



CAMPBELL RESEARCH & CONSULTING

The Impact of Privacy Legislation on NHMRC Stakeholders

Comparative Stakeholder Analysis

Prepared for

National Health and Medical Research Council

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Terms and acronyms

Table 1: Terms & acronyms used in this report	
AHEC	Australian Health Ethics Committee
AH&MRC	Aboriginal Health and Medical Research Council
AHMAC	Australian Health Minister's Advisory Council
AHMAC Code	Draft National Health Privacy Code prepared by AHMAC
CATI	Computer Assisted Telephone Interviews
CAHEC	Coalition of Aboriginal Health Ethics Committees
Consumers	A term to include both the General Public and Health Consumers
CR&C	Campbell Research & Consulting
Data Custodians	Individuals responsible for the day to day management of datasets that contain health information
General Public	In ST1 and ST2, all consumers who are not described as Health Consumers.
Handbook	Human Research Ethics Handbook
Health Consumers	Health Consumers (ST1 and ST2) are persons who are high users of the health system including persons with life threatening, serious or communicable diseases
Health Guidelines	Guidelines on Privacy in the Private Health Sector (OFPC)
Health information	The Commonwealth Privacy Act includes any information collected by a health service provider during the course of providing treatment and care to an individual, from which the identity of an individual is apparent or can reasonably be ascertained. (For a more detailed explanation see ST10)
HREC	Human Research Ethics Committee
IPPs	Information Privacy Principles
IPP Guidelines	Guidelines to the Information Privacy Principles (OFPC)
NACCHO	National Aboriginal Community Controlled Health Organisation
National Statement	The NHMRC National Statement on Ethical Conduct in Research Involving Humans (1999)
NHMRC	The National Health & Medical Research Council
NPPs	National Privacy Principles
NPP Guidelines	Guidelines to the National Privacy Principles (OFPC)
OFPC	Office of the Federal Privacy Commissioner
Privacy Act	The Commonwealth Privacy Act (1988)

Table 1: Terms & acronyms used in this report	
Privacy Commissioner's Review	Proposed review of Commonwealth privacy legislation
Research Guidelines	Inclusive term for both Sections 95 and 95A Guidelines (NHMRC)
Section 95 Guidelines	Guidelines issued by the NHMRC approved by the Federal Privacy Commissioner under Section 95 of the <i>Privacy Act 1988</i> , (March 2000) to provide a framework for the conduct of medical research using information held by Commonwealth agencies where identified information needs to be used without consent.
Section 95A Guidelines	Guidelines issued by the NHMRC approved by the Federal Privacy Commissioner under Section 95A of the <i>Privacy Act 1988</i> , (December 2001) provide a framework for HRECs and those involved in conducting research, the compilation or analysis of statistics or health service management to weigh the public interest in research, or the compilation or analysis of statistics, or health service management activities against the public interest in the protection of privacy. The guidelines contain procedures to follow in preparing proposals to be submitted to an HREC for approval to collect, use or disclose health information held by organisations without consent .
ST1 General Public and Health Consumers (Qualitative)	Study 1: Qualitative research with the General Public and Health Consumers
ST2 General Public and Health Consumers (Quantitative)	Study 2: A CATI survey of the General Public and Health Consumers
ST3 Health Professionals	Study 3: A CATI survey of medical and allied health professionals
ST4 Health & Medical Researchers	Study 4: A self-completion web-based survey of health and medical researchers
ST5 Data Custodians	Study 5: A self-completion web-based survey of data custodians
ST6 Human Research Ethics Committees	Study 6: A self-completion web-based survey of members of Human Research Ethics Committees
ST7 Peak Bodies	Study 7: A self-completion web-based survey of peak bodies representing healthcare professionals, consumers, researchers and government.
ST8 Comparative report	Comparative Report including all executive summaries and comparative graphs
ST10 Legal Analysis & Recommendations	Report for part two of the consultancy
Working Committee	The Privacy Working Committee established by the NHMRC in late 2003
2001 Amendments	Privacy Amendment (Private Sector) Act 2001

1. Introduction

1.1 Background

The National Health and Medical Research Council (NHMRC) is Australia's leading expert body promoting the development and maintenance of public and individual health standards. Under the National Health and Medical Research Council Act (1992) the NHMRC has four statutory obligations:

1. To raise the standard of individual and public health throughout Australia.
2. To foster development of consistent health standards between the States and Territories.
3. To foster medical research and training; and public health research and training throughout Australia.
4. To foster consideration of ethical issues relating to health.

The NHMRC has extensive links with the Australian community, national and international health and research agencies and many other bodies. These bodies, together with researchers; human research and animal ethics committees; the general public and health consumers; and participants in research form NHMRC's key stakeholders.

The Commonwealth Privacy Act (the Privacy Act) was introduced in 1988. Initially applying only to Commonwealth public sector agencies, it was amended in 2001 and now also applies to the private sector throughout Australia. The Privacy Act contains two sets of principles – the Information Privacy Principles (IPPs), which guide the collection, use and disclosure of personal information by Commonwealth public sector agencies, and the National Privacy Principles (NPPs) which guide the collection, use and disclosure of personal information by private sector organisations.

The effect of the Privacy Act is that, unless a limited range of exceptions applies, health information cannot be collected, used or disclosed without the consent of the data subject.

Sections 95 and 95A of the Privacy Act provide, however, for Guidelines to be developed to enable the use of health information in the conduct of specific activities (including research of various types) without the consent of the data subject, provided an assessment is made by a Human Research Ethics Committee (HREC) that the research and other activities are, on balance, substantially in the public interest.

The NHMRC has developed Guidelines under Sections 95 and 95A to address aspects of the collection, use and disclosure of health information in medical research (Section 95) and research relevant to public health and public safety; compilation or analysis of statistics relevant to public health and public safety; and the management, funding or monitoring of a health service (Section 95A).

Compliance with the guidelines is reported annually to NHMRC through the Australian Health Ethics Committee – a Principal Committee of NHMRC. The NHMRC reports to the Office of the Federal Privacy Commissioner which is responsible for administering the Commonwealth Privacy Act 1988.

However, since the introduction of the private sector amendments, the inclusion of State and Territory legislation, industry codes of practice and administrative decisions have resulted in the privacy framework becoming more complex.

Since December 2001, a range of NHMRC stakeholders have expressed concern that implementation and/or interpretation of Commonwealth and State privacy legislation is compromising research and health care that would otherwise improve outcomes for both individual and public health. It has been suggested that this is an unintended effect of the privacy legislation and, more particularly, the private sector amendments to the Privacy Act.

The introduction of the Privacy Amendment (Private Sector) Act 2001 included a stipulation that the amendments be reviewed, commencing no later than two years after their introduction. The NHMRC intends to make a submission to this review.

Given the level of concern exhibited by stakeholders and the lack of objective documentation, the NHMRC established a Privacy Working Committee late in 2003. The main role of the Working Committee was to investigate the situation further and collect information which would assist in the formulation of the submission.

Campbell Research & Consulting was commissioned by the NHMRC to conduct a project comprising two components:

Part One:

First, to conduct seven separate, but related, studies with the following stakeholder groups:

- ST1. General Public;
- ST2. Health Consumers;
- ST3. Medical and Allied Health Professionals;
- ST4. Medical and Health Service Researchers;
- ST5. Health Data Custodians;
- ST6. Human Research Ethics Committees; and
- ST7. Peak Bodies – professional and consumer.

Subsequently ST1 was reported as qualitative research with both the General Public and Health Consumers while ST2 reported the results of Computer Assisted Telephone Interview (CATI) surveys with both these groups.

Part Two:

Secondly, to assist the NHMRC Privacy Working Committee to develop a report, in the format of advice to government, that will provide the foundation for a submission on behalf of the NHMRC to the review of the privacy legislation.

The anticipated review of the Privacy Act has not been announced at the time of writing. Consequently the output from the second part of the project focussed on addressing:

1. The issues associated with the effect of the Commonwealth Privacy Act and the patchwork of privacy regulation and how they affect the provision of health services and the conduct of health and medical research.
2. Approaches that can contribute to the improvement of both health service delivery and health and medical research.

1.2 Project objectives

The overall objectives of the project were to provide a comprehensive consultation with stakeholders to inform the NHMRC. Specifically:

- The objective of the first stage was to provide the NHMRC with a comprehensive assessment of the key issues for consumer, researcher and other key stakeholders as a foundation on which to develop an informed submission to the Australian government for the forthcoming review of privacy legislation.
- The objective of the second stage was to provide the NHMRC with advice, grounded in the consultations, which can address privacy issues to facilitate the NHMRC to effectively continue its legislative responsibilities while meeting privacy principles established by the government.

2. Qualitative research with the General Public and Health Consumers (ST1)

This report documents the findings of nine focus groups conducted with consumers. These groups were conducted with Health Consumers and the General Public¹.

The focus groups were conducted in metropolitan areas (Brisbane, Melbourne and Adelaide) and in two non-metropolitan regional centres in New South Wales (Lismore) and Victoria (Shepparton). All Health Consumer groups included participants with current or previous involvement in medical research. Health Consumer participants were recruited via letters sent to support groups and clinics inviting members to contact CR&C if they wished to participate.

Consumer experiences of, and attitudes toward privacy in health care and medical research were explored. Differences in perspective of Health Consumers who have a high level of interaction with the health system were explored.

Consumer perceptions of privacy in relation to health care

“Privacy” was considered to be intertwined with the concept of “confidentiality”. For consumers, confidentiality was more formal and related to the exchange of information while privacy was more personal and intimate. The code(s) of ethics for health professionals, particularly medical practitioners, were the basis for trust in maintaining the confidentiality of information that consumers provided to their treating professionals.

Privacy legislation was found to be only vaguely familiar to most consumers. However, all consumers assumed that health care professionals have to behave in accordance with strict ethical standards and a professional code of ethics that guarantees the protection of health information disclosed in the course of treatment. The assumption by consumers that there was a “zone of confidentiality”, based on the fundamental trust that was expected to develop between patients and their treating doctors, was said to provide sufficient protection of a consumer’s individual rights in the health care context.

Consumers believed that the sharing of information between health professionals was usually done on a “need-to-know basis”, because health professionals would not have any interest in requesting more information than was strictly needed.

The issue of consent (verbal or written) had a two-fold interpretation:

- Participants reported that the act of requesting consent represented a demonstration of respect by medical practitioners. Health professionals should request consent as a matter of “*courtesy*” (assuming consumers are medically able to give their consent). However consumers (especially consumers from the General Public) did not see themselves as having the expertise to give consent on any other basis.
- When written consent is requested, consumers understood this procedure to be mostly a form of protection for the medical professionals against future litigation risks.

¹ “*Health Consumers*” refers to participants of focus groups who have a high level of interaction with the health system. Participants for these groups were recruited from persons living with a chronic, life threatening illness, serious mental health condition, or a chronic infectious disease such as HIV/AIDS. The term “*General Public*” is used to refer to participants in focus groups drawn from the general population, and who are not “Health Consumers”. The term “*consumers*” is used generically, to refer to participants in focus groups that comprise the “General Public” and “Health Consumers” when they shared similar views and opinions.

Consumers assumed that health information would be provided without hindrance to other health professionals for the purpose of treating a specific condition and that the medical and other staff would ensure the confidentiality of information and non-disclosure to non-treating staff including administrative staff and researchers.

Consumer perceptions of privacy in relation to medical research

In general, consumers did not understand what medical research entailed. For example, some considered “organ donation” and “blood donation” to be “medical research”. Overall, consumers did not have a clear understanding of the purposes or operational mechanisms of medical research. When consumers had been personally involved in medical research, they demonstrated high levels of satisfaction with the experience and the way in which their privacy had been respected. However, most had little familiarity and knowledge of research, and demonstrated a level of diffidence in relation to who researchers are, what research is conducted for, and how research is used. Further, although consumers supported research warmly as a concept, they indicated that they were unlikely to draw any direct, personal benefit from participating in research.

The overall lack of understanding and personal interest in, medical research explains why participants across all focus groups had higher expectations and requirements of privacy in medical research, than they demonstrated in relation to privacy in health care. In this context, consumers expected that invitations to participate in research should be mediated by their treating GP, or specialist, who were seen as the persons most able to act as gatekeeper and interpreter.

Consumers did not want to be contacted directly by researchers. They were also quite concerned about how their medical information may be used, and wished to be asked for consent via their treating practitioner prior to their medical information being used by researchers.

Consumer attitudes toward linked databases were, in general, cautious. Considering the potential risk of misuses of linked databases and the possible problems arising from database linkage, the overall view was that linking databases should be avoided. Consumers did not think that technical solutions to preserve individual privacy (they could only think of de-identification and allocation of a number) would be sufficient to prevent abuses if unethical research was to be undertaken.

Human Research Ethics Committees were mostly unknown to consumers and as such were considered to be an interesting and reassuring concept, although the committees’ powers and efficacy were not entirely convincing.

Differences between the General Public and Health Consumers were substantial, but impacted on the overall perspective of the privacy legislation only by degree. In health care, the trust placed in the treating medical practitioner prevails for both groups. However, Health Consumers expected to be involved in the medical decision-making process in a much more thorough and systematic way than members of the General Public. General Public consumers saw the trust in health care professionals as a sufficient warranty that their privacy rights would be respected. Privacy requirements were seen as a way for Health Consumers to ensure that they are not left out of the decision loop. Furthermore, people with a stigmatised health condition (eg. HIV/AIDS, mental health condition) shared a deeper understanding of the importance of the privacy legislation to protect their individual rights than other group participants.

Differences between metropolitan and non-metropolitan consumers related mainly to the fact that individual privacy is perceived as much harder to accomplish in a small town than in a capital city. However this was understood to be a characteristic of small town living, which could not be changed to any substantial extent by legislation, no matter how strict.

Conclusions

The impact of the Privacy legislation from the perspective of consumers, as explored through the conduct of focused discussion groups in several locations across Australia, was found to be manifold.

- Consumers were not able to distinguish clearly between confidentiality and privacy and considered confidentiality to relate to disclosure of information (or protection from inappropriate disclosure).
- Most consumers were only vaguely aware of the existence of the privacy legislation. When they did know about the legislation, it was mainly through their employment. However, Health Consumers had a higher awareness of the legislation.
- In relation to **health care**, consumers generally did not see that the legislation has had a significant impact on their daily dealing with the health system. They assumed that privacy requirements are already being complied with through the ethical standards and the strict code of conduct that they believed health professionals have to implement in the conduct of their work.
- Consumers may have noticed that they are being asked to sign consent forms more systematically. However they tended to attribute this new procedure to a form of protection for medical organisations against the consequences of being held legally liable for medical negligence or adverse events, rather than as a measure of protection of their individual rights.
- Most consumers were unsure about what **medical research** encompasses and of the implications of medical research for consumers. Hence the impact of the privacy legislation on medical research could only be understood approximately, at a hypothetical rather than practical level. Also, the lack of familiarity with medical research tended to generate a degree of mistrust among consumers, and contributed to their conservative approach to the application of privacy principles.
- In brief, in health care, consumers were overall unaware of the requirements of the Privacy legislation, whereas they were more supportive of its implementation as a measure of protection of their individual rights where research was concerned.

Overall, they believed that the consent process, despite being cumbersome for researchers, was useful and legitimate. They also thought that the restrictions imposed by the legislation on the use and sharing of medical information was a justified safeguard against potential misuses of health data.

It is the “zone of confidentiality” which is taken for granted by consumers that facilitates effective health care, with disclosure to other treating professionals taken-for-granted where it relates specifically to the condition being treated and the protection of information from disclosure to non-treating persons including administrative staff and researchers.

3. Quantitative research with the General Public and Health Consumers (ST2)

This report analyses the results of a survey of consumers. A Computer Assisted Telephone Interview (CATI) survey was conducted with 301 members of the general public and 60 Health Consumers. The definition of “Health Consumers” was extended (from that used in the qualitative recruitment) to include persons who had visited a GP more than once a week or a medical specialist more than once a month in the previous year.

The survey results confirm many of the findings of the qualitative research (ST1).

Awareness of privacy legislation

Overall awareness of any specific laws or regulations that govern the use of health information was found to be low. Less than half of the consumers who responded to the survey were aware of the existence of the Commonwealth Privacy Act. Health Consumers had a higher level of awareness of the existence of privacy legislation in a general sense.

Privacy was commonly equated with confidentiality:

“Information about me must be kept confidential”.

“Doctors must keep information confidential unless they have [written/signed] permission”.

While consumer understanding of how health professionals were affected by privacy law in the collection and disclosure of information (from the responses to the “Doug and Mabel scenario”) was inconsistent, there was general agreement (from the responses to the “Jenny scenario”) that consumers did not consider disclosure of health information by professionals to researchers appropriate without consent.

