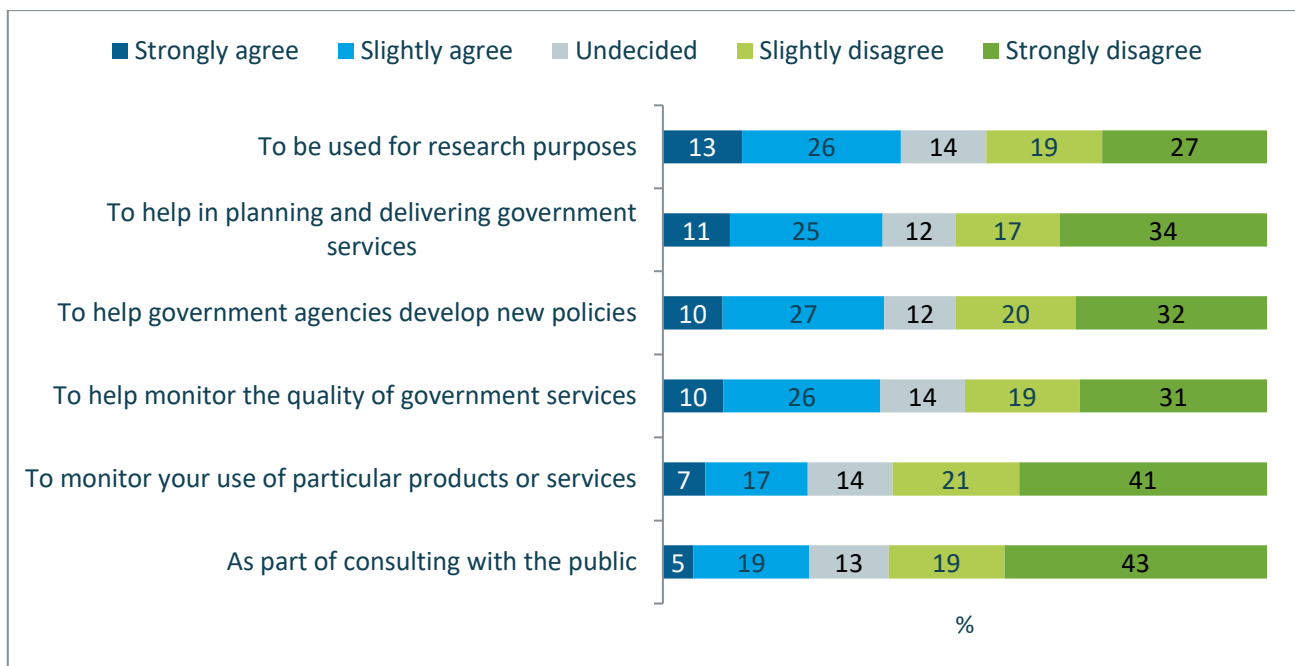
### 3.2.1. Agreement with personal information being disclosed

Respondents were also asked if they would be prepared to have their personal information – such as their name, address, date of birth, or images – disclosed for different purposes, again assuming that the people using the information would be able to identify them.

In contrast with the sharing of their health information, respondents were less agreeable with the sharing of their personal information. Despite this, there was a similar pattern of agreement, such that respondents were more likely to strongly or slightly agree with their personal information being disclosed in order *to be used for research purposes* (49%), followed by disclosure of their personal information for various government uses (36-37%).

Again, few respondents strongly or slightly agreed with their personal information being disclosed *to monitor their use of particular products or services* (24%) or *as part of consulting with the public* (24%).

Figure 4 Agreement with personal information being disclosed



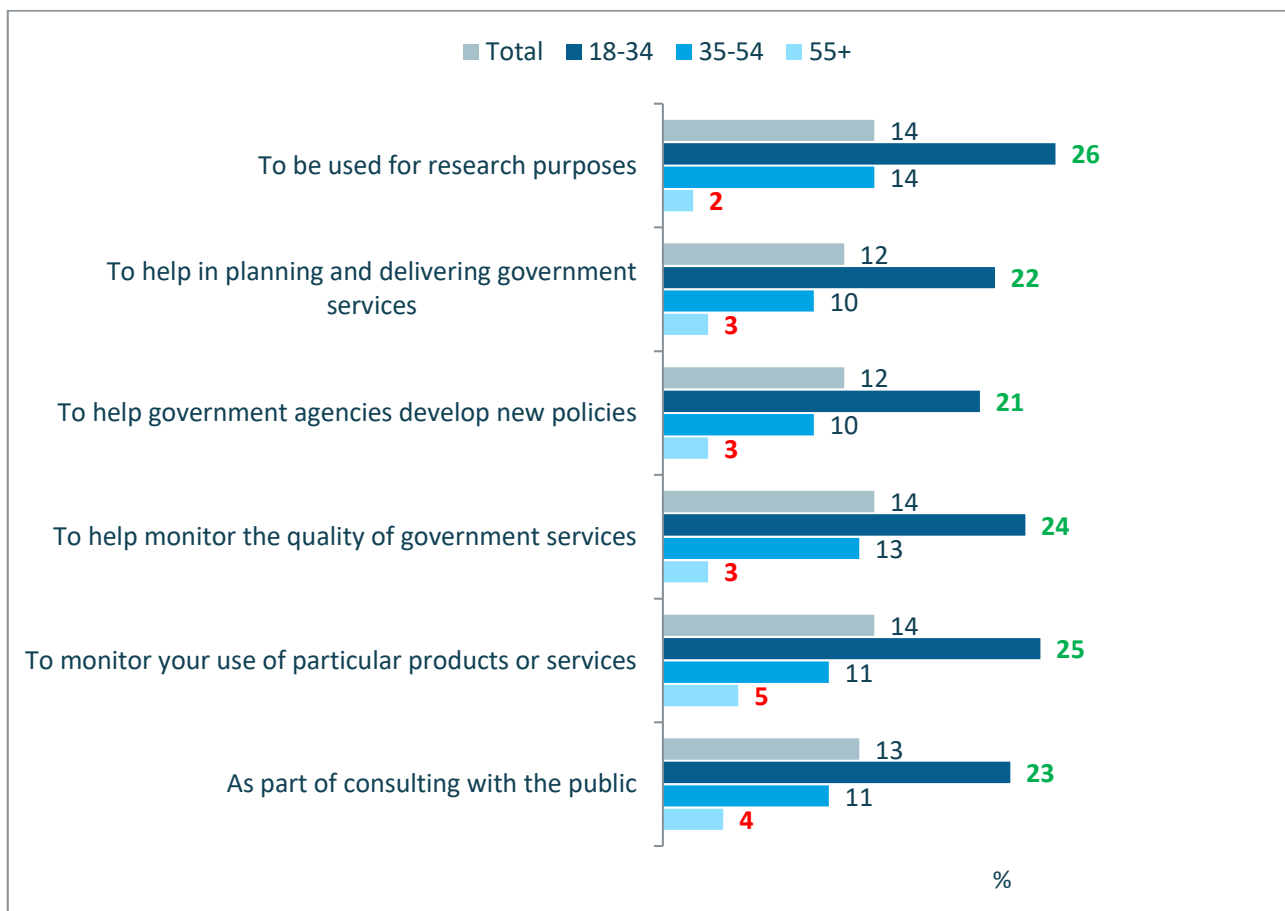
10. I would now like to find out whether you would be prepared to have information about you disclosed for different purposes, assuming that the people using the information would be able to identify you.

And what about your **personal information such as name, address, date of birth, or images**, would you agree or disagree with your information being used for each of these purposes...

Total n=500

As with the disclosure of health information, younger respondents aged 18-34 years were significantly more likely to be undecided about their personal information being disclosed, while older respondents aged 55+ were significantly less likely to be undecided, as shown in Figure 5.

Figure 5 Undecided about personal information being disclosed



10. I would now like to find out whether you would be prepared to have information about you disclosed for different purposes, assuming that the people using the information would be able to identify you.

And what about your **personal information such as name, address, date of birth, or images**, would you agree or disagree with your information being used for each of these purposes...

Total n=500



### 3.3. Disclosure of information by government providers as a condition of service

#### 3.3.1. Agreement with health information being disclosed

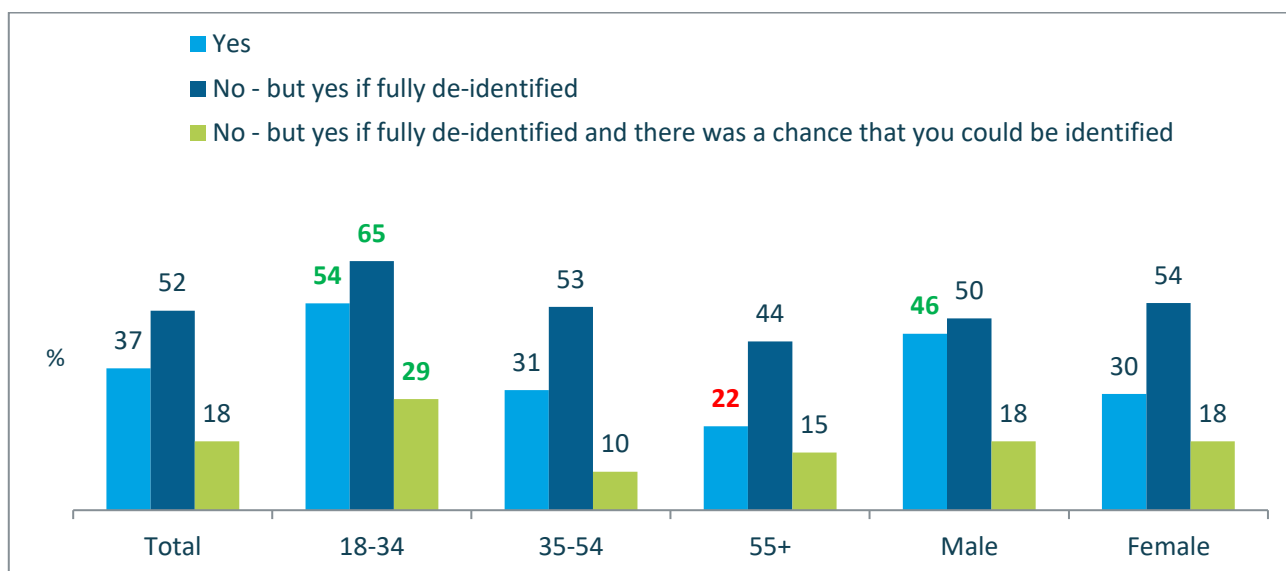
Respondents were asked if government providers should be able to make it a condition of obtaining the service that they can use their health information for other purposes.

More than a third agreed with this; in particular, young respondents aged 18-34 (54%), males (46%), and respondents who do not have any children (46%) were significantly more likely to indicate ‘yes’, especially compared to those aged 55+ (22%).

Of those who initially indicated that they would not like to have to agree to their health information being disclosed in order to obtain a government service, more than half then indicated that yes, they would agree to this information being provided if they were told that it could be *fully* de-identified (52%); those who answered ‘yes’ were significantly more likely to be aged 18-34 years (65%).

Further, a third of those who initially indicated ‘no’ felt that they would agree to their information being provided if it was de-identified, even if there was still a chance that they could be identified (18%); these respondents were significantly more likely to not have any children (29%).

Figure 6 Agreement with health information being disclosed in order to obtain a government service



11. Do you believe that a government service provider should be able to make it a condition of obtaining the service that you must consent to the use of your health information to be used for purposes other than for the service you are seeking?

Total n=500; 18-34 n=202; 35-54 n=115; 55+ n=183; Male n=213; Female n=287

12. Would you agree to your **health** information being provided if you were told that this information could be ‘fully de-identified’?

13. Would you agree if your **health** information was ‘de-identified’ and there was still a chance that you could be identified?