Attitudes toward privacy of health information

The survey responses confirmed the qualitative finding that consumers and the general public trust medical practitioners to maintain confidentiality. However, Health Consumer respondents identified greater concern regarding the way health information was used. Whilst trust extended to agreement among the General Public that *all health professionals treating me should have automatic access to my health information*, Health Consumer respondents were less likely to agree that treating health professionals should have automatic access.

Most of the General Public and Health Consumer respondents felt that privacy laws reassured them that their health information would be treated confidentially and that their *health information is treated with greater confidentiality than a few years ago*. Respondents were generally more concerned about the confidentiality of their financial information than their health information.

There was a substantial minority of consumers who were concerned about the potential misuse of their health information.

Experience of the impact of privacy legislation

Few members of the General Public, but 17% of the 60 Health Consumers respondents, had *ever* experienced a breach of confidentiality of their health information. All of the Health Consumers identified that this breach had caused them problems.

Few respondents had made a complaint, although complaints were more likely among the Health Consumer respondents.

Health Consumer respondents commonly recalled signing consent forms to allow a doctor or other health provider to release information about their health to other health professionals while only a

minority of the General Public recalled doing so. Even fewer recalled signing a consent form allowing a researcher to access their health records.

Access to and linking of databases

The results from the survey showed there was general acceptance for APPROVED researchers to access and match medical information from databases. There remained a substantial minority who considered such access to be unacceptable.

However, the overall acceptability of researchers accessing information from databases increased significantly when records were identified by a unique number rather than a name. 82% of the General Public and 86% of Health Consumer respondents found this to be acceptable. Similar responses were given to the acceptability of *a system of unique protected numbers, rather than names, was used to code health information for ALL Australians.*

Use of health data for research

Health Consumers were more likely to disagree that the public benefit of most medical research outweighs the importance of individual privacy.

Attitudes towards the use of health information for research were divided for members of both the General Public and Health Consumer respondents. For both groups there was a general attitude of support for researchers to have access to health information but a substantial minority did not agree with automatic access, reinforcing the concerns identified by both the General Public and Health Consumers in the qualitative research.

Although half of all consumers agreed that they would not mind if their name was given to a researcher so they could INVITE me to participate in research, over a third disagreed.

A similar proportion agreed that:

Unless I choose to opt out approved health researchers should have automatic access to my health information.

The important role for all consumers of the treating medical team was identified in the response to the Jenny scenario where nearly all consumers indicated that Jenny should be approached through her medical practitioner and not directly by researchers.

Participation in health research

Participation in medical research was low amongst the General Public but was higher among Health Consumers. Reinforcing the findings of the qualitative research, most people who had not previously participated in a medical research study indicated they would do so if asked.

The motivation for participating in medical research was primarily altruistic. Virtually all potential research participants **expected** to be told how their privacy would be protected during the study.

Those who had participated in research were equally likely to *recall* being recruited by an approach from the researcher as by a treating health professional. The majority felt confident that the information collected during the study would be kept confidential. Virtually all participants were satisfied with their involvement in the study overall.

Conclusions

Consumers had very little awareness of privacy legislation and a poor understanding of medical research. Even for consumers with extensive experience of the Australian Health System, privacy is generally not distinguished from professional confidentiality, particularly the trust placed in the code of ethics of the medical profession. However, the confidence and trust is not automatic. It must be reinforced by respect by the professional for the patient.

Importantly, when consumers support the sharing of information between professionals, it is not automatic access to all information. Rather, as the qualitative research clearly identified, it is on a “need to know basis” with relevant information being defined by consumers as that which is known to impact on the treatment. It is not unfettered access to all information and it does not include access to that information by administrative staff or researchers.

There is considerable support for researchers to be able to contact patients directly; however a substantial minority, especially Health Consumers, did not support such access. The lack of understanding of medical research combined with the trust placed in the treating medical practitioner meant that consumers require reassurance about research and what it means to them before participating.

Health Consumers, in particular, did not consider that the benefits of research outweighed the protection of privacy, and were less inclined to agree to automatic access to medical reports for researchers to contact them directly. The fact that one in five of the small sample of Health Consumers reported that breaches of their privacy had caused them problems is a matter of concern that warrants further investigation.

However, there was considerably more support for the use of health data which is considered to be important, particularly if it was de-identified using a number. The qualitative research identified an assumption by consumers that health information is used for research anyway. The concern by consumers is that information about them as a person is treated confidential. There is more acceptance of the use of that information in a research context when it is identified by a number and widespread support for a unique protected number for all Australians.

4. Medical and Allied Health Professionals (ST3)

The objective of the survey of medical and allied health professionals was to identify the range of views about privacy across a broad spectrum of health professionals and to identify the experience of medical and allied health professionals with privacy issues. A total of 203 Computer Assisted Telephone Interviews (CATI) interviews were carried out with 50 GPs, 50 medical specialists, 53 nurses, 25 pharmacists and 25 chiropractors.

The sample size for the survey as a whole is small and for individual groups is even smaller.

Survey results are not claimed to be representative of the population of GPs, specialists, nurses, pharmacists or chiropractors. They are indicative of attitudes toward and experiences of privacy issues.

Awareness and Knowledge of Privacy Legislation

Medical and allied health professionals who responded to the survey rated their personal knowledge of privacy legislation as moderate to high. However, there was a relatively low level of awareness of which specific privacy legislation applied to their professional work.

The most common sources of information identified without prompting, were professional colleagues and professional associations. Other sources included government privacy offices, publications (including the NHMRC Guidelines) while a small number used the internet.

Over half the respondents indicated that they had made changes to their work practices over the last two years because of the Commonwealth Privacy legislation. Most commonly, the areas where changes occurred were when health information was shared with other professionals outside their practice and the documentation of policy and procedures.

Other areas where changes had been made included: sharing information with other professionals in the same practice, collecting health information from a patient, collecting information from health professionals outside their organisation and staff induction and training. Nearly all organisations where the medical and allied health professionals worked had a privacy policy.

While only a minority of medical and allied health respondents identified that the Commonwealth Privacy Act applied to their professional practice, most turned to Commonwealth Privacy legislation when making decisions about disclosing data to health professionals outside their organisation, the main area where privacy legislation impacted on their professional practice.

Seeking and obtaining consent from patients

Use of consent forms was a common procedure when disclosing patient health information **outside the organisation**, with a third indicating that standard forms were used, while a similar proportion indicated that they were used “only when needed”. Signed consent was also sought for use of patient information within the organisation.

Close to half the medical and allied health respondents indicated that consent forms were used if health information was to be used for research purposes or to disclose health information for research purposes.

The majority of medical and allied health respondents claimed there was little likelihood of patient privacy accidentally being compromised when disclosing patient information about them. However, most were able to offer many potential examples of situations in which accidental disclosure may occur. A small proportion was aware of a breach of privacy within their organisation that had created problems for a patient. Ten percent of respondents had received a complaint from a patient regarding disclosure of personal information at some time in their professional careers.

Regardless of the apparent lack of any negative experience regarding breaches of privacy, the majority of survey respondents (70%) agreed with the statement “*I am concerned about my legal liability if I breach privacy even if it is in the patient's best interest*”, indicating they are highly aware, and sensitive to the potential legal implications of compromising patient confidentiality.

Perceived Impact of Privacy Legislation

Medical and allied health respondents generally indicated that the Commonwealth Privacy legislation had had a positive impact on protecting the privacy of individuals. However, only a minority had a clear opinion about whether the legislation had an impact on health services or health research. Most either did not know or had mixed views.

While most medical and allied health respondents agreed that concerns about privacy legislation could delay the timely transfer of important patient information, fewer considered that automatic access to health information should be given to all treating professionals.

The majority of medical and allied health respondents considered that there was no difference between their privacy obligations and their existing duty of confidentiality. Also, the majority considered that professional ethics was sufficient to reassure patients about the confidential treatment of health information.

The main benefit of the Commonwealth privacy legislation identified by medical and allied health respondents was for their patients, specifically increasing the protection of patient privacy. The next most common benefit was the reduction in the risk of liability. A substantial minority were unable to identify any benefit.

Nearly all respondents were able to identify difficulties arising from legislation. The most common difficulty pertained to access to, and exchange of, patient information. The other common difficulty was “more work for the health professional”.

Two thirds of the medical and allied health respondents were unable to suggest any ways to maximise the benefits they considered had resulted from the legislation. A small proportion (less than 10%) suggested:

- Improving awareness through education;
- Liberalising access to, and exchange of, information between health professionals; and
- Simplifying the information and the paperwork relating to the Privacy Act.

Half could not offer any suggestions to minimise the difficulties they perceived associated with the legislation. The approach to overcome difficulties was not different to those suggested for maximising benefits.

Privacy and Research

Only a small minority of medical and allied health professionals interviewed considered that privacy legislation has had a negative impact of research. Most identified data linkage as being important for determining effective treatments while half agreed that privacy legislation struck *the right balance between protecting the rights of individuals and enabling effective health care research*. Nevertheless half disagreed that the balance is right or were uncertain.

Conclusions

The main impact of privacy legislation on the medical and allied health professionals interviewed in the survey has been an increase in workload. The results indicate that it is *concern* about disclosure of health information arising from the privacy legislation that has created difficulties, not necessarily the legislation itself. A theme, that is repeated in the other stakeholder surveys, of uncertainty and lack of specific knowledge about the complex patchwork of privacy legislation emerges.

Medical and allied health professionals who were interviewed for this survey have similar views to consumers in assuming that there is no difference between privacy and confidentiality and it is the ethics of professional practice that is the primary reassurance of the protection of privacy of individuals.

The Commonwealth Privacy Act is considered to be the benchmark for making decisions about privacy, particularly in regard to disclosure of health information outside the organisation, even though only a minority identified the Commonwealth legislation applying to their professional practice.

The main privacy issues for medical and allied health professionals responding to the survey was the disclosure of health information outside their organisation, although there is some concern about the use of health information within the organisation.

While the sample sizes for the survey are small, the results indicate that the Commonwealth privacy legislation *is* having an impact on professional practice across a wide range of medical and allied health professionals.

There are indications of long term culture change, with most medical and allied health professional respondents indicating that their organisations have a privacy policy. A minority of health professionals identified that a privacy policy was being integrated in to staff induction and training.

While privacy is one of a number of competing demands on the time of medical and allied health professionals, it is assistance in finding a way through the maze that is the key issue identified by respondents who consider they already take privacy as an important part of their everyday professional work.

The implications for research are also substantial. With health professionals agreeing that researchers should not have automatic access to patient health information, and increasing workloads associated with privacy (and other issues) the reliance upon treating medical and allied health professionals for recruitment for research will continue to increase the administrative burden on health professionals.

5. Medical and Health Service Researchers (ST4)

The survey of Medical and Health Service Researchers was administered as an opt-in web-based self completion survey. It was initially proposed to restrict the survey to recipients of NHMRC grants. However the sample was extended because of the low response from the opt-in sampling process and the high level of interest from non-NHMRC Medical and Health Service Researchers.

Sample of Medical and Health Service Researchers

The survey was administered to 188 Medical and Health Service Researchers who agreed to participate. 112 Medical and Health Service Researchers (hereafter, 'Research respondents') responded to the survey, yielding a response rate of 60%.

Research respondents have been conducting research for an average of 13 years (excluding postgraduate studies). Most Research respondents were located in a university or a public hospital, and half of the Research respondents were NHMRC Research Fellows or academics. Six in ten Research respondents did not do clinical work. Three in four had received a recent NHMRC grant.

In general, five in ten Research respondents collected data from sources covered by the Commonwealth Privacy Act. Four in ten Research respondents obtained health information for their research projects from the Commonwealth and three in ten from the private sector.

Survey results are not claimed to be representative of the population of Medical and Health Service Researchers. They are indicative of the range of attitudes toward and experiences of privacy issues.

Main privacy issues

The most common issues raised related to restricted access to registries or databases hindering research by affecting scientific rigor. Access to registries was commonly linked to recruitment and consent. Where consent was not possible, or was difficult or problematic, privacy legislation was considered to impede recruitment. Sampling was identified as a major factor affecting scientific rigor. Sample bias undermines confidence in the generalisability of results to the study populations. In the case of epidemiological studies, access to databases was restricted where consent had not been obtained at the point of data collection and vital data had thus been made inaccessible.

The role of HRECs was highlighted. Issues about HRECs included inconsistency between committees in their decision making, particularly in regard to multi-site studies, and non-researchers making decisions about research which affects the capacity of important research projects to proceed, or proceed in the most scientifically rigorous manner.

Solutions to assist working within this framework were identified.

In some instances Research respondents identified harm arising from the privacy legislation, particularly in relation to studies where persons who may be identified as being at risk cannot be informed of their potential risk because of privacy regulation.

Also the impact of the range of laws affecting privacy was characterised as a "bureaucratic maze" presenting Research respondents with lengthy processes before research can start. This resulted in increased administrative burden which increases research costs and decreases research outputs.

Awareness of and access to privacy legislation

Half of the Research respondents rated their level of knowledge about privacy issues as *high* or *very high*. Four in ten rated it as *moderate*.

The most common source of information about privacy was the NHMRC Guidelines followed by Human Research Ethics Committees. Fewer than four in ten Research respondents obtain information about privacy through State/ Territory Government agencies, the Internet and professional workshops or seminars. Three in ten look to the Commonwealth Privacy Commissioner for information about privacy, and fewer than two in ten refer to professional publications.

The most common privacy requirements identified by Research respondents were professional ethics and Commonwealth privacy legislation for public sector agencies.

Three in four Research respondents reported that they consider the Commonwealth privacy legislation when making decisions about disclosing health information to people outside their organisation or agency. There was a relatively high level of awareness of general legislation but little awareness of the detail of the privacy framework, with only a minority aware of the Information and National Privacy Principles and Section 95 or 95A of the Commonwealth Act.

Compromising privacy

Almost all Research respondents considered that the accidental disclosure of personal health information about an individual involved in research was *unlikely*. Nearly all Research respondents reported that they were not aware of any situation where a compromise of privacy has resulted in harm to participants involved in their research. Over the past two years, one in ten Research respondents were subject to an audit of their level of compliance with privacy requirements.

Changes in work practices

Over the past two years, three in ten Research respondents had to change their research practices in order to accommodate the Commonwealth privacy legislation.

A theme consistent across nearly all responses was the administrative burden created by privacy legislation. The administrative burden was reflected in additional cost in terms of staff time, overall time taken for approval and start up of research and the associated cost of changed research practices to accommodate privacy requirements.

Impact on research

Research respondents considered the privacy framework to be compromising the scientific rigor of research and preventing projects from commencing. Since the 2001 Amendments to the Privacy Act were introduced two years ago:

- One in three reported that the scientific rigor of their research had been compromised because of privacy issues; and
- Two in ten Research respondents were involved with research projects that have not commenced because of privacy issues; while
- Few have been involved with research projects that had to be terminated because of privacy issues.

General attitudes towards privacy

In general, Research respondents favoured automatic access to individual information without obtaining specific consent. Research respondents almost universally agreed that the ability to link information was an important component in determining treatment effectiveness.

Most Research respondents favoured HREC approval as a means by which Research respondents could access health information to recruit research participants.

More specifically, Research respondents *agreed* that:

- *Treating health professionals and approved health researchers should have automatic access to an individual's health information unless that individual chooses to opt out;*
- *Public health consumers should be eligible for invitations to participate in research;*
- *Consumers would allow their name to be given to a researcher to invite them to participate in health research;*
- *Privacy guidelines were in danger of impeding ethically acceptable research;*
- *The current privacy framework was compromising the integrity of health research;*
- *Linking of health information is important to determine treatment effectiveness;*
- *Ethics Committees had become overly concerned about litigation associated with privacy issues;*
- *Ethics committees should approve access to health information for recruitment; and*
- *Ethics committees were balancing considerations of research and individual privacy.*

Research respondents *disagreed* that:

- *Researchers should never be allowed access to medical records without consent;*
- *The privacy framework balanced individual rights and effective health research; and*
- *Ethics committees should put participants' privacy ahead of facilitating health research.*

Specific attitudes to privacy

Three in four Research respondents indicated that privacy issues had become more *complex* over the past two years.

Three in four Research respondents also indicated that the *time* they spent on privacy issues increased over the past two years.

Few Research respondents considered privacy legislation to have had a positive impact on *research*, and one in four considered the impact to be negative. The overwhelming majority of Research respondents had either mixed perceptions or were unsure about the impact of Commonwealth privacy legislation upon health care and health research in Australia.

Half the Research respondents were either unsure or had mixed perceptions about the impact of Commonwealth privacy legislation upon the protection of *individual privacy*.

Scenarios

Based upon consideration of key issues presented in five scenarios Research respondents indicated that:

- They *should* be permitted to match data and access patient contact details than would otherwise be allowed under the current legislation.
- Treating health professionals *should* be permitted to access patient summary information, and disclose patient health information to another (relevant) party than would otherwise be allowed under current legislation.
- An HREC *would not* and *should not* allow researchers to access health records without consent.

Benefits of the privacy legislation

Around half of the Research respondents acknowledged that the Commonwealth privacy legislation had resulted in more consistency between different states or jurisdictions (49%) and greater protection of individual rights (46%). 41% of the Research respondents acknowledged that the privacy legislation had resulted in clearer boundaries for decision making.

21% did not identify benefits arising from privacy legislation

Difficulties of the privacy legislation

73% Research respondents identified increased administrative burden as a difficulty arising from the Commonwealth privacy legislation. 34% identified greater confusion about decision making.

Suggestions to improve the current system

The main suggestions for improvement to the current Commonwealth privacy legislation involved the development of clear guidelines, increased education of ALL stakeholders, and greater coordination of legislation. A range of other suggestions were made including accreditation of researchers and appeal processes for HREC decisions, funding to cover the cost of increased administrative costs and the introduction of standard consent procedures in clinical settings to allow use of health information for research purposes.

Conclusions

The Commonwealth Privacy Act has affected most Research respondents. The most common issue raised has been the administrative burden resulting in additional cost. Most Research respondents are able to work within the privacy framework, albeit at a cost in terms of both money and productivity.

Other concerns include the impact on scientific rigor, particularly regarding the recruitment of appropriate subjects to research, and access to data. In some cases, researchers have not proceeded with research projects, less commonly research projects have been terminated before completion. While less commonly reported, the impact of stopping research from proceeding and restricting the scientific rigor of research was considered to be of grave concern to those Research respondents involved.

The complexity and administrative burden has increased over the two years since the 2001 Amendment has come into effect, even though only a minority directly identified that their work is affected by the Commonwealth Act as it applies to the private sector.

The impact of the 2001 Amendment, and indeed the 1988 Act, is difficult for Research respondents to separate from the plethora of State, Territory and other Commonwealth legislation which affects privacy and access to identifying data. Most Research respondents identified more than one privacy requirement applying to their work. These requirements include the ethical code of professional practice that most Research respondents work within (and consider themselves as having worked within before privacy legislation).

Research respondents consider themselves to have a good grasp of privacy issues, although only a minority were aware of specific detail of Commonwealth privacy legislation.

The NHMRC Guidelines and HRECs were identified as the most important sources of information about privacy. Only a minority mention the Federal Privacy Commissioner or state government departments. No Research respondents referred directly to the legislation as a source of information. That is, Research respondents are seeking advice and help in the form of interpretive guidelines both for themselves and for the HRECs that are making decisions about permitting (or not permitting) research to proceed.

Improved consistency and provision of guidelines both in the legislation and the way it is interpreted were identified as solutions for improving understanding and compliance with the privacy legislation. Education for all stakeholders including HREC members and data custodians is seen as vital. Research respondents did not, however, identify any specific detail of the legislation as requiring change.

6. Data Custodians (ST5)

Campbell Research & Consulting was commissioned by the NHMRC to undertake consultations with key stakeholder groups about the impact of the Commonwealth privacy legislation. This report (Study 5 Data Custodians) documents the results of a series of interviews, teleconferences, and an on-line (Internet) self completion survey of 37 data custodians.

Survey results are not claimed to be representative of the population of Data Custodians. They are indicative of attitudes toward and experiences of privacy issues.

“Data Custodians” were defined as individuals who were responsible for day-to-day management of datasets that contain health information.

The relevance of Commonwealth legislation to data custodians

Many State/Territory-based Data Custodian respondents perceived limited relevance of Commonwealth legislation to their daily work. This was primarily because of the over-riding applicability of State/Territory legislation or the de-identification of health information when it is disclosed to external sources. At both State and Commonwealth levels, stakeholder consultations indicated that there has been some confusion amongst some individuals regarding confidentiality and privacy. Accordingly, Data Custodian respondents have had to increase the amount of ongoing education to explain to researchers the differences between adherence to confidentiality requirements and the capacity to continue providing information under privacy legislation. (This included State/Territory as well as Commonwealth legislation.)

A broad picture of survey respondents

In general, Data Custodian respondents were relatively experienced managers within their respective organisations with a substantial amount of experience as a data custodian (typically 5 years). This has provided a good picture upon which changes in data management practices associated with any changes in the Commonwealth privacy framework have been examined. Indeed, more than 80% of Data Custodian respondents had more than two years experience, permitting opportunities for them to experience the impact of the private sector amendments (2001). Most data custodians responded from State/Territory or Commonwealth departments or agencies. This was in line with the definition of data custodian adopted for the study and representative of the large number of data custodians in the public sector.

General issues about privacy

Although most Data Custodians collected sensitive and potentially identifiable information, fewer could actually confirm criteria to determine if the data they collected were identifiable. A relative lack of awareness of such criteria amongst a small number of custodians may introduce a level of risk in the recognition of potentially identifiable information at the point of disclosure both within, and external to, those agencies even if the agency has clear definitions. Of those who were able to indicate criteria for defining potentially identifiable information, definitions included a range of aspects from “personal information”, to information that had the potential to be linked, or any non-aggregate information.

Some simply referred to the application of components of State or Commonwealth privacy frameworks.

The absence of a uniform approach defining identifiable information may also increase perceived complexity and administrative burden for both the Data Custodian respondents themselves and researchers as prospective users. This is even more so when attempting to reconcile privacy requirements across different jurisdictions.

It is important to note that discussions between researchers and data custodians about the detail required by researchers were able to identify instances where specific questions could be answered using less sensitive (and more readily disclosable) information. That is, if researchers plan their projects more carefully the need for identifiable data can be reduced in some instances.

Around one third of Data Custodian respondents collected information from other organisations, indicating a potential for Commonwealth legislation to have a noticeable impact upon data management practices. Surprisingly, despite some reported concerns about obtaining consent from individuals whose information is contained in their datasets, only around one third of Data Custodian respondents reported the routine use of signed consent forms allowing the release of health information for research purposes or for other treating health professionals.

Almost all Data Custodian respondents reported disclosing information to other organisations, and around 80% of these reported disclosing information to Commonwealth agencies or other national level organisations. Notably, one in three of those custodians who disclosed information were from State/Territory agencies, further underscoring the potential for Commonwealth legislation to have a noticeable impact upon data management practices. Consistent with verbal reports during the conduct of the assignment, many Data Custodian respondents disclosed information that was considered to be de-identified prior to disclosure thereby complying with the National Privacy Principles.

Specific issues about privacy

Data Custodian respondents generally believed the risk to privacy of individuals resulting from disclosure of information was low. Some support for this perception was found by the recollection of only one adverse incident attributed to breach of privacy.

A moderate to high level of knowledge about privacy was reported by Data Custodian respondents. This appears consistent with the occupational requirements of these individuals. Surprisingly around one in ten Data Custodian respondents did report their level of knowledge to be low, prompting cause for concern and a need for ongoing educational initiatives to update and refresh privacy awareness and knowledge rather than assuming that database managers will automatically understand privacy issues.

Organisational requirements to observe privacy of health information contained in datasets were most commonly applied to data management practices, followed by professional requirements and then legislative requirements. This may reflect the level of local knowledge of Data Custodian respondents and not necessarily reflect the degree of legislative consideration that may have applied to the development of local policies and procedures.

It was encouraging to note that most Data Custodian respondents (80%) had *considered* Commonwealth privacy legislation when disclosing information to external sources and had a high level of awareness of the Commonwealth Privacy Act, the role of HRECs, and the need to consider different legislation depending upon the agencies involved in the disclosure of health information. Knowledge of specific differences between the privacy principles applying to Commonwealth agencies and private sector organisations was somewhat lower. Similarly, knowledge of the difference between guidelines written to clarify differences between Commonwealth and private sector agencies was also comparatively lower than general awareness of the legislation.

These results imply that Data Custodian respondents were utilising other sources of information to assist in determining specific privacy issues, rather than relying on the legislation or interpretive guidelines themselves. The use of State/Territory agencies by Data Custodian respondents to obtain information about privacy provides further evidence suggesting that other (possibly more specialised) staff were used to make key privacy-related decisions. Interestingly, only half of the Data Custodian respondents reported turning to the Office of the Federal Privacy Commissioner or the NHMRC guidelines as sources of information about privacy, indicating greater scope for education and encouragement to use these sources.

Almost half of the Data Custodian respondents reported changing their work practices to accommodate the Commonwealth privacy legislation. The development of policies, procedures, publications, and the increased frequency of education about privacy were the most commonly reported changes to work practices. Although this indicates that the legislation has increased awareness and had some “bite” amongst Data Custodian respondents, it also suggests an increase in administrative burden, particularly associated with increased requirements for education of both data custodians and data users.

General attitudes towards privacy

Although many approved of access to health information by researchers, the majority of Data Custodian respondents did not feel that this access should be granted automatically, implying that some level of scrutiny should be applied to all occasions of data access. Many Data Custodian respondents considered that the rigorous application of privacy guidelines could impede research, and were unsure if the current framework was striking the right balance between the rights of individuals and the facilitation of effective health research. Despite this lack of surety, Data Custodian respondents did perceive that HRECs were appropriately considering this balance. Other Data Custodian respondents reported experiencing an increased administrative burden associated with applications to HRECs in order to appropriately address privacy issues.

Importantly, where legislation had been operating for a period of time at a Commonwealth or State/Territory level, Data Custodian respondents reported a clear level of knowledge about their duties and requirements under the respective legislation, and minimal problems with privacy issues. These reports suggest that with increased time, and a building of awareness and knowledge, specific issues that are perceived to be associated with Commonwealth legislation may reduce.

In general, Data Custodian respondents endorsed the view that there were more positive than negative outcomes from the Commonwealth privacy legislation. Although a higher level of administrative burden was perceived to have resulted from the Commonwealth privacy legislation, many Data Custodian respondents perceived that the legislation afforded greater consistency between different jurisdictions, clearer boundaries for decision making, and greater protection of individual rights. These benefits demonstrate a balanced consideration of the legislation from data custodians in the field.

Specific attitudes towards privacy

Privacy issues were perceived to have become more complex over the past two years and required more time to be spent by Data Custodians. This was unsurprising, given the additional legislative activities underway in many State/Territory jurisdictions as well as the introduction of the 2001 Amendments to the Commonwealth Privacy Act (1988). Attitudes about the importance of HRECs were also understandable. Where relevant, HRECs were generally seen to be very important in approving requests for release of information to external organisations.

Surprisingly, most Data Custodian respondents were unable to ascertain a clear benefit or disadvantage of the Commonwealth privacy legislation upon health care or health care research. Although these findings may reflect an early picture of uncertainty, they may equally reflect a limited awareness or

knowledge of the full impact (positive or negative) of the Commonwealth legislation, upon which data custodians could base any judgement. By contrast, most Data Custodian respondents reported that the Commonwealth legislation had a positive impact upon the protection of individual privacy. Again, however, this may reflect a conceptual knowledge of the intended impact of the legislation rather than any specific levels of awareness per se.

A clear majority of Data Custodian respondents felt that it was acceptable for researchers to access and match health information, underscoring the importance of these activities to improving public health. Many also approved of the use of unique numbers rather than names to code and access health information.

Conclusions

Many Data Custodian respondents are involved in disclosure of information to external sources, and report considering the Commonwealth privacy legislation as a guide to the collection, use and disclosure of information. Although Data Custodian respondents are aware of the key aspects of the Commonwealth privacy framework, they rely mainly upon local guidelines and professional obligations to understand privacy issues, and seek advice from their peers when required. Local policies and procedures are often developed under the auspices of specific State (or Commonwealth statutory authority) legislation, which may or may not have been informed by the Commonwealth Privacy Act.

Based upon the responses to the survey, it appears that the current privacy framework is working in an adequate manner. There is no doubt that changes in privacy legislation are impacting upon the work practices and everyday work culture of Data Custodian respondents. However, no issues relating to specific aspects of the Commonwealth Privacy Act were identified. Rather, ongoing issues surrounding the interpretation of the Act were evident.

Importantly the Commonwealth Privacy Act was considered by Data Custodians when making decisions about privacy. It was also seen as a driver toward greater consistency in privacy legislation, if not directly applicable in all circumstances.

7. Members of Human Research Ethics Committees (ST6)

This report documents the results of consultations with a stakeholder group of Human Research Ethics Committee members (Study 6). Consultations were undertaken via an on-line (Internet) survey.

Sample of HREC Respondents

Members of all Human Research Ethics Committees registered with the NHMRC were invited to participate in the survey. A total of 132 HREC members agreed to participate and 80 HREC members responded to the survey, yielding a response rate of 61%.

Survey results are not claimed to be representative of the population of HREC Members. They are indicative of attitudes toward and experiences of privacy issues.

HREC respondents had substantial experience as members of the Ethics Committee – five years on average. There was a good spread of HREC respondents across the categories that were required to make up HRECs. They were mainly from universities (40%) and public hospitals (33%), although a range of other organisations was included.

Awareness and knowledge of privacy legislation

HREC respondents rated their knowledge of privacy issues as moderate to high.

The main sources of privacy information for HREC respondents were:

- NHMRC guidelines (84%);
- HRECs themselves (79%);
- Work colleagues (61%); and
- Professional workshops (60%).

A minority of HREC respondents use State or Territory government agencies, the Commonwealth Privacy Commission and the Internet. Lawyers were mentioned infrequently (4%).

HREC respondents generally considered that they were well supported by their institution, although the level of support for privacy matters was lower than support for their general committee role and procedures. One in ten HREC respondents reported that institutional support regarding privacy legislation was confusing; up to two in ten indicated they did not receive any support but would have liked the support.

At least half of the HREC respondents were aware of all key aspects of privacy legislation. However, awareness of the *details* of privacy principles, Section 95 and Section 95A was lower.

At least half of the HREC respondents were also aware that an HREC can approve disclosure of health information by a Commonwealth department or a private sector organisation to a researcher where individual consent has not previously been given, and that organisations holding health information are not obliged to follow the recommendations of an HREC.

Applying the privacy legislation

While the Commonwealth Privacy Act was commonly used as a guide to best practice, three in ten HREC respondents did not know if specific aspects of the Act had been applied.

Between one third and two thirds of HREC respondents were unsure when to apply Commonwealth and State/Territory privacy legislation.

Three in ten HREC respondents did not know if their HREC has applied any State or Territory legislation or regulations to determine privacy issues relevant to a research submission.

Seven in ten HREC respondents indicated that interpretation of privacy legislation has caused problems for their HREC when evaluating submissions.

Just over half (56%) of HREC respondents indicated that over the past two years research submissions involving screening medical records for recruiting research participants have required clarification by their HREC because of privacy issues.

Around five in ten HREC respondents indicated that the following type of research submissions required clarification:

- Research involving linking databases (51%);
- Clinical trials (48%);
- Epidemiology studies (46%);
- Genetic research / family studies (45%); and
- Survey based research (45%).

Just under one in five (16%) HREC respondents indicated that permission was withdrawn for a research project because of privacy issues in the past two years.

Few HREC respondents (9%) considered approval by another HREC as sufficient for approval for their own HREC for multi-centre research.

General attitudes towards privacy

There was strong disagreement by HREC respondents with any notion of automatic access by researchers or health professionals to health information.

HREC respondents agreed on the importance of linking health information, generally disagreed that the privacy framework is compromising the scientific integrity of research but were mixed about whether the right balance between protecting the rights of individuals and enabling effective health research had been struck.

There were mixed views on whether legal representatives on HRECs were the major contributors to decisions about privacy and whether researchers demonstrated a good understanding of privacy legislation. There was strong agreement that there are too many different laws affecting privacy.

HREC respondents considered that the balance of research benefits against individual privacy was ALWAYS considered and disagreed that HRECs were more concerned about preventing litigation than fostering research. There were mixed views about whether ALL research participants should be required to give informed consent before approval was granted and whether privacy was put ahead of facilitating research.

Specific attitudes towards privacy

Eight in ten HREC respondents indicated that privacy issues had become more *complex* over the past two years.

Eight in ten HREC respondents also indicated that the *time* they spent on privacy issues increased over the past two years.

Half of the HREC respondents were unable to report a clear positive or negative impact of the Commonwealth privacy legislation upon health research and health care. Two in three HREC respondents reported a positive impact of the Commonwealth privacy legislation upon the protection of individual privacy.