Total (Q11 ‘No’) n=315; 18-34 n=93; 35-54 n=79; 55+ n=143; Male n=115; Female n=200

### 3.3.2. Agreement with personal information being disclosed

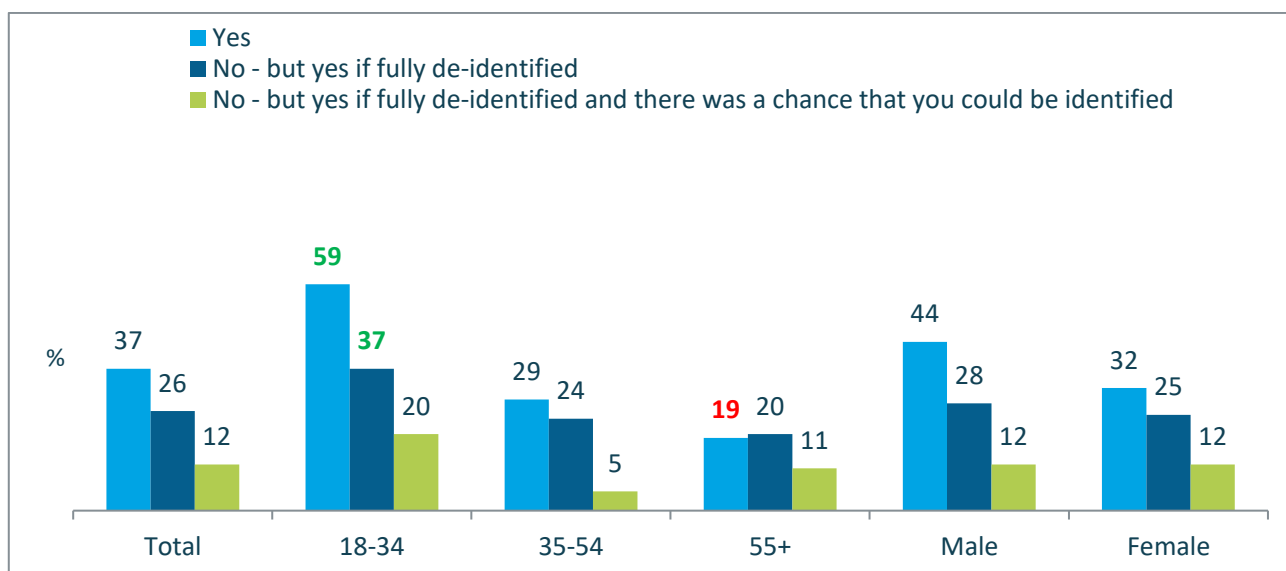
Respondents were then asked if government providers should be able to make it a condition of obtaining the service that they can use their personal information for other purposes.

More than a third agreed that yes, government providers should be able to make using their personal information for other purposes a condition of obtaining the service; those aged 18-34 (59%) or who did not have children (50%) were significantly more likely to agree, while those aged 55+ (19%) or who did not believe that data collected about them could be *fully* de-identified (29%) were significantly less likely to indicate 'yes'.

Of those who initially answered no, a quarter then indicated that they would agree to their personal information being provided outside of government if they were told that this information could be *fully* de-identified (26%), particularly those aged 18-34 years (37%) or who did believe that data collected about them could be *fully* de-identified (36%).

Further, 12% of those who initially answered no would agree to their personal information being provided outside of government if it was de-identified, even if there was still a chance that they could be identified; this was marginally lower amongst those aged 35-54 years (5%).

Figure 7 Agreement with personal information being disclosed in order to obtain a government service



14. And what if it was your personal information that they could use for other purposes? Do you believe that a government service provider should be able to make it a condition of obtaining the service that they can use your personal information?

Total n=500; 18-34 n=202; 35-54 n=115; 55+ n=183; Male n=213; Female n=287

15. Would you agree to your **personal** information being provided outside of government if you were told that this information could be 'fully de-identified'?

16. Would you agree if your **personal** information was 'de-identified' and there was still a chance that you could be identified?

Total (Q14 'No') n=313; 18-34 n=83; 35-54 n=82; 55+ n=148; Male n=119; Female n=194

## 4. Privacy breaches

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### 4.1. Activities prohibited under the current privacy legislation

Respondents were asked a series of questions regarding activities prohibited under the current privacy legislation; namely, which of a series of four activities are currently prohibited, which of these activities should be prohibited, and which activity is of most concern.

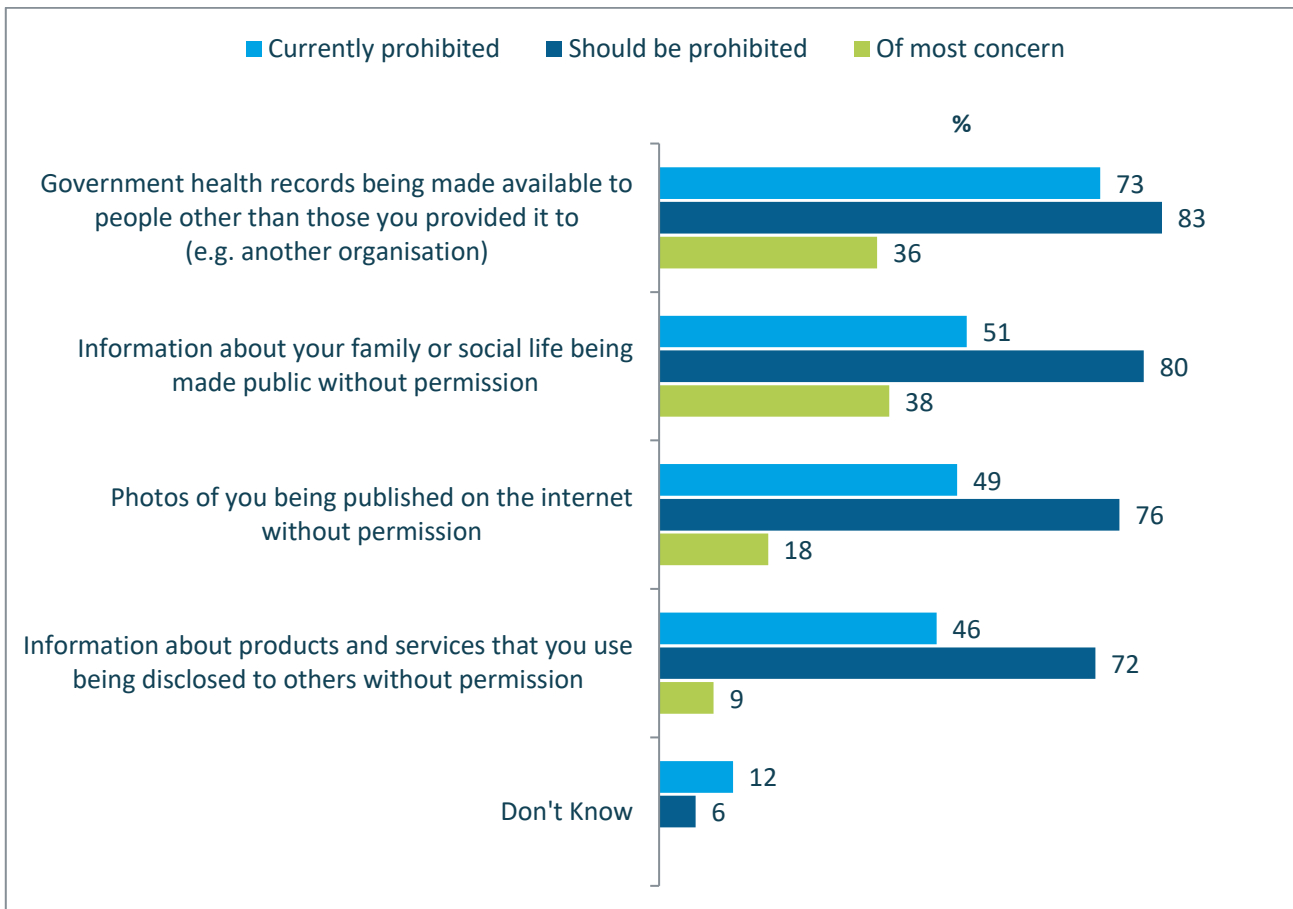
The activity of most concern was *information about your family or social life being made public without permission* (38%), particularly amongst those aged 55+ (50%). While four fifths of all respondents felt that this activity should be prohibited (80%), only half believed that it currently is prohibited under the privacy legislation (51%).

*Government health records being made available to people other than those you provided it to (e.g. another organisation)* was also of great concern (36%), particularly amongst those who do not have children (46%). However, while this activity had the highest proportion of respondents indicating that it should be prohibited under privacy legislation (83%), it also had the highest proportion believing that it currently is prohibited (73%).

While approximately three quarters of respondents indicated that *photos of you being published on the internet without permission* and *information about products and services that you use being disclosed to others without permission* were activities that should be prohibited under the privacy legislation (76%; 72%), they were of comparatively lower concern (18%; 9%).

Younger respondents were significantly less likely than average to indicate that *information about your family or social life being made public without permission* was the most concerning activity (24%), they were significantly more likely to be most concerned with *photos of you being published on the internet without permission* (26%).

Figure 8 Activities prohibited under the current privacy legislation



3. Which of the following activities do you believe are currently prohibited under the privacy legislation? (MR)

4. And which of them do you believe should be prohibited under the privacy legislation? (MR)

5. And which activity would you say is of most concern to you? (SR)

Total n=500

## 4.2. Reasons why these activities are of most concern

### 4.2.1. Information about your family or social life being made public without permission

Of those who indicated that *information about your family or social life being made public without permission* was the activity of most concern to them (n=188), the majority indicated that this was due to it being *nobody's business but mine* (72%), that *the information could be used in ways that I don't know about* (65%), and that *the information could be used in ways that put me at a disadvantage* (57%).

Table 1 Reasons why information about your family or social life being made public without permission is the activity of most concern

	Total (n=188) %	18-34 (n=48) %	35-54 (n=48) %	55+ (n=92) %	Male (n=77) %	Female (n=111) %
Nobody's business but mine	72	65	66	80	62	80
The information could be used in ways that I don't know about	65	75	66	58	64	65
The information could be used in ways that put me at a disadvantage	57	56	50	62	48	64
The information could be embarrassing or damaging	48	44	45	52	44	51
It's not a good thing for our society as a whole	47	33	50	53	44	50
Other (please specify)	1	2	-	-	-	1

7. You said, information about your family or social life being made public without permission concerned you most, why does that concern you?  
Total n=188; 18-34 n=48; 35-54 n=48; 55+ n=92; Male n=77; Female n=111; Yes n=66; No n=81; Not sure n=41

#### 4.2.2. Government health records being made available to people other than those you provided it to (e.g. another organisation)

Those who felt that *government health records being made available to people other than those you provided it to (e.g. another organisation)* was of most concern (n=180) predominantly indicated that this was due to the information being *nobody's business but mine* (72%), that *the information could be used in ways that I don't know about* (69%), and that *the information could be used in ways that put me at a disadvantage* (62%).

There was equal concern shown for the self as well as the community, with half of respondents being concerned that *the information could be embarrassing or damaging* (51%) and that *it's not a good thing for our society as a whole* (50%).

Table 2 Reasons why government health records being made available to people other than those you provided it to (e.g. another organisation) is the activity of most concern

	Total (n=180) %	18-34 (n=76) %	35-54 (n=44) %	55+ (n=60) %	Male (n=75) %	Female (n=105) %
Nobody's business but mine	72	63	70	83	64	77
The information could be used in ways that I don't know about	69	66	80	67	64	73
The information could be used in ways that put me at a disadvantage	62	54	70	65	60	63
The information could be embarrassing or damaging	51	50	55	50	48	53
It's not a good thing for our society as a whole	50	42	59	53	39	58
Health records are especially private and sensitive/in a way other info is not	3	1	5	3	3	3
I have had problems with that aspect in the past/that's the most applicable to me	2	1	-	3	4	-
Health information should only be given to other health providers	1	-	2	2	-	2
Other	1	-	2	-	-	1

7. You said, government health records being made available to people other than those you provided it to e.g. another organisation concerned you most, why does that concern you?

Total n=180; 18-34 n=76; 35-54 n=44; 55+ n=60; Male n=75; Female n=105; Yes n=77; No n=56; Not sure n=47



### 4.2.3. Photos of you being published on the internet without permission

For those who indicated that *photos of you being published on the internet without permission* was the most concerning activity (n=88), three fifths indicated that this is because *the information could be used in ways that I don't know about* (61%) and *the information could be embarrassing or damaging* (58%). A slightly smaller proportion indicated that their concern was because it's *nobody's business but mine* (55%) and *the information could be used in ways that puts me at a disadvantage* (51%).

Table 3 Reasons why photos of you being published on the internet without permission is the activity of most concern

	Total (n=88) %	18-34 (n=53) %	35-54 (n=14)* %	55+ (n=21)* %	Male (n=38) %	Female (n=50) %
The information could be used in ways that I don't know about	61	60	64	62	58	64
The information could be embarrassing or damaging	58	47	79	71	55	60
Nobody's business but mine	55	53	43	67	63	48
The information could be used in ways that put me at a disadvantage	51	53	57	43	58	46
It's not a good thing for our society as a whole	35	30	43	43	32	38
This is the most likely/ the most difficult to control	2	2	7	-	-	4
I don't know how people do it/ get the details/ photo/ don't understand it	1	-	-	5	3	-
Children are the most important consideration/ should be protected	1	-	-	5	-	2

7. You said, photos of you being published on the internet without permission concerned you most, why does that concern you?