Two in three HREC respondents considered data linkage by *approved* researchers to be acceptable. The proportion of HREC members approving data linkage increased to nine in ten when only unique numbers (rather than names) were used for data linkage. Only one in ten considered a system of unique protected numbers unacceptable.

Scenarios

While slightly more consider that Commonwealth privacy legislation *would* allow researchers to access health records in order to match data without consent, a greater proportion of HREC respondents considered the legislation *should* allow data matching to occur (although a substantial minority disagreed).

While slightly less consider that Commonwealth privacy legislation *would* allow for researchers to access contact information of grant recipients in order to recruit them for research without consent, a greater proportion of HREC respondents considered the legislation *should* allow the researcher to have the data (although a substantial minority disagreed).

While a minority considered privacy legislation *would* allow GPs to access health records to improve the coordination of medical services without the active consent of the patient, a similar proportion were unsure. HREC respondents were equally divided about whether GPs *should* have access to this data.

There was a mixed view as to whether the Commonwealth privacy legislation *would* allow health care providers to disclose health information of one party to another without consent, but a clear majority considered health care providers *should* be allowed access and that the interest in preventing harm outweighs the protection of individual privacy.

There was a clear majority of HREC respondents who were of the view that HRECs *would* not and *should* not permit researchers to access health records in order to recruit people for research without consent, and that the public interest in improving health outcomes in this instance does not outweigh the consumers' right to privacy.

Main privacy issues

HREC respondents provided considerable detail about the privacy issues that they had to deal with as a member of an HREC. These included:

- The historical context.
 - It was noted that HRECs had been dealing with privacy issues before the recent changes to the Privacy Act.
- HRECs' focus on protection of individuals through ensuring consent and in ensuring that appropriate procedures are put in place for storage of health information.
- There were grey areas that were difficult. Issues of identifying research from Quality Assurance were raised.
- De-identification of health information was important to protect research participants. This was particularly difficult in small rural communities.

- Balancing public good of research against privacy and not compromising scientific integrity with S95 and S95A working well (although at least one would like to see these provisions extended to non-medical research).
- Divergent views on streamlining approval for multi-centre studies were expressed.
- The administrative burden created by privacy legislation and the problems associated with legislative complexity were dominant themes.
- Solutions.
 - HREC respondents commented on the arbitrary nature of being employed by an organisation to gain access to health information with some researchers taking posts to meet disclosure principles.
 - Others emphasised the need for better planning by researchers so that they did not collect identifiable information unnecessarily and to limit disclosure of sensitive information.

Benefits of the privacy legislation

More than half of the HREC respondents indicated that the Commonwealth privacy legislation had resulted in:

- Clearer boundaries for decision making (70%);
- Greater protection of individual rights (63%); and
- More consistency between different states or jurisdictions (55%).

One in ten HREC respondents indicated that there had been *no benefits* arising from the Commonwealth privacy legislation.

Difficulties of the privacy legislation

Six in ten HREC respondents reported increased administrative burden and over four in ten reported increased difficulty or confusion in trying to interpret the legislation.

Two in ten HREC respondents indicated that there had been *no difficulties* arising from the Commonwealth privacy legislation.

Conclusions

HREC respondents consider themselves to have a moderate to high level of privacy knowledge. However, there is a lack of detailed understanding for a minority of members. Up to three in ten have either not received support from their institution or have found the information provided confusing. There was also a substantial proportion who was unsure when to apply different legislations.

Overall HREC respondents consider privacy has become more complex and time consuming with a divergent range of views emerging. The scenarios identify very mixed perceptions of what is currently permitted and what should be permitted.

One clear position is that HREC respondents consider themselves to be autonomous bodies with little support for rationalisation of decision making in the case of multi-centre trials.

Overall the legislation is considered to benefit privacy of individuals while HREC respondents have mixed or uncertain views regarding the impact on research and health care.

With privacy being only one role of the HRECs, the findings of this research support the need for more support in the form of interpretive guidelines and consistency in legislation to simplify the work of HREC members.

8. Peak Bodies (ST7)

Approach

This report documents the results of consultations with Peak Body Representatives (Study 7). Consultations were undertaken via an on-line (internet) survey.

Sample of Peak Body Representatives

An invitation to participate in the survey was sent to 306 Peak Bodies representing health care professionals, consumers, researchers and government. 51 Peak Bodies (hereafter, 'Peak Body respondents') responded to the survey, yielding a response rate of 17%.

Most Peak Body respondents were CEOs or other executive officers who had been working for the Peak Body for an average of five years and with privacy issues for an average of nine years.

Half the Peak Body respondents represented health professionals with the remainder distributed between health consumer organisations and those representing researchers.

Survey results are not claimed to be representative of the population of Peak Bodies. They are indicative of attitudes toward and experiences of privacy issues.

Awareness of and access to privacy legislation

Half the Peak Body respondents rated their organisation's knowledge about privacy issues as high, or very high.

Almost half of the Peak Body respondents indicated that their organisation had developed specific guidelines on privacy for its members.

Peak Body respondents most frequently indicated that their members became aware of Commonwealth privacy legislation through publications (41%) such as newsletters and electronic publications. Other sources of awareness included:

- Internet (16%);
- Word of mouth (16%); and
- Workshops and seminars (14%).

Half of the Peak Body respondents reported some difficulties in determining how Commonwealth privacy legislation applies to members.

Almost all Peak Body respondents were aware of general aspects of privacy legislation, including:

- The Commonwealth Privacy Act (1988) that applies to public agencies (90%);
- The Amendment (2001) to the Commonwealth Privacy Act (80%); and
- The role of Human Research Ethics Committees (79%).

Around seven in ten Peak Body respondents were aware of more specific privacy requirements such as:

- The need to consider different legislation depending upon the agencies involved in disclosure of health information (73%);
- The privacy provisions of individual States/Territories (68%);
- The 11 Information Privacy Principles for Commonwealth agencies (67%); and
- That individual statutory authorities may have their own privacy provisions (59%).

Fewer Peak Body respondents were aware of usage of privacy guidelines such as:

- The use of Section 95A Guidelines (41%); and
- The use of Section 95 Guidelines (30%).

Few were aware of the difference between Section 95 and Section 95A guidelines (24%).

Compromising privacy

The majority of Peak Body respondents were not aware of a situation where a compromise of privacy had resulted in harm to members of their organisation.

Few Peak Body respondents were aware of any instances where problems have occurred for any of their members as a result of health information being disclosed in either a public or private sector organisation. Specific examples were few. They included:

- Release of health information to employers;
- Members being contacted by marketing organisations; and
- Consumers being contacted by the HIC.

Changes in work practices

Peak Body respondents reported that a range of procedures had to be changed as a result of Commonwealth privacy legislation over the past two years:

- The majority (77%) reported that they had changed their documentation and policy procedures;
- Around six in ten reported that they had changed their data management practices (63%) and/ or staff induction procedures (62%);
- Five in ten reported they had changed their complaints handling (54%) and/ or monitoring (46%) procedures; and

Two in ten reported that they had not changed anything (18%), or that the question did not apply to them (19%).

General attitudes towards privacy

Peak Body respondents generally agreed that:

- People who benefit from a publicly-funded health system should be automatically eligible to be INVITED to take part in publicly-funded health research (64%);
- Linking health information is important to determine the effectiveness of treatments (94%); and
- The rigorous application of privacy guidelines has a danger of impeding health research which would otherwise be judged ethically acceptable (57%).

There was no clear pattern of response for the other attitudinal statements, with a fairly even distribution of agreement and disagreement, or a relatively high proportion of Peak Body respondents indicating that they neither agreed nor disagreed.

Specific attitudes to privacy

The majority of Peak Body respondents reported that privacy issues had become more complex in the past two years, and that the amount of time they had to spend on privacy issues had increased.

The majority of Peak Body respondents did not know whether Commonwealth privacy legislation had had a negative or positive impact on *health research* and the *provision of health care* in Australia, or reported that the legislation had mixed impacts.

In contrast to the provision of health care and research, over half of Peak Body respondents reported that Commonwealth privacy legislation had a good impact on *protecting the privacy of individuals*.

Most Peak Body respondents indicated that it is acceptable:

- For researchers to *access* (77%) and *match* (73%) information from databases;
- For researchers to access health information from databases where records are identified by a unique number rather than a name (89%); and
- To use a system of unique protected numbers rather than names used to code health information for all Australians (75%).

Main privacy issues

The range of privacy issues that Peak Bodies respondents have had to deal with included:

“the release of health information, confidentiality of health records, maintaining privacy in the electronic environment, keeping abreast of current legislation both Commonwealth and state driven.”

The dominant issue for Peak Bodies respondents is the release of information about members. Where the Peak Body represented consumers, the Peak Body was able to work within the privacy framework through appropriate consent and de-identification processes. Issues about exchange of information between health professionals were mentioned but no substantial experiences were documented.

The restriction of disclosure of health information to family members of consumers was identified as a potential source of harm for consumers by one Peak Body respondent. Another emphasised the benefit of consumer access to health information enabled by the privacy legislation.

Organisations have also been faced with having to develop policies for members to manage their role as data custodians and ensure the confidentiality of electronic information. The difficulty of protecting individual privacy in a small community was also mentioned.

Privacy Issues Affecting Aboriginal and Torres Strait Islander Peoples

General privacy issues affecting Aboriginal and Torres Strait Islander peoples include: encroachment of community consent/opinion through academia; unfettered access to data and irresponsible use of data without approval; and identification of Aboriginal communities through small samples. Suggestions to address these privacy issues included respecting and complying with the position of NACCHO in relation to all research in Aboriginal health, and having a process of regular monitoring and reporting of privacy compliance to parliament. Review by Aboriginal Health Research Ethics Committees was considered by organisations representing Aboriginal and Torres Strait Islander community to be essential to maintain respect for privacy and ethical research.

Benefits of the privacy legislation

Peak Body respondents reported a range of benefits arising from the Commonwealth privacy legislation for their members, including:

- Greater protection of individual rights (40%);
- More consistency between different states or jurisdictions (22%); and
- Clearer boundaries for decision making (20%).

22% of Peak Body respondents reported no benefits.

Difficulties of the privacy legislation

Peak Body respondents reported a range of difficulties arising from the Commonwealth privacy legislation for their members, including:

- Increased administrative burden (35%);
- Greater confusion about decision making (27%);
- Limited use of existing data (25%);
- Delays in service delivery (15%); and
- Increased cost of operation (10%).

17% of Peak Body respondents reported no difficulties.

Suggestions to improve the current system

The majority of Peak Bodies respondents had no suggestions to improve difficulties. The most commonly mentioned suggestions entailed development of guidelines, support and education.

Conclusions

The experienced executives who responded to the survey on behalf of professional, consumer and researcher Peak Bodies identified the increasing complexity of the privacy framework as an issue resulting in an increased administrative burden. Some were able to identify substantial breaches of privacy on behalf of their members. The impact of the Commonwealth privacy framework on the delivery of health services or the conduct of research was either mixed or unknown while the impact on protecting individual privacy was known.

The key issues for Peak Body respondents focused on policy development and working within the current privacy framework. In some instances harm associated with disclosure (or non-disclosure) of health information were identified but the bulk of respondents identified the issues of dealing with complexity of compliance.

The great majority were unable to identify suggestions for managing difficulties. Any suggestion focused on development of guidelines, education and provision of support mechanisms.

9. Comparing Stakeholder Perspectives (ST8)

9.1 This report

Each of the seven stakeholder studies was designed as a stand alone study addressing objectives specifically tailored to the stakeholder group. While not all elements of the privacy framework apply to every stakeholder group, many apply to a number of different stakeholders. In order to identify the differences between stakeholder perspectives, the survey instruments were designed, where possible, to include the same, or similar, questions.

The following section of this report presents comparative perspectives of the privacy framework for:

- Self-rated knowledge of privacy issues;
- Sources used to obtain information about privacy issues;
- Awareness of specific aspects of the privacy legislation;
- Attitudes toward:
 - obtaining consent for research,
 - access to health information by health professionals and researchers,
 - moral obligations of consumers to provide access to health information when they receive publicly funded services,
 - the impact of privacy legislation on health services and research (including data linkage),
 - the balance between privacy and research,
 - the influence of litigation on HRECs;
- Perception of changes in the complexity and administrative burden of privacy compliance; and
- The impact of privacy regulation on health research, health services and individual privacy.

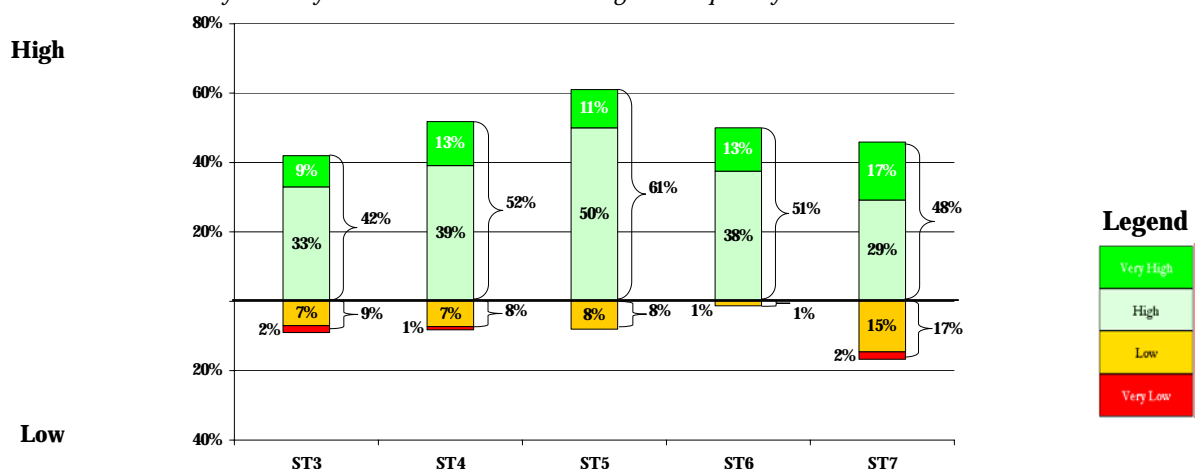
9.2 Awareness of and access to privacy legislation

9.2.1 Knowledge of privacy issues

There were similar levels of self rated knowledge about privacy issues for all stakeholder respondents (Figure 1).

Figure 1: Self-rated level of knowledge

Q. How would you rate your current level of knowledge about privacy issues?



Base: All respondents
 ST3 = 203 ST4 = 112 ST5 = 37 ST6 = 80 ST7 = 51
 Note: Sample sizes require caution when generalising to populations.
 Percentages may not add to 100% because "moderate" is not included.

9.2.2 Sources of information about privacy

Sources of information about privacy were identified using an unprompted question for the CATI survey of medical and allied health professionals and using a prompted question for the self completion on-line surveys of researchers, data custodians and HREC members.

There was a considerable variation between the sources of information about privacy identified by the stakeholder respondents (Table 2). The lower level of use reported in the unprompted questions is a function of the questions. Unprompted responses are always lower than prompted responses.

Table 2: Sources of information about privacy				
<i>Q. How do you personally access information about privacy of health information?</i>				
	ST3¹ Health Professionals (203) Unprompted %	ST4² Researchers (112) Prompted %	ST5² Data Custodians (37) Prompted %	ST6² HRECs (80) Prompted %
NHMRC Guidelines	6	86	49	84
HRECs	3	78	41	79
Conversations with work colleagues	13	66	54	61
State/ Territory Governments or agencies	-	38	65	41
Internet	10	37	22	41
Professional Workshops or seminars	-	34	43	60
Federal Privacy Commissioner	2	28	51	39
Professional publications	10	13	22	14
Professional associations	27	-	-	-
Other sources	18	9	14	11

Note: Percentages may add to more than 100% because of multiple responses.

1 **Unprompted** questions (used in ST3) mean that respondents were not given response options.

2 **Prompted** questions (used in ST4, ST5 and ST6) mean that respondents were given response options. Prompted responses will generally be higher.

Sample sizes require caution when generalising to populations.

There were other differences between the health researcher, data custodian and HREC respondents. Health researcher and HREC respondents identified similar patterns of information:

- NHMRC guidelines and HRECs were the most commonly identified sources followed by work colleagues;
- State/Territory governments or agencies, the Internet and professional publications were identified by equal proportions of both health researcher respondents and HREC respondents; and

- Fewer health researcher respondents than HREC respondents identified professional workshops or seminars and the Federal Privacy Commissioner as sources of privacy information.

Data custodian respondents most commonly identified State/Territory governments or agencies. They were also more likely to identify the Federal Privacy Commissioner and professional publications than health researcher or HREC respondents.

Health professional respondents were most likely to identify professional associations as the source of information about privacy of health information. Other sources identified were work colleagues and the Internet.