Total n=88; 18-34 n=53; 35-54 n=14\*; 55+ n=21\*; Male n=38; Female n=50; Yes n=41; No n=24\*; Not sure n=23\*

\*CAUTION: Small base size

#### 4.2.4. Information about products and services that you use being disclosed to others without permission

Of the respondents who indicated that the activity that concerned them most was *information about products and services that you use being disclosed to others without permission* (n=44), two thirds reasoned that *the information could be used in ways that I don't know about* (66%). This reasoning was most likely amongst those who do not believe that data can be fully de-identified (93%), however caution should be taken due to the small base size (n=14).

Other reasons for *information about products and services that you use being disclosed to others without permission* being the activity of most concern included that *the information could be used in ways that put me at a disadvantage* (57%) and that it is *nobody's business but mine* (52%).

Table 4 Reasons why information about products and services that you use being disclosed to others without permission is the activity of most concern

	Total (n=44) %	18-34 (n=25)* %	35-54 (n=9)* %	55+ (n=10)* %	Male (n=23)* %	Female (n=21)* %
The information could be used in ways that I don't know about	66	64	56	80	70	62
The information could be used in ways that put me at a disadvantage	57	52	67	60	57	57
Nobody's business but mine	52	60	33	50	48	57
It's not a good thing for our society as a whole	39	32	33	60	39	38
The information could be embarrassing or damaging	32	36	11	40	35	29
It's very annoying	5	4	11	-	4	5
I don't know how people do it/get the details/photo/ don't understand it	5	4	-	10	4	5

7. You said, information about products and services that you use being disclosed to others without permission concerned you most, why does that concern you?

Total n=44; 18-34 n=25\*; 35-54 n=9\*; 55+ n=10\*; Male n=23\*; Female n=21\*; Yes n=16\*; No n=14\*; Not sure n=14\*

\*CAUTION: Small base size

### 4.3. Response if information could be provided to others

Respondents were asked how they would respond if they became aware that the information they had to provide when getting services could be made available to others, but they didn't know who, and there was a chance that they may be able to be re-identified.

More than two thirds of respondents would *go elsewhere for the service if there was an alternative* (68%) if they found out that their information could be provided to others, particularly those aged 55+ (79%). In addition, two thirds of respondents would *make a complaint* (61%); again, those aged 55+ were significantly more likely than the total to do this (73%).

A small proportion of respondents *would not worry* about the possibility of their information being provided to others (16%), while only a small proportion would *get information/ ask for information about the process/ contact the authority concerned* (1%).

Table 5 Response if information could be provided to others

	Total (n=500) %	18-34 (n=202) %	35-54 (n=115) %	55+ (n=183) %	Male (n=213) %	Female (n=287) %
Go elsewhere for the service if there was an alternative	68	55	71	79	62	72
Make a complaint	61	51	59	73	62	60
Go without the service(s)	40	30	45	48	35	44
Use the service but provide incomplete personal or health information	30	28	34	30	30	30
Depends NFI	22	24	22	21	23	22
Use the service but provide inaccurate personal or health information	16	20	16	11	19	14
I would not worry	5	7	3	3	4	6
Get info/ ask for info about the process/ contact the authority concerned	1	1	2	1	0	1
Grumble/ freak out/ shriek	1	1	-	1	1	1
I would sue/ go into a class action suit	1	0	1	1	1	0
Other	1	1	-	1	1	0

17. If you became aware that the information you had to provide when getting services could be made available to others, but you didn't know who, and there was a chance that you may be able to be re-identified, what would you do? \*NFI = no further information

Total n=500; 18-34 n=202; 35-54 n=115; 55+ n=183; Male n=213; Female n=287; Yes n=200; No n=175; Not sure n=125

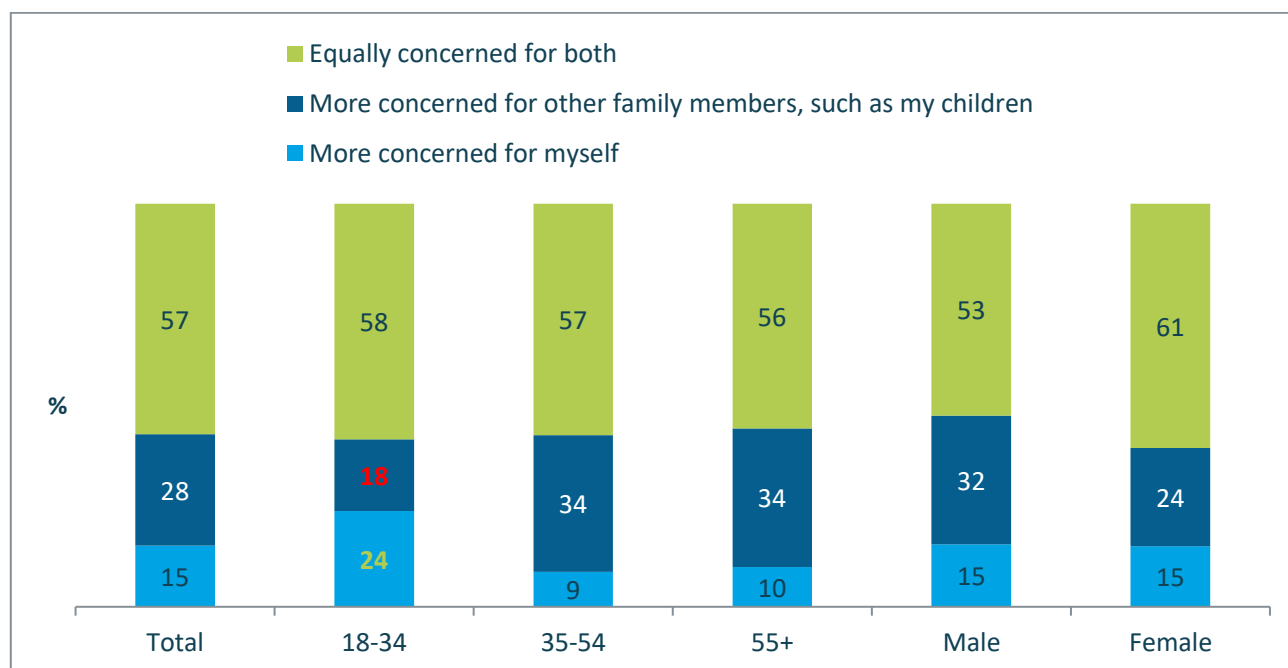
#### 4.4. Concern about possible privacy breaches

Respondents were asked if, in general, they were more concerned about possible privacy breaches for themselves or for other family members such as their children.

More than half of respondents indicated that they were equally concerned for both themselves and their family members (57%), while more than a quarter indicated that they were primarily concerned for their family members (28%).

Younger respondents aged 18-34 were significantly less likely than the total to be primarily concerned for other family members (18%), and were subsequently more likely to be more concerned about possible privacy breaches for themselves (24%).

Figure 9 Concern about possible privacy concerns



6. In general, are you more concerned about possible privacy breaches for yourself or for other family members such as your children?

Total n=500; 18-34 n=202; 35-54 n=115; 55+ n=183; Male n=213; Female n=287

## 4.5. Ideal course of action for privacy breaches

Respondents were asked what the ideal solution or course of action would be in the event of various privacy breaches.

If respondents' privacy had been breached by *internet providers on-selling their information*, most felt that legal action (39%) or a criminal offence (27%) was the most appropriate course of action. Those who indicated that financial compensation would be an appropriate solution were significantly more likely to be aged 18-34 years (17%).

Similarly, legal action (42%) or a criminal offence (27%) was seen to be the most appropriate course of action for a privacy breach involving *an employee of the public sector releasing data to a non-Government organisation without your consent*.

If respondents' privacy had been breached by *a neighbour installing cameras that looked directly into their premises or someone was posting unwanted images of them online*, most indicated that the ideal solution would be an order issued to require the neighbour to take the material down (37%); however, younger respondents aged 18-34 were significantly less likely to indicate this (29%).

For all privacy breaches, few respondents felt that financial compensation (3-9%) or an order issued to require the offender to apologise (3-5%) was an ideal solution.

Figure 10 Ideal course of action for privacy breaches



18. If your privacy had been seriously breached by... [breach]... what do you think would be the ideal solution or course of action?  
Total n=500

## 4.6. Impression of how seriously those in authority are taking privacy

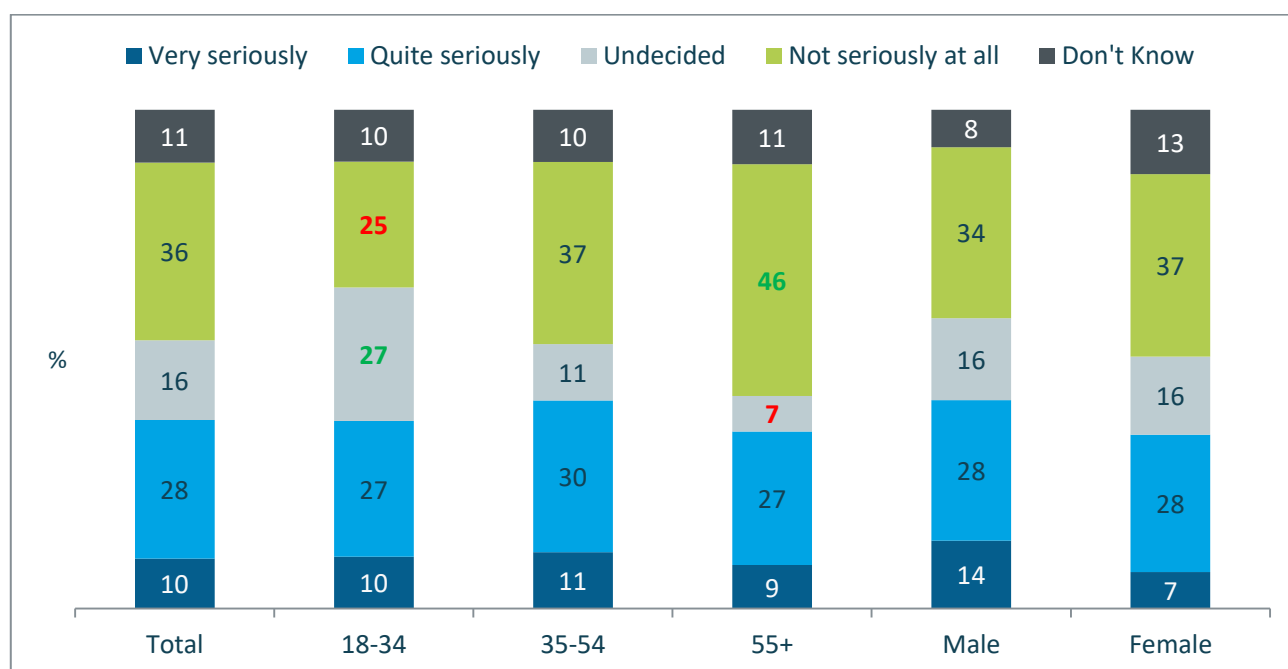
Respondents were asked to rate how seriously they think that those in authority, including elected representatives, are taking privacy.

While slightly more than a third of respondents indicated that those in authority are taking privacy very or quite seriously (38%), a similar proportion felt that they were not taking it seriously at all (36%).

Younger respondents aged 18-34 years were least likely to feel that those in authority were not taking privacy seriously at all (25%), however they were most likely to be undecided (27%); the opposite trend was significant for those aged 55+ (not seriously at all 46%; undecided 7%).

Respondents who were unsure whether data collected about them can be *fully* de-identified were significantly more likely to be undecided (27%) or not know (18%), however were significantly less likely to indicate that those in authority are not taking privacy seriously at all (23%).