9.2.3 Awareness of privacy legislation

There was a considerable variation between stakeholder respondents in awareness of aspects of the Commonwealth privacy framework (Table 3).

Table 3: Awareness of aspects of Commonwealth privacy framework				
<i>Q. Before taking part in this survey, were you aware of any of the following aspects of the privacy framework?</i>				
Specific aspect	ST4 (112) %	ST5 (37) %	ST6 (80) %	ST7 (51) %
The role of Human Research Ethics Committees	98	97	97	79
That individual statutory authorities may have their own privacy provisions	77	88	64	59
The need to consider different legislations depending upon the agencies involved in disclosure of health information	77	91	82	73
The Commonwealth Privacy Act (1988) that applies to public agencies	76	94	92	90
The privacy provisions of individual States/Territories	61	77	70	68
The Amendment (2001) to the Commonwealth Privacy Act	59	82	77	80
The 10 National Privacy Principles for the private sector	44	81	62	74
The 11 Information Privacy Principles for Commonwealth agencies	40	68	68	67
The use of Section 95 Guidelines (Commonwealth)	39	71	63	30
The use of Section 95A Guidelines (private sector)	31	78	57	40
The difference between Section 95 and 95A Guidelines	24	57	53	24
The difference between the Information and National Privacy Principles	20	53	55	43

Note: Percentages may add to more than 100% because of multiple responses. Sample sizes require caution when generalising to populations.

While nearly all health researcher, data custodian and HREC respondents were aware of the role of HRECs, fewer peak body respondents were aware of their role.

Health researcher respondents had similar levels of awareness to peak body respondents, with some differences:

- Health researcher respondents had higher levels of awareness of statutory authorities having their own privacy requirements; and
- Peak body respondents had higher levels of awareness of the NPPs and IPPs.

9.3 General attitudes towards privacy

An additional 13 questions were constructed to identify general attitudes towards privacy and research. Questions were grouped into three categories:

- Obtaining consent to participate in research:
 - Researchers should never be allowed access to medical records unless they have obtained specific consent;
 - Unless an individual chooses to opt out, health professionals who provide them with treatment should have automatic access to their health information;
 - Unless an individual chooses to opt out, approved health researchers should have automatic access to their health information;
 - People who benefit from a publicly-funded health system should be automatically eligible to be INVITED to take part in publicly-funded health research; and
 - Most health consumers would not mind if their names were given to a researcher in order to invite them to participate in health research;
- Impacts of privacy regulations upon the conduct of research:
 - The rigorous application of privacy guidelines has a danger of impeding health research which would otherwise be judged ethically acceptable;
 - The current privacy framework is compromising the scientific integrity of health research;
 - The current privacy framework strikes the right balance between protecting the rights of individuals and enabling effective health research; and
 - Linking health information is important to determine the effectiveness of treatments;
- The operation of Ethics Committees:
 - Ethics Committees have become overly concerned about litigation associated with privacy issues;
 - Ethics Committees appropriately balance the contribution of research to improving healthcare, and the privacy of individuals;
 - Ethics Committees should always put participants' privacy ahead of facilitating health research; and
 - Ethics Committees should be able to approve access of researchers to health information in order to recruit participants for health research.

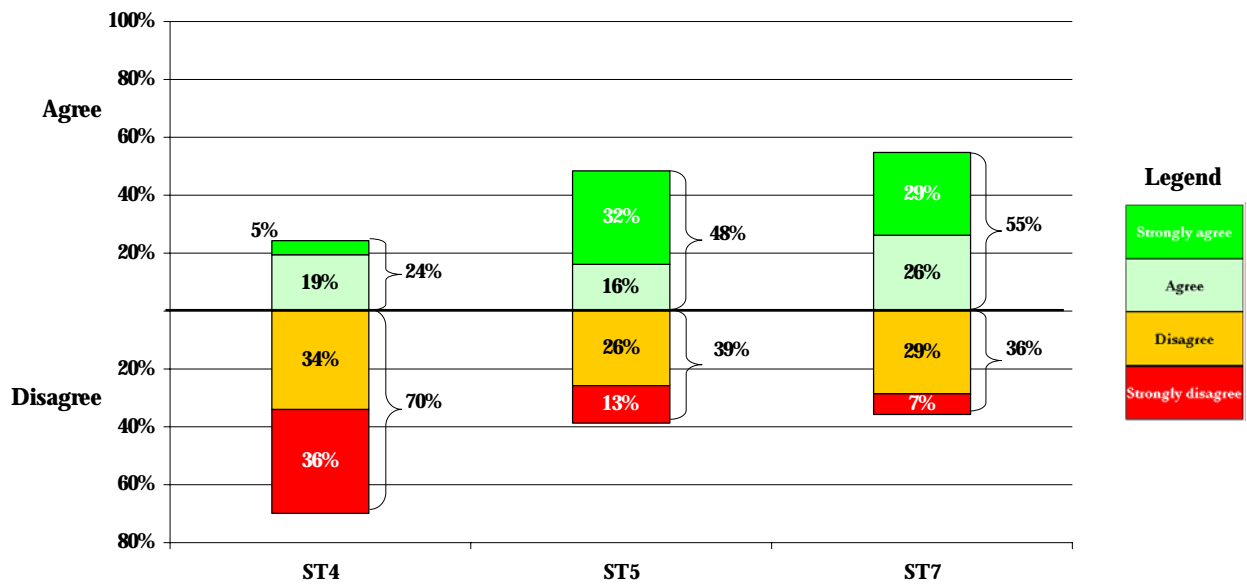
Respondents to the survey were asked to what extent they agreed or disagreed with these statements relating to the confidentiality and use of health information. The comparative responses are reported in the following pages (Figure 2 - Figure 14).

9.3.1 Obtaining consent to participate in research

A high proportion of health researcher respondents had stronger levels of disagreement than both data custodian and peak body respondents in their attitudes about privacy and consent to participate in research. Data custodian and peak body respondents had similar opinions about privacy and consent to participate in research, with the majority agreeing that researchers should never be allowed access without specific consent (Figure 2) or have no clear opinion (neither).

Figure 2: Attitudes about privacy and consent to participate in research

Q. *Researchers should never be allowed access to medical records unless they have obtained specific consent*

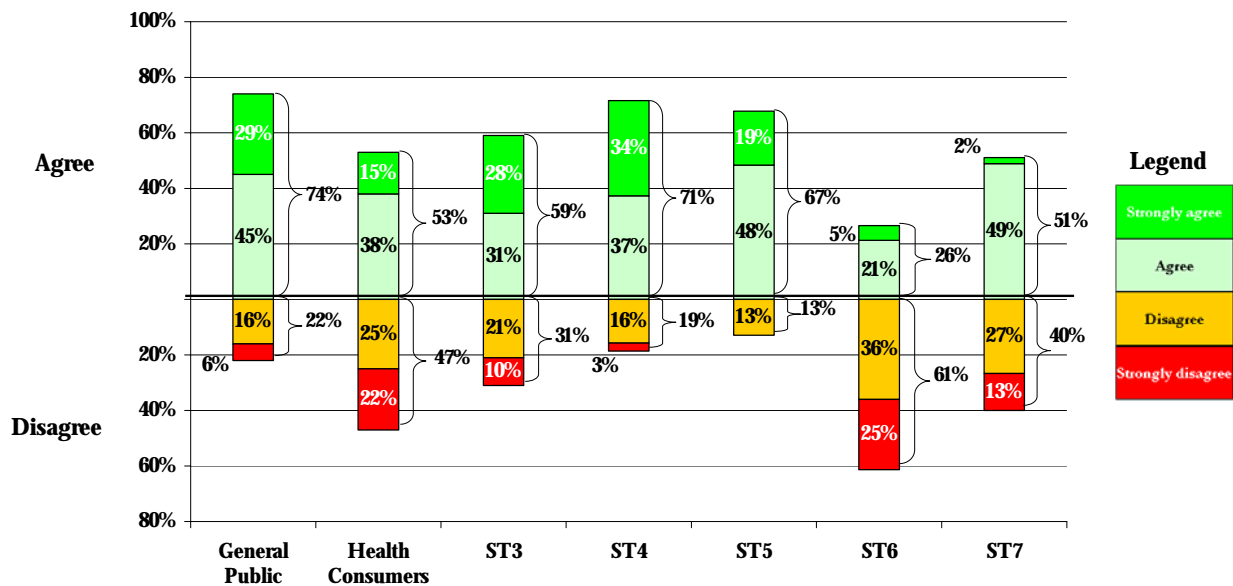


Base: All respondents
 ST4 = 112 ST5 = 37 ST7 = 51
 Note: Sample sizes require caution when generalising to populations.
 Percentages may not add to 100% because "neither agree nor disagree" is not included.

The General Public, health researcher and data custodian respondents had similar views about automatic access to health information by service providers (Figure 3), with greater proportions agreeing that automatic access should be given to *health providers* (unless an individual has opted out). Health Consumer respondents and peak body respondents had similar views about automatic access, with higher levels of disagreement than other stakeholder respondents. HREC respondents had the highest proportion of respondents who disagreed with health professionals having automatic access.

Figure 3: Attitudes about automatic access to information by service providers

Q. *Unless an individual chooses to opt out, health professionals who provide them with treatment should have automatic access to their health information*



Base: All respondents
 General Public = 301 ST3 = 203 ST5 = 37 ST7 = 51
 Health Consumers = 60 ST4 = 112 ST6 = 80

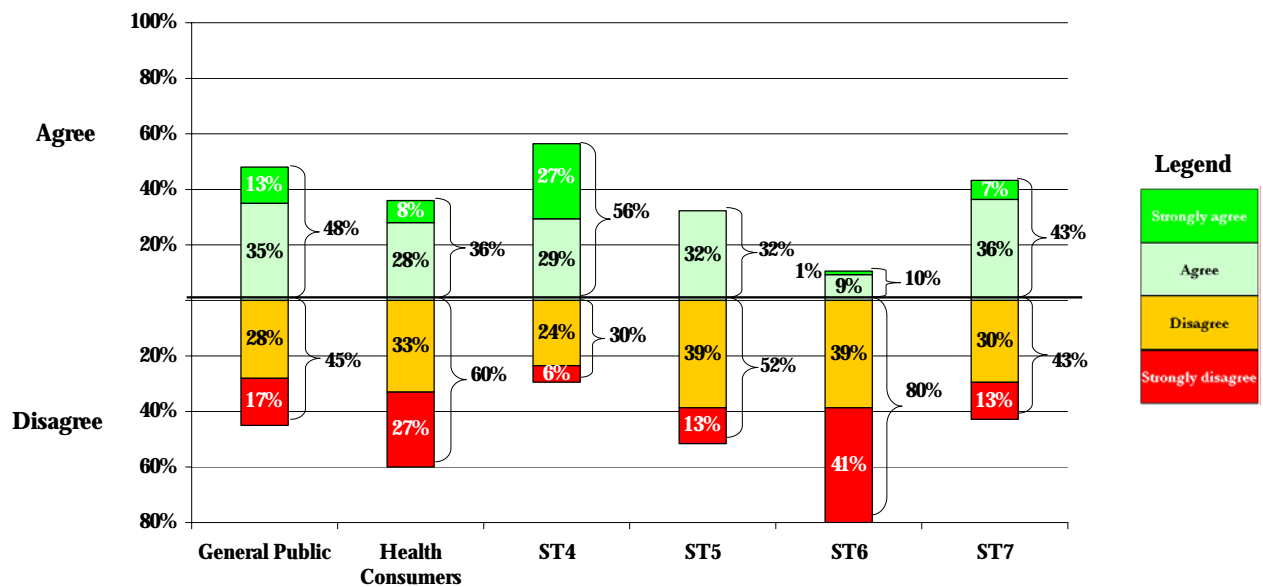
Note: Sample sizes require caution when generalising to populations.
 Percentages may not add to 100% because "neither agree nor disagree" is not included.

A high proportion of HREC respondents strongly disagreed that unless an individual chooses to opt out, automatic access to health information by *researchers* should be allowed (Figure 4). By contrast, health researcher respondents had the lowest level of disagreement among stakeholder respondents. General Public and peak body respondents had similar views to each other, tending to agree as much as they disagree with the provision of automatic access.

Health Consumer and data custodian respondents had similar perceptions, tending to disagree more than agree with the provision of automatic access to health information by researchers.

Figure 4: Attitudes automatic access to information by health researchers

Q. *Unless an individual chooses to opt out, approved health researchers should have automatic access to their health information*



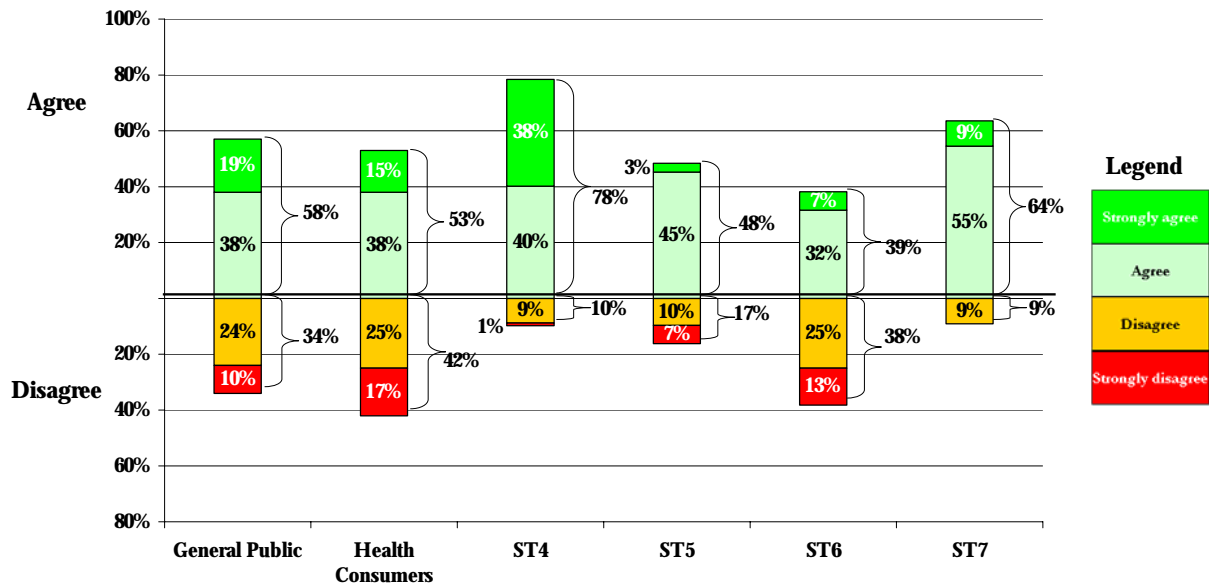
Base: All respondents
 General Public = 301 ST4 = 112 ST6 = 80
 Health Consumers = 60 ST5 = 37 ST7 = 51
 Note: Sample sizes require caution when generalising to populations.
 Percentages may not add to 100% because "neither agree nor disagree" is not included.

General Public, Health Consumer and HREC respondents had similar attitudes toward automatic eligibility of inviting people who benefit from a publicly-funded health system to take part in publicly-funded health research (Figure 5).

Health researcher respondents and peak body respondents had generally similar views about automatic eligibility, with researcher respondents most likely to strongly agree that there should be automatic access.

Figure 5: Attitudes about personal obligations to allow data use

Q. *People who benefit from a publicly-funded health system should be automatically eligible to be INVITED to take part in publicly-funded health research*



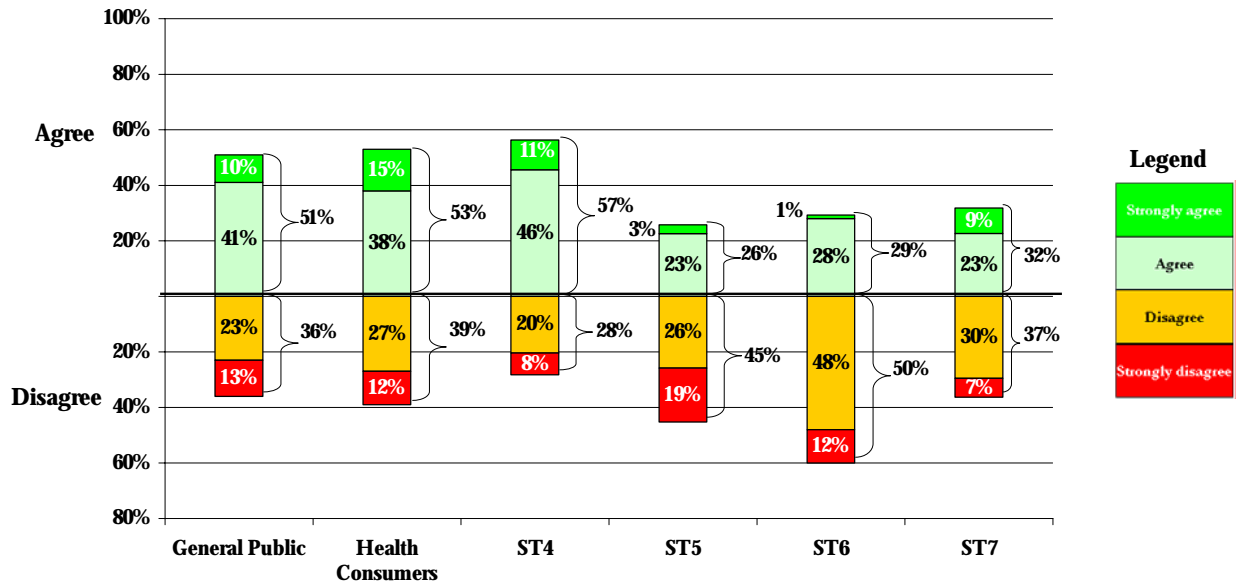
Base: All respondents
 General Public = 301 ST4 = 112 ST6 = 80
 Health Consumers = 60 ST5 = 37 ST7 = 51

Note: Sample sizes require caution when generalising to populations.
 Percentages may not add to 100% because "neither agree nor disagree" is not included.

Data custodian, HREC and peak body respondents were less likely to agree that Health Consumers would not mind their names being given to researchers than the consumer respondents (Figure 6). Health researcher respondents' attitudes were closer to both the General Public and Health Consumer respondents about this issue than the other three stakeholders.

Figure 6: Health consumers do not mind having their names given to researchers

Q. *Most health consumers would not mind if their names were given to a researcher in order to invite them to participate in health research*



Base: All respondents
 General Public = 301 ST4 = 112 ST6 = 80
 Health Consumers = 60 ST5 = 37 ST7 = 51

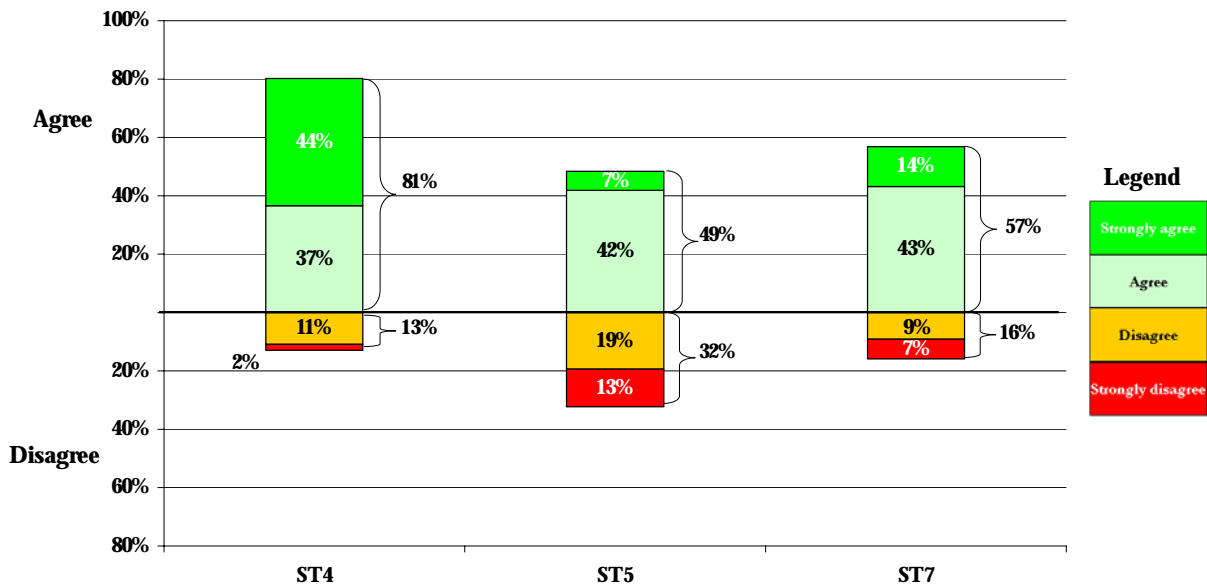
Note: Sample sizes require caution when generalising to populations.
 Percentages may not add to 100% because "neither agree nor disagree" is not included.

9.3.2 Impacts of privacy legislation upon the conduct of research

Health researcher respondents were more likely to strongly agree than data custodian and peak body respondents that the rigorous application of privacy guidelines has a danger of impeding health research which would otherwise be judged ethically acceptable (Figure 7). By contrast, more data custodian respondents disagreed that the rigorous application of privacy guidelines has a danger of impeding research.

Figure 7: Attitudes about privacy guidelines impeding research

Q. *The rigorous application of privacy guidelines has a danger of impeding health research which would otherwise be judged ethically acceptable*

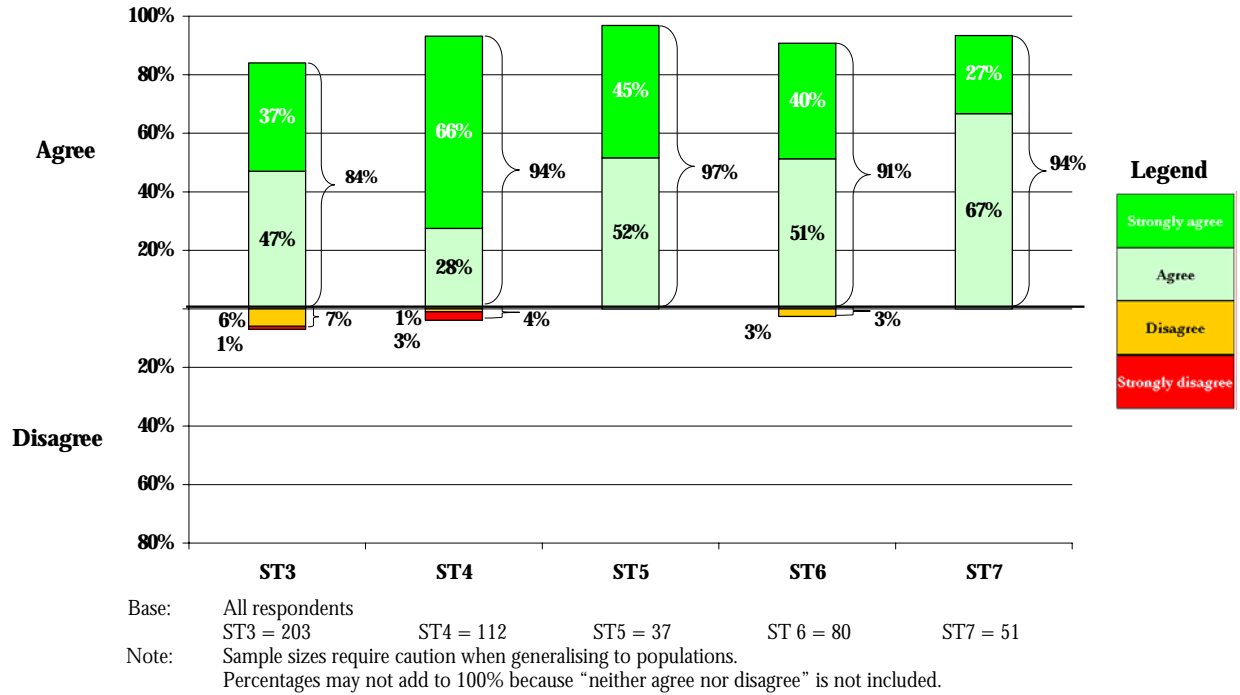


Base: All respondents
 ST4 = 112 ST5 = 37 ST7 = 51
 Note: Sample sizes require caution when generalising to populations.
 Percentages may not add to 100% because "neither agree nor disagree" is not included.

Overall, there were no considerable differences in the attitude of all stakeholder respondents toward the importance of linking health information to determine the effectiveness of treatment (Figure 8). There was clear recognition of the importance of linkage across all stakeholder groups.

Figure 8: Attitudes about linking data

Q. *Linking health information is important to determine the effectiveness of treatment*

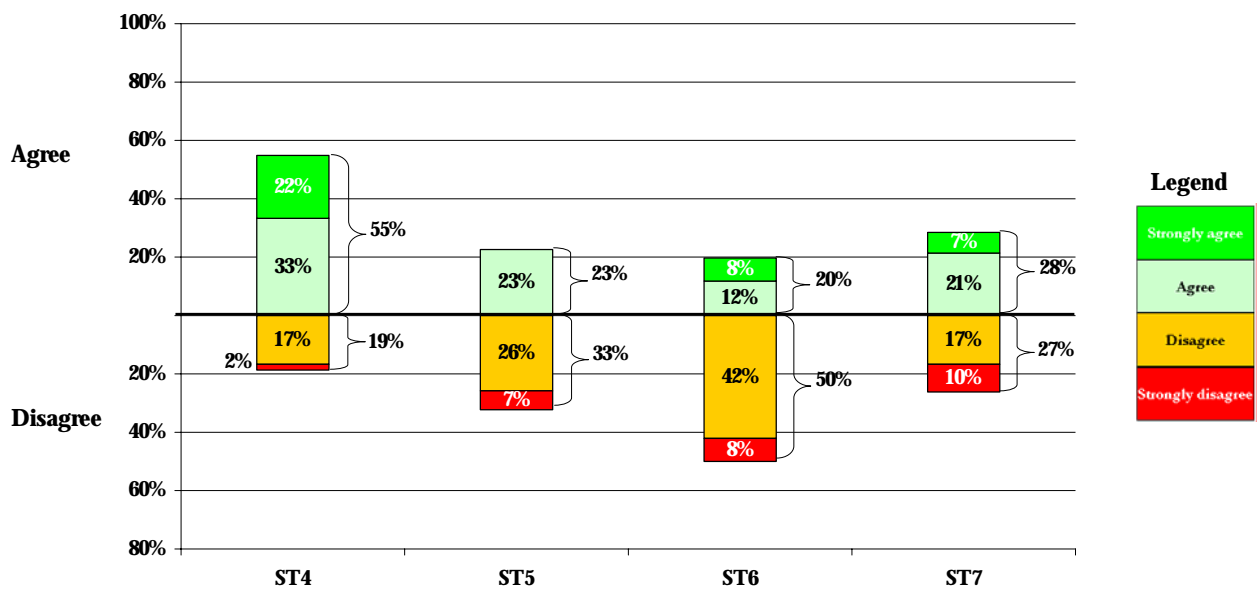


HREC respondents were more likely to disagree than other stakeholder respondents that the current privacy framework is compromising the scientific integrity of health research (Figure 9). In contrast, health researcher respondents were more likely to agree with this view than other stakeholder respondents.

Data custodian respondents and peak body respondents had similar views about the privacy framework compromising scientific integrity, with high proportions neither agreeing nor disagreeing.

Figure 9: Attitudes about privacy regulations and scientific integrity

Q. *The current privacy framework is compromising the scientific integrity of health research*



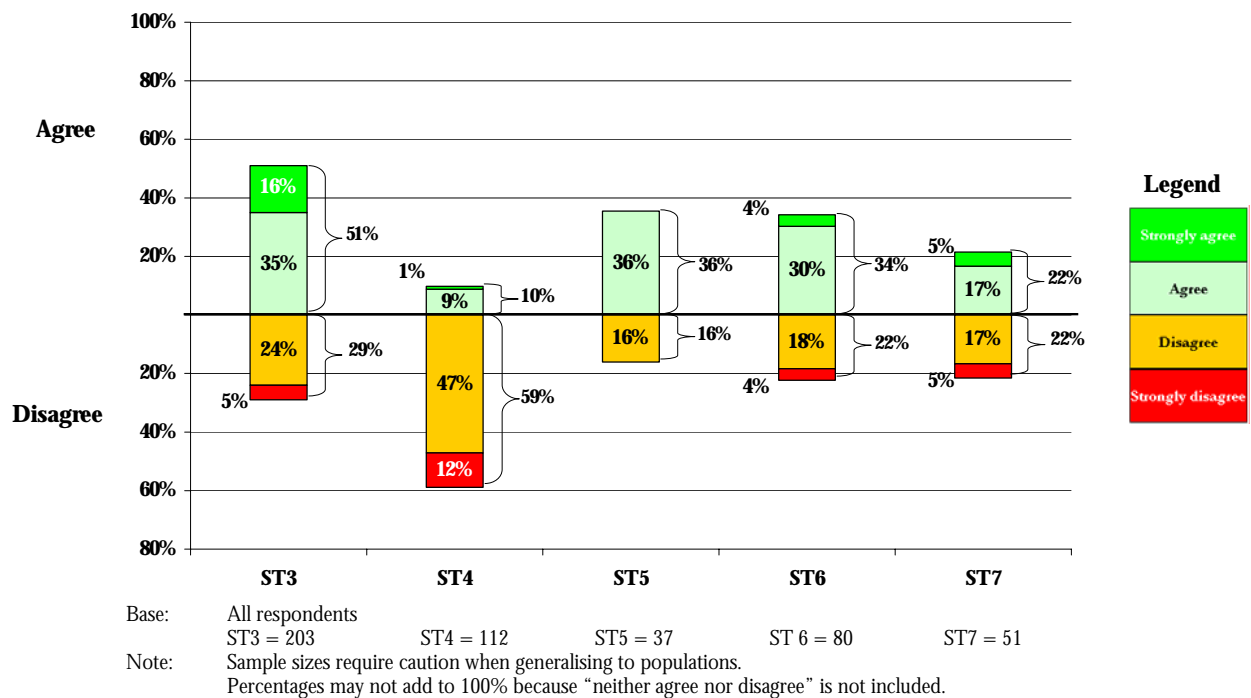
Base: All respondents
 ST4 = 112 ST5 = 37 ST 6 = 80 ST7 = 51
 Note: Sample sizes require caution when generalising to populations.
 Percentages may not add to 100% because "neither agree nor disagree" is not included.

Health researcher respondents were more likely to disagree than other stakeholder respondents that the current privacy framework strikes the right balance between protecting the rights of individuals and enabling effective health research (Figure 10). In contrast, health professional respondents tended to agree that the current framework strikes the right balance.

HREC, data custodian and peak body respondents had similar opinions about the privacy framework striking the right balance between privacy and research, with high proportions neither agreeing nor disagreeing.

Figure 10: Attitudes about privacy framework and the balance between privacy and research

Q. *The current privacy framework strikes the right balance between protecting the rights of individuals and enabling effective health research*

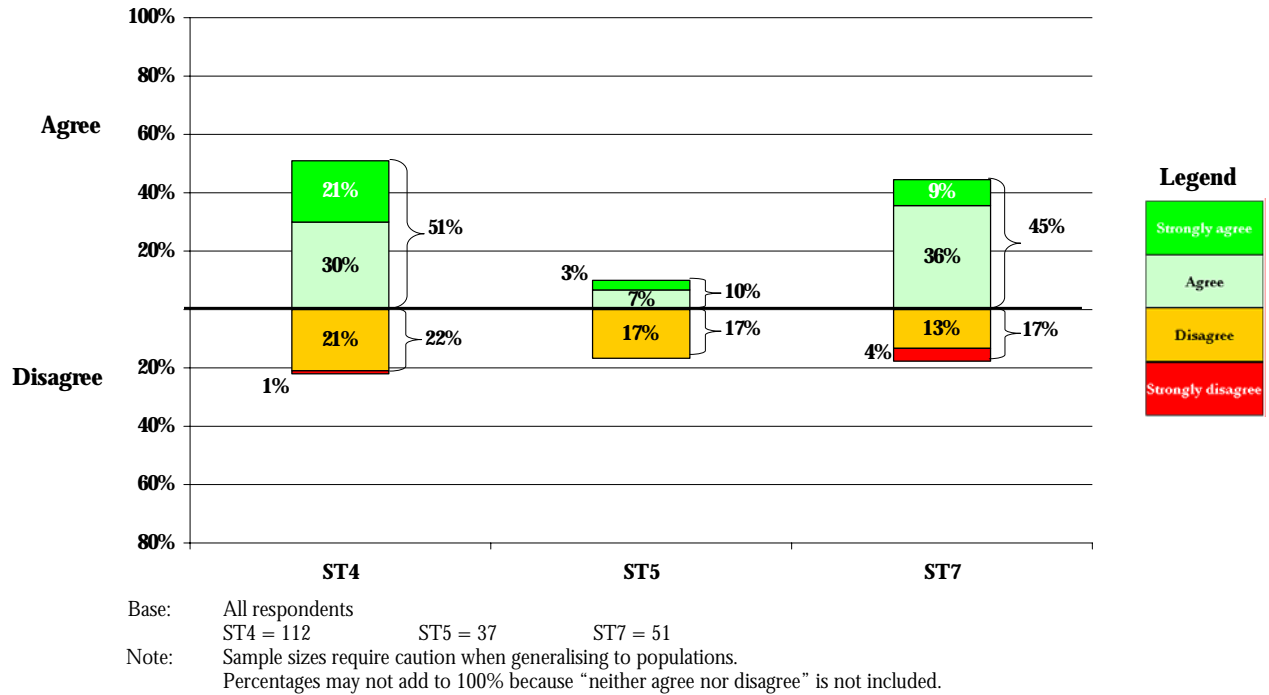


9.3.3 The operation of Ethics Committees

Health researcher respondents and peak body respondents tended to have similar perceptions that the ethics committees have been overly concerned about litigation associated with privacy issues (Figure 11). An overwhelming majority of data custodian respondents neither agreed nor disagreed that Ethics Committees have become overly concerned about litigation.