Figure 11 Impression of how seriously those in authority are taking privacy



19. How seriously do you think those in authority, including elected representatives are taking privacy  
Total n=500; 18-34 n=202; 35-54 n=115; 55+ n=183; Male n=213; Female n=287



## 5. Participant Profile

	Total %	18-34 %	35-54 %	55+ %	Male %	Female %
<b>Gender</b>	<b>(n=500)</b>	<b>(n=202)</b>	<b>(n=115)</b>	<b>(n=183)</b>	<b>(n=213)</b>	<b>(n=287)</b>
Male	43	48	43	36	100	0
Female	57	52	57	64	0	100
<b>Age</b>	<b>(n=500)</b>	<b>(n=202)</b>	<b>(n=115)</b>	<b>(n=183)</b>	<b>(n=213)</b>	<b>(n=287)</b>
18-34	40	100	0	0	46	37
35-54	23	0	100	0	23	23
55+	37	0	0	100	31	41
<b>Children still living at home</b>	<b>(n=500)</b>	<b>(n=202)</b>	<b>(n=115)</b>	<b>(n=183)</b>	<b>(n=213)</b>	<b>(n=287)</b>
Yes	31	24	71	15	33	30
No	41	22	17	78	40	42
I do not have children	27	54	11	7	27	28
<b>Grandchildren (amongst those who have children)</b>	<b>(n=364)</b>	<b>(n=92)</b>	<b>(n=102)</b>	<b>(n=170)</b>	<b>(n=156)</b>	<b>(n=208)</b>
Yes	40	4	10	78	29	49
No	60	96	90	22	71	51
<b>Working status</b>	<b>(n=500)</b>	<b>(n=202)</b>	<b>(n=115)</b>	<b>(n=183)</b>	<b>(n=213)</b>	<b>(n=287)</b>
Working full time	38	48	58	14	52	27
Working part time	19	16	25	18	15	22
Student	10	25	-	-	11	10
Unemployed	3	4	3	2	3	3
Engaged in home duties	5	4	6	6	1	8
Retired	23	-	5	60	17	28
Refused	2	3	3	1	1	3

1. Which of the following age brackets do you belong to? / 2. Are you... (gender) / 22. Do you have any children still living at home?

Total n=500; 18-34 n=202; 35-54 n=115; 55+ n=183; Male n=213; Female n=287

23. And do you have any grandchildren?

Total (excl. Q22 'I do not have children') n=364; 18-34 n=92; 35-54 n=102; 55+ n=170; Male n=156; Female n=208

24. Which of these categories best describes you?

Total n=500; 18-34 n=202; 35-54 n=115; 55+ n=183; Male n=213; Female n=287

	Total %	18-34 %	35-54 %	55+ %	Male %	Female %
<b>Main language spoken at home</b>	<b>(n=500)</b>	<b>(n=202)</b>	<b>(n=115)</b>	<b>(n=183)</b>	<b>(n=213)</b>	<b>(n=287)</b>
English	92	89	94	95	92	92
Arabic (incl. Lebanese)	0	-	1	-	-	0
Cantonese/ Mandarin	1	2	-	-	1	1
German	0	0	-	-	-	0
Greek	0	-	1	-	-	0
Italian	0	-	-	1	-	0
Other	6	8	4	4	7	5
Refused	0	-	-	1	-	0
<b>Frequency of accessing social media</b>	<b>(n=500)</b>	<b>(n=202)</b>	<b>(n=115)</b>	<b>(n=183)</b>	<b>(n=213)</b>	<b>(n=287)</b>
Every day	55	77	52	32	51	57
Every few days	12	12	14	9	15	9
Once a week	6	5	8	7	6	6
Once a fortnight	1	1	2	-	2	0
About once a month	3	1	3	4	4	1
Less often than once a month	3	1	3	5	3	3
Never	21	2	19	42	18	23
<b>Online media sources regularly used</b>	<b>(n=397)</b>	<b>(n=198)</b>	<b>(n=93)</b>	<b>(n=106)</b>	<b>(n=175)</b>	<b>(n=222)</b>
Facebook	88	92	91	76	86	89
YouTube	59	72	61	34	68	52
Smartphone apps	48	59	48	27	45	50
Instagram	37	51	27	20	29	43
Twitter	18	21	17	11	20	16
Podcasts	15	19	12	10	14	15
None of the above	4	1	1	11	2	5

25. What is the main language spoken at home?

Total n=500; 18-34 n=202; 35-54 n=115; 55+ n=183; Male n=213; Female n=287

20. How often do you access social media?

Total n=500; 18-34 n=202; 35-54 n=115; 55+ n=183; Male n=213; Female n=287

21. Which of these types of online media sources do you regularly use?

Total (excl. Q20 'Never') n=397; 18-34 n=198; 35-54 n=93; 55+ n=106; Male n=175; Female n=222

## Appendix – Survey instrument

### INTRODUCTION

Good afternoon/ evening, we are currently conducting a survey on people’s attitudes and concerns regarding privacy. Could I please speak to someone in the household aged 18 or over?

**RE-INTRODUCE IF NECESSARY AND CONTINUE**

RECORD POSTCODE \_\_\_\_\_

AUTOCODE AREA (**CHECK QUOTAS**):

Sydney	1
Other NSW	2

1. Which of the following age brackets do you belong to? (**CHECK QUOTAS**)

18-24	1	55-64	5
25-34	2	65-74	6
35-44	3	75 +	7
45-54	4		

2. Are you ...(**CHECK QUOTAS**)

Male	1
Female	2

In this survey we are interested in getting your opinions about possible breaches of privacy that could relate to you or your family. When we talk about privacy breaches, we mean the disclosure of information about you to other people. That information could be personal details such as your name, address, or phone number; it could be information from your health records; it could be information about the products or services that you use; or it could be about the things you have been doing in your life and could include photographs.

3. Which of the following activities do you believe **are** currently prohibited under the privacy legislation?

**READ OUT; MULTIPLE RESPONSE**

[Codes in table below]

4. And which of them do you believe **should** be prohibited under the privacy legislation? **READ OUT;**

**MULTIPLE RESPONSE**

[Codes in table below]

5. And which activity would you say is of most concern to you? **READ OUT; SINGLE RESPONSE**

	Q3 (MR)	Q4 (MR)	Q5. (SR)
Government health records being made available to people other than those you provided it to e.g. another organisation	1	1	1
Photos of you being published on the internet without permission	2	2	2
Information about products and services that you use being disclosed to others without permission	3	3	3
Information about your family or social life being made public without permission	4	4	4

6. In general, are you more concerned about possible privacy breaches for yourself or for other family members such as your children? **READ OUT**

- More concerned for myself 1
- More concerned for other family members, such as my children 2
- Equally concerned for both 3

7. You said, **(INSERT FROM Q5)** concerned you most, why does that concern you? **MULTIPLE RESPONSE**

- Nobody's business but mine 1
- The information could be used in ways that I don't know about 2
- The information could be embarrassing or damaging 3
- The information could be used in ways that put me at a disadvantage 4
- It's not a good thing for our society as a whole 5
- Other (please specify) \_\_\_\_\_ 6

**DATA**

8. Do you believe that data collected about you can be *fully* de-identified, in the sense that your identity would not be apparent to anyone?