Figure 11: Attitudes about Ethics Committees and litigation

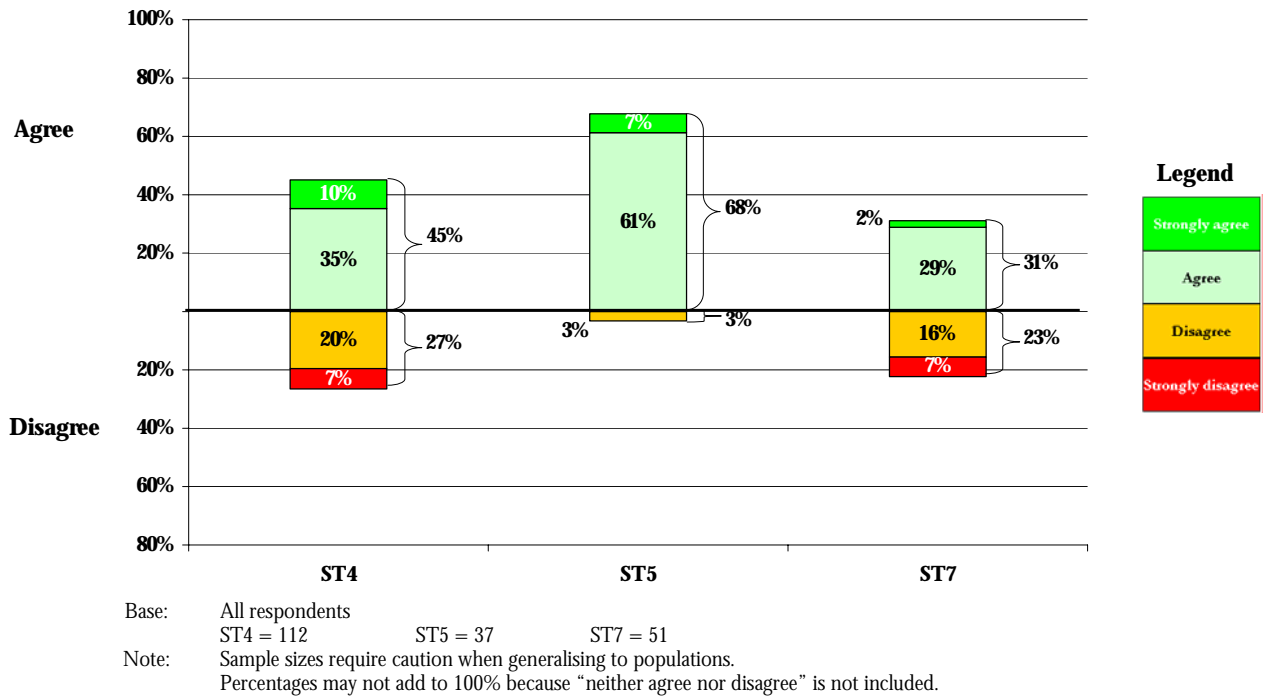
Q. *Ethics Committees have become overly concerned about litigation associated with privacy issues*



Data custodian respondents were most likely to agree that Ethics Committees appropriately balance the contribution of research to improving healthcare with individual privacy (Figure 12). Health researcher respondents and peak body respondents had similar levels of disagreement, while peak body respondents tended to be more likely not to have a clear position than health researcher respondents.

Figure 12: Attitudes about Ethics Committees and balancing demands

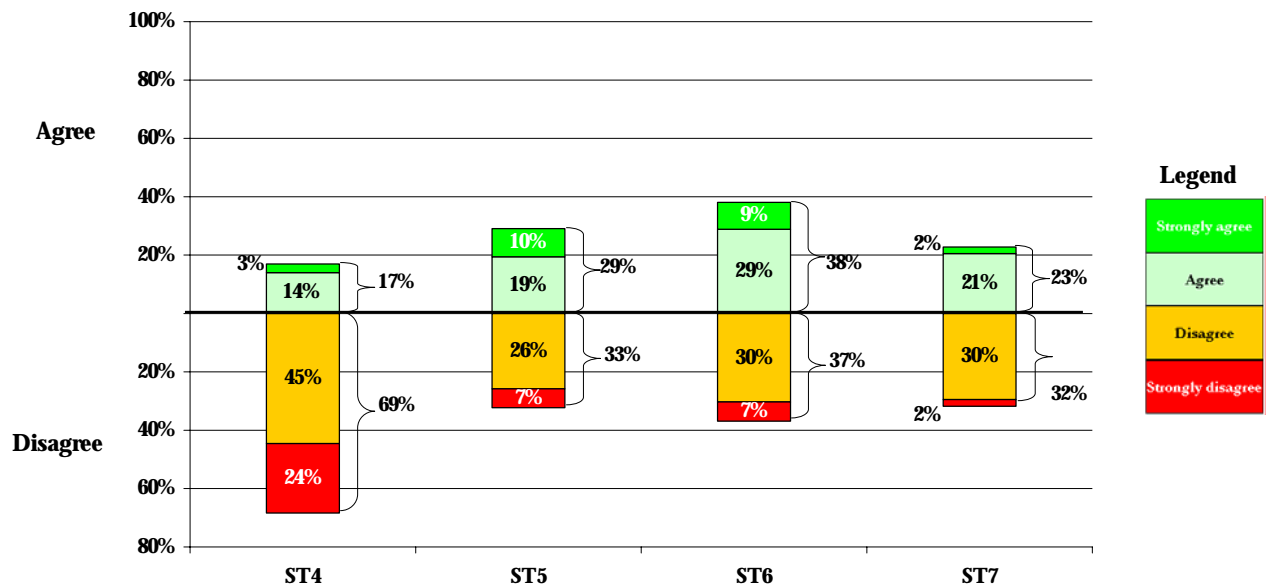
Q. *Ethics Committees appropriately balance the contribution of research to improving healthcare, and the privacy of individuals*



Of all stakeholder respondents, health researcher respondents were more likely to disagree that Ethics Committees should always put participants' privacy ahead of facilitating health research (Figure 13). Data custodian respondents, HREC respondents and peak body respondents had similar attitudes about whether participant privacy should be put ahead of research.

Figure 13: Attitudes about patients' privacy versus research

Q. *Ethics Committees should always put participants' privacy ahead of facilitating health research*

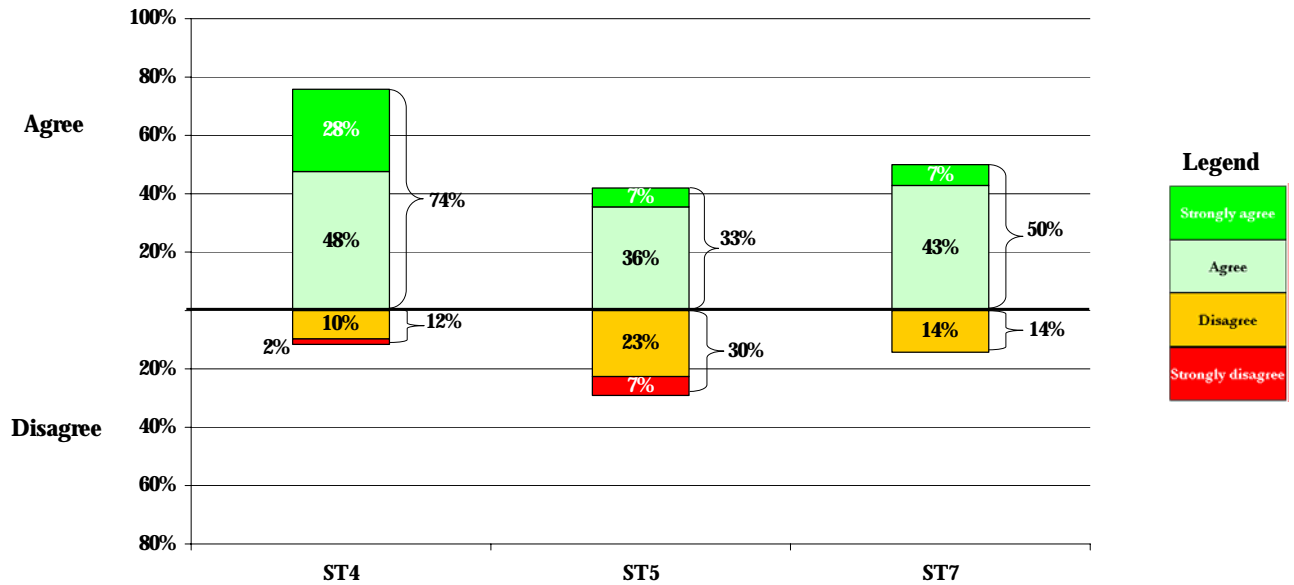


Base: All respondents
 ST4 = 112 ST5 = 37 ST 6 = 80 ST7 = 51
 Note: Sample sizes require caution when generalising to populations.
 Percentages may not add to 100% because "neither agree nor disagree" is not included.

Health researcher respondents were more likely to agree than the other stakeholder respondents that Ethics Committees should be able to approve access to recruit participants for research (Figure 14). By contrast, data custodian respondents were more likely to disagree than other stakeholder respondents that Ethics Committees should be able to approve access to recruit.

Figure 14: Attitudes about Ethics Committees approving access to recruit

Q. *Ethics Committees should be able to approve access of researchers to health information in order to recruit participants for health research*



Base: All respondents
 ST4 = 112 ST5 = 37 ST7 = 51
 Note: Sample sizes require caution when generalising to populations.
 Percentages may not add to 100% because "neither agree nor disagree" is not included.

9.4 Specific attitudes to privacy

9.4.1 The impact of changes in privacy regulation over the past two years

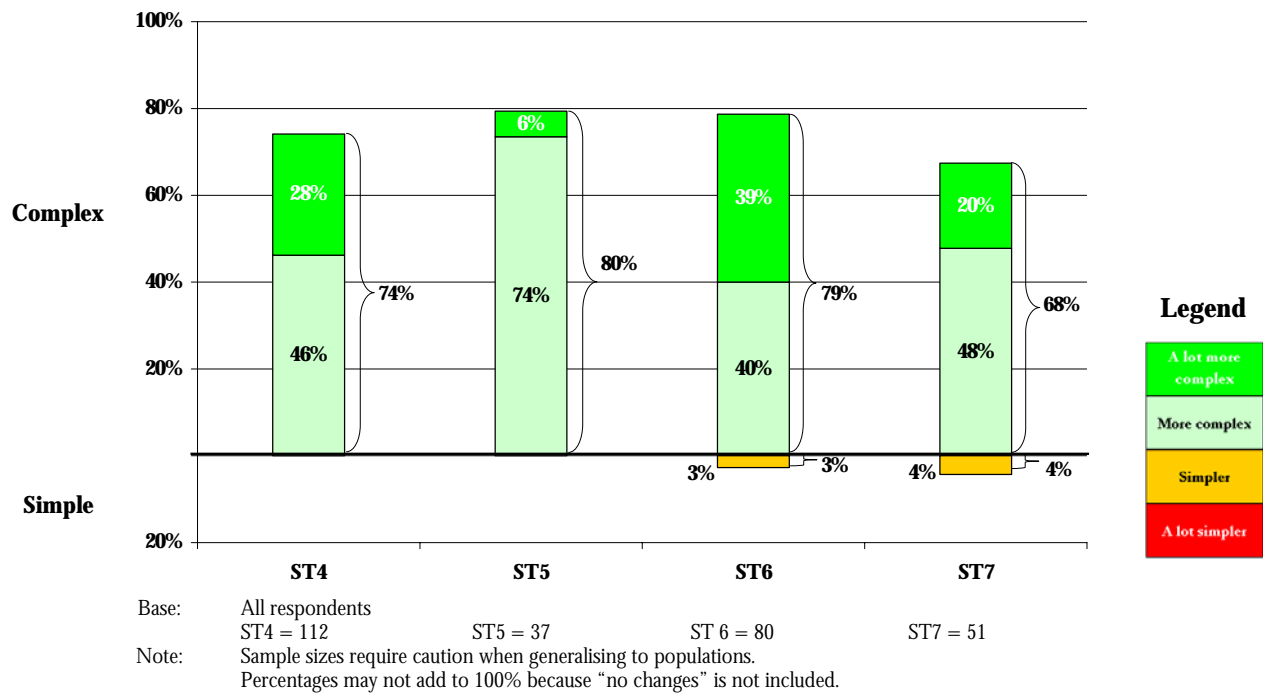
The complexity of privacy issues

The majority of stakeholder respondents agreed that privacy issues had become more complex over the past two years (Figure 15). Very small proportions of peak body and HREC respondents indicated that the privacy issues had become simpler over the past two years.

Data custodian respondents were least likely to indicate that privacy issues had become a *lot more* complex. In contrast, a considerably higher proportion of HREC respondents (39%) indicated that privacy issues had become a *lot more* complex over the past two years.

Figure 15: Changes in complexity of privacy issues

Q. Over the past two years, how would you rate any change in the complexity of privacy issues?

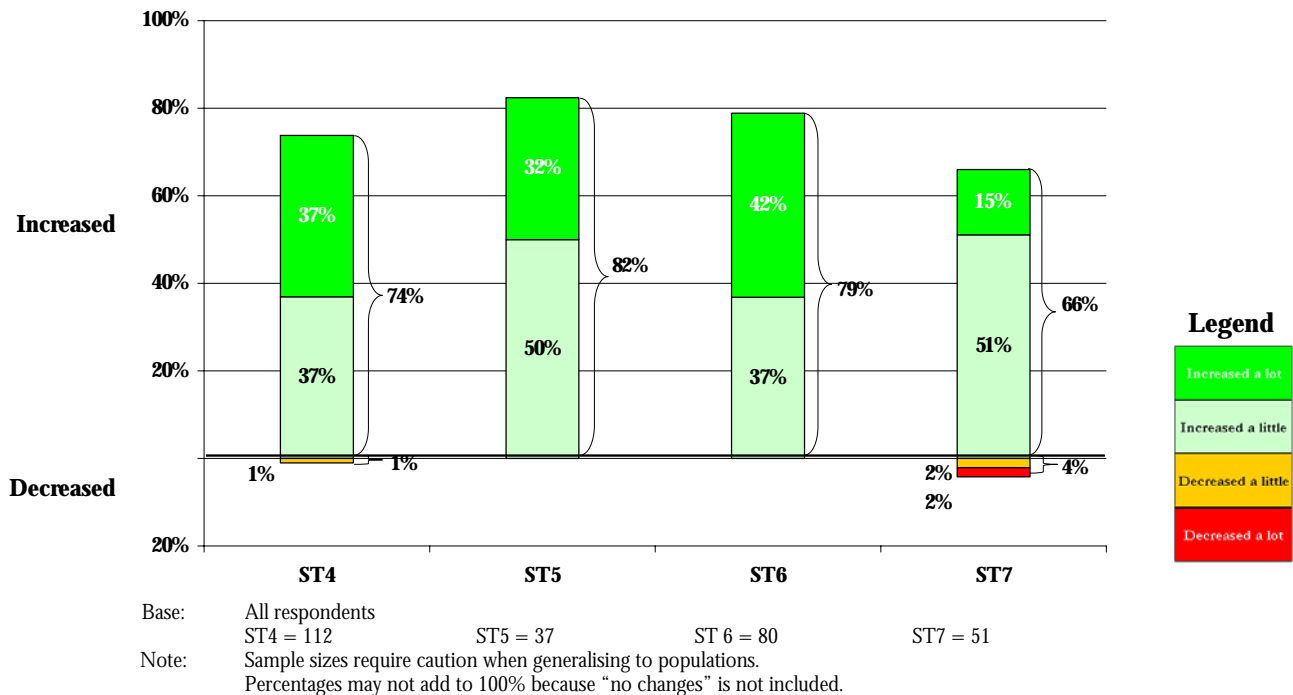


The amount of time spent on privacy issues

The majority of stakeholder respondents indicated that over the past two years the amount of time spent addressing privacy issues had increased or increased a lot (Figure 16). There were no major differences across the various stakeholder groups.

Figure 16: Changes in time spent addressing privacy issues

Q. *Over the past two years, how would you rate any change in the amount of time you spend addressing privacy issues?*



9.4.2 General impact of Commonwealth privacy legislation

There were differences in the opinion of stakeholder respondents about the impact of Commonwealth privacy legislation on research (Figure 17) and health services (Figure 19), while there was closer agreement about the positive impact of privacy legislation on protecting individual privacy (Figure 21).

HREC and health professional respondents were more likely to consider that the Commonwealth privacy legislation had a positive impact on health research while researcher respondents were more likely to consider the impact to be negative (Figure 17).

However, the overwhelming view across all stakeholder respondents was ambivalence (Figure 17) or uncertainty (Figure 18). Very few considered the legislation had no impact.

Ambivalence and uncertainty also dominated the perceptions of the impact of Commonwealth privacy legislation on the provision of health care (Figure 19 and Figure 20). Again there were differences in the perceptions of the different stakeholder groups with a minority of health professional respondents, HREC and peak body respondents considering the impact on health services to be good, while more researcher respondents considered the impact to be bad.

The majority of all stakeholder respondents except researcher respondents considered Commonwealth privacy legislation to have a beneficial effect on protecting the privacy of individuals (Figure 21).

Overall, health researcher respondent perceptions differed from other stakeholder respondents in regard to the impact of privacy legislation on research, health service provision and the privacy of individuals (Figure 21). Researcher respondents were:

- More likely to consider the legislation to have a negative impact on research and health services; and
- Less likely to have a positive view on the impact on privacy of individuals.

Figure 17: The impact of Commonwealth privacy legislation upon health research

Q. Overall, how would you rate the impact of the Commonwealth privacy legislation upon health research in Australia?

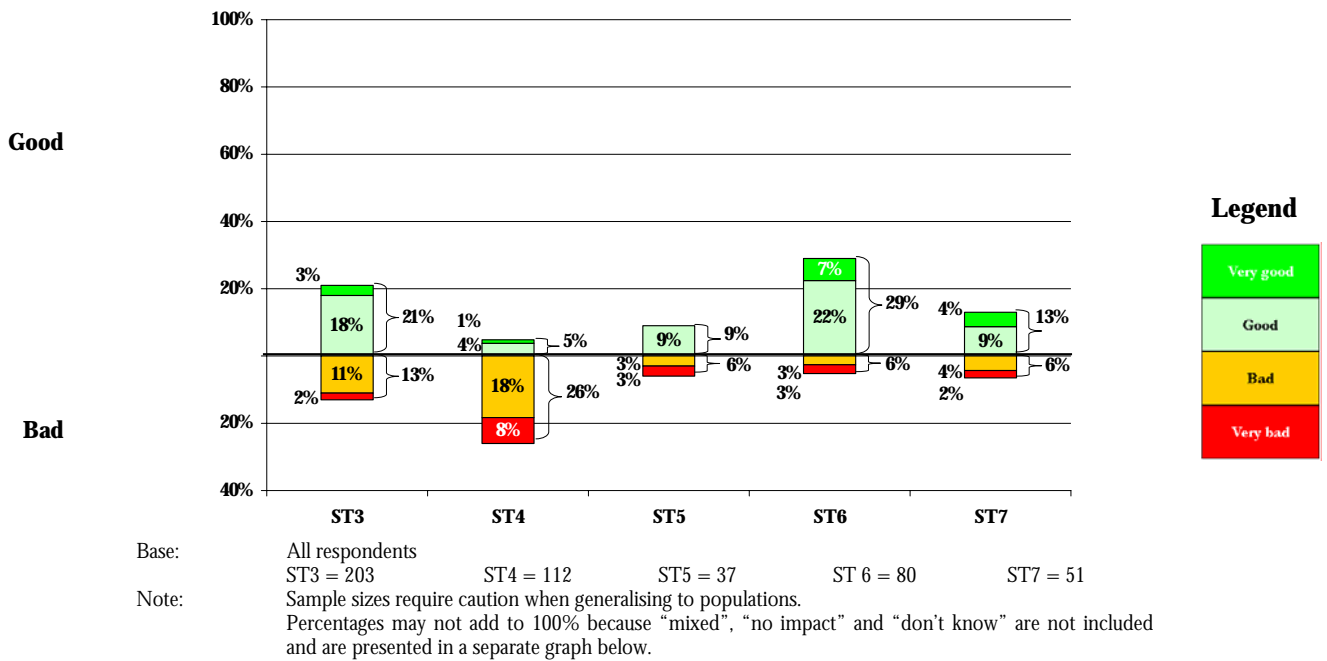


Figure 18: The impact of Commonwealth privacy legislation upon health research

Q. Overall, how would you rate the impact of the Commonwealth privacy legislation upon health research in Australia?

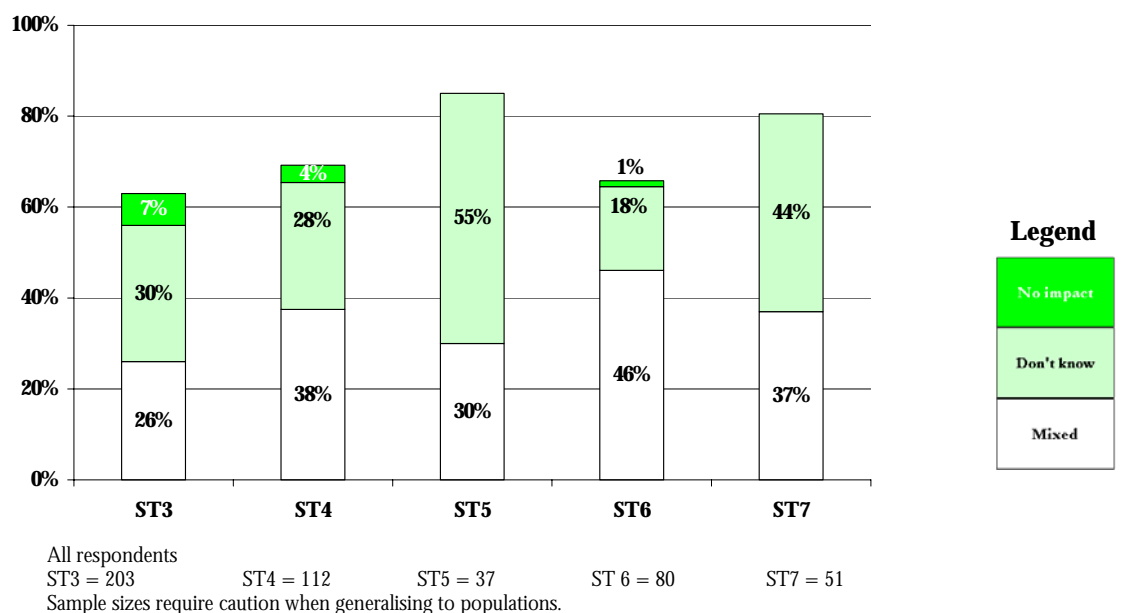


Figure 19: The impact of Commonwealth privacy legislation upon provision of health care
Q. Overall, how would you rate the impact of the Commonwealth privacy legislation upon the provision of health care in Australia?

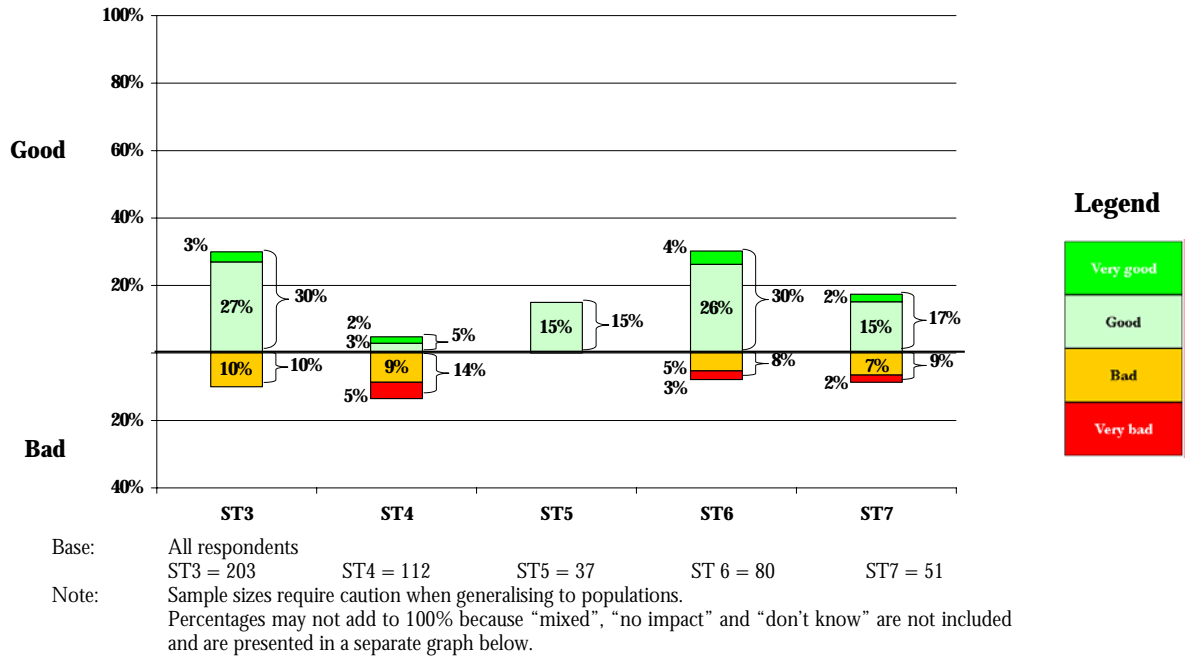


Figure 20: The impact of Commonwealth privacy legislation upon provision of health care
Q. Overall, how would you rate the impact of the Commonwealth privacy legislation upon the provision of health care in Australia?

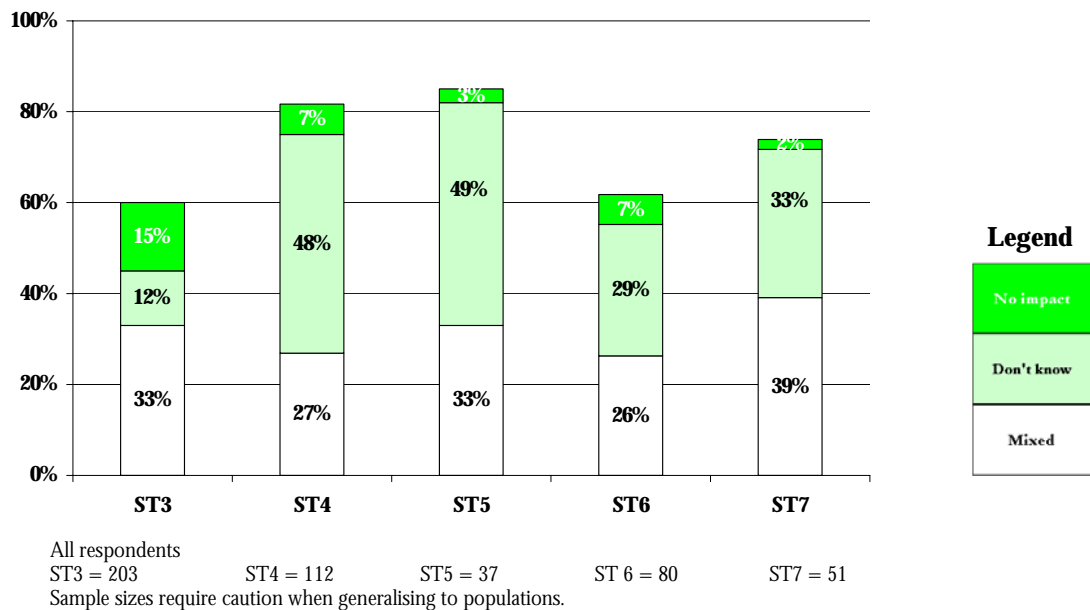
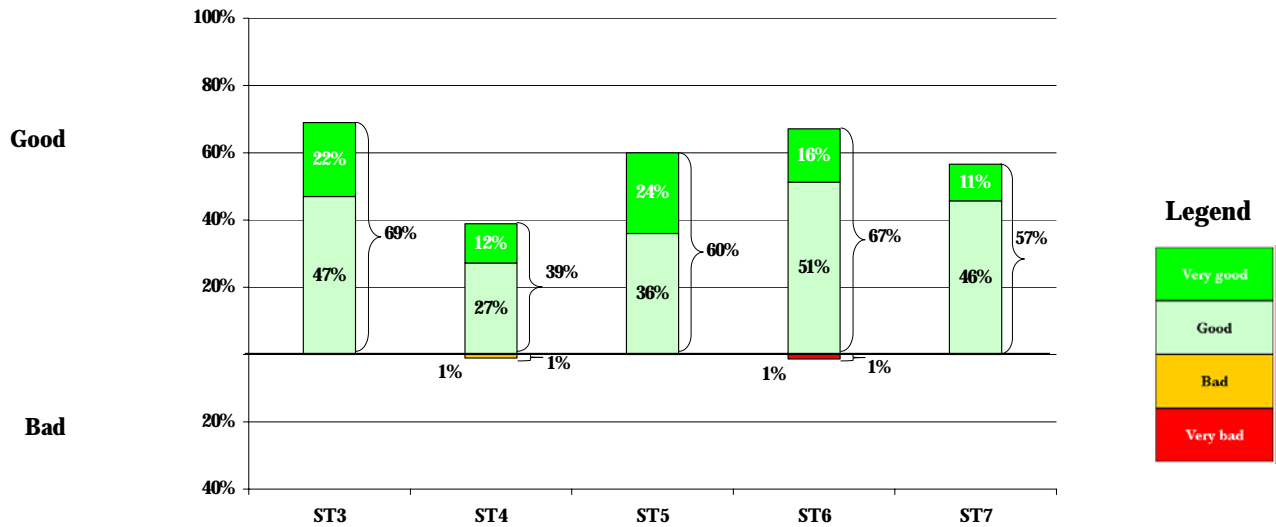


Figure 21: The impact of Commonwealth privacy legislation upon protecting individual privacy

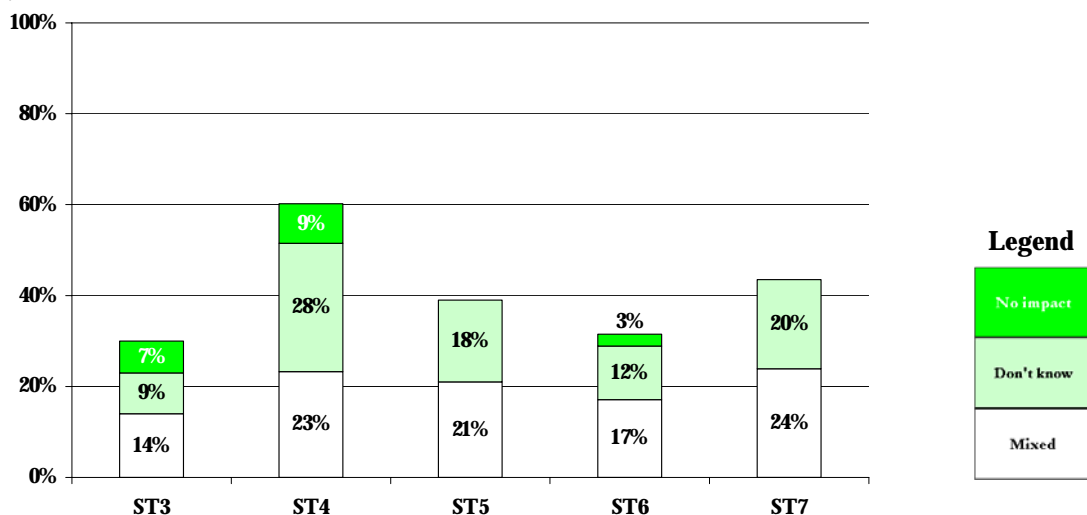
Q. Overall, how would you rate the impact of the Commonwealth privacy legislation upon protecting the privacy of individuals in Australia?



Base: All respondents
 ST3 = 203 ST4 = 112 ST5 = 37 ST6 = 80 ST7 = 51
 Note: Sample sizes require caution when generalising to populations.
 Percentages may not add to 100% because "mixed", "