- Yes 1
- No 2
- Not sure 3

9. I would now like to find out whether you would be prepared to have information about you disclosed for different purposes, assuming that the people using the information *would* be able to identify you.

Firstly, thinking about you or your family's **health** information. Would you agree or disagree with your information being used for each of the following purposes .....**READ OUT** [CODES IN TABLE BELOW].....**If agree:** would that be strongly or slightly agree? **If disagree:** would that be strongly or slightly disagree?

10. And what about your **personal information such as name, address, date of birth, or images**, would you agree or disagree with your information being used for each of these purposes.....**READ OUT** [CODES IN TABLE BELOW].....**If agree:** would that be strongly or slightly agree? **If disagree:** would that be strongly or slightly disagree?

Codes for Q9 + Q10	Strongly agree	Slightly agree	Undecided	Slightly disagree	Strongly disagree
To help in planning and delivering government services	1	2	3	4	5
To help government agencies develop new policies	1	2	3	4	5
As part of consulting with the public	1	2	3	4	5
To help monitor the quality of government services	1	2	3	4	5
To monitor your use of particular products or services	1	2	3	4	5
To be used for research purposes	1	2	3	4	5

11. Do you believe that a government service provider should be able to make it a condition of obtaining the service that they can use your **health** information for other purposes?

- Yes 1 ASK Q
- No 2 ASK Q 13 & 14

12. And what if it was your personal information that they could use for other purposes? Do you believe that a government service provider should be able to make it a condition of obtaining the service that they can use your personal information?

- Yes 1 ASK Q
- No 2 ASK Q 15 and 16

**IF Q11 CODE NO, ASK Q13 & Q14:**

13. Would you agree to your **health** information being provided if you were told that this information could be 'fully de-identified'?

- Yes 1
- No 2

14. Would you agree if your **health** information was 'de-identified' and there was still a chance that you could be identified?

- Yes 1
- No 2

**IF Q12 CODE NO, ASK Q15 & Q16:**

15. Would you agree to your **personal** information being provided outside of government if you were told that this information could be 'fully de-identified'?

- Yes 1
- No 2

16. Would you agree if your **personal** information was 'de-identified' and there was still a chance that you could be identified?

- Yes 1
- No 2

**ASK ALL:**

17.If you became aware that the information you had to provide when getting services could be made available to others, but you didn't know who, and there was a chance that you may be able to be re-identified, what would you do? **READ OUT; MULTIPLE RESPONSE**

- Go elsewhere for the service(s) if there was an alternative 1
- Go without the service(s) 2
- Make a complaint 3
- Use the service(s) but provide incomplete personal or health information 4
- Use the service(s) but provide inaccurate personal or health information 5
- Other: (please specify) 6
- Depends 7
- I would not worry 8

18.If your privacy had been seriously breached by .... [INSERT BREACH FROM TABLE BELOW].... what do you think would be the ideal solution or course of action? **READ OUT; SINGLE RESPONSE**

	A neighbour installing cameras that looked directly into your premises or someone was posting unwanted images of you online	An employee of the public sector releasing data to a non-Government organisation without your consent	Internet Service providers on-selling your information
Legal action	1	1	1
Financial compensation	2	2	2
Criminal offence	3	3	3
An order issued by someone in authority for example, the privacy commissioner to require them to take the material down or return it	4	4	4
An order issued by someone in authority for example, the privacy commissioner to require them to apologise	5	5	5

19.How seriously do you think those in authority, including elected representatives, are taking privacy?  
**READ OUT**

- Very seriously 1
- Quite seriously 2
- Undecided 3
- Not seriously at all 4



## CLASSIFICATION

Finally, a few questions to ensure that we have spoken to a good cross-section of people.

20. How often do you access social media?

- |                              |   |
|------------------------------|---|
| Every day                    | 1 |
| Every few days               | 2 |
| Once a week                  | 3 |
| Once a fortnight             | 4 |
| About once a month           | 5 |
| Less often than once a month | 6 |
| Never                        | 7 |

**IF ACCESS SOCIAL MEDIA (Q20 CODES 1-6) ASK:**

21. Which of these types of online media sources do you regularly use?

- |                   |   |
|-------------------|---|
| YouTube           | 1 |
| Twitter           | 2 |
| Facebook          | 3 |
| Podcasts          | 4 |
| Smartphone apps   | 5 |
| Instagram         | 6 |
| None of the above | 7 |

22. Do you have any children still living at home?

- |                        |   |                  |
|------------------------|---|------------------|
| Yes                    | 1 |                  |
| No                     | 2 |                  |
| I do not have children | 3 | <b>GO TO Q25</b> |

23. And do you have any grandchildren?

- |     |   |
|-----|---|
| Yes | 1 |
| No  | 2 |

24. Which of these categories best describes you?

- |   |   |
|---|---|
| Working full time                                     | 1 |
| Working part time                                     | 2 |
| Student   | 3 |
| Unemployed  | 4 |
| Engaged in home duties                                | 5 |
| Retired   | 6 |
| Refused/ Prefer not to say ( <b>DO NOT READ OUT</b> ) | 7 |

25. What is the main language spoken at home?

- |                                 |   |                    |    |
|---------------------------------|---|--------------------|----|
| English                         | 1 | Tagalog (Filipino) | 12 |
| Arabic (Including Lebanese)     | 2 | Turkish            | 13 |
| Australian Indigenous Languages | 3 | Vietnamese         | 14 |
| Cantonese/Mandarin              | 4 | French             | 15 |
| German                          | 5 | Dutch              | 16 |

Greek	6	Hindi	17
Italian	7	Indonesian	18
Macedonian	8	Punjabi	19
Polish	9	Other (please specify) _____	20
Serbian/Croatian	10	N.A./Refused ( <b>DO NOT READ OUT</b> )	21
Spanish	11		

**Thank you very much for your time.**

**Once again thank you for participating – your time and feedback have been invaluable.**

**In case my supervisor needs to check my work, can I have your first name please?**

**And can I confirm your phone number is: (02) XXXX XXXX?**

**And your postcode?**

### **Privacy Statement**

Please be assured of complete confidentiality. Woolcott Research is a member of the Australian Market Research Society and is bound by privacy and data protection legislation. Your information remains completely confidential and will only be used for market research purposes, you will not be contacted for any sales or marketing purpose as a result of your participation in this survey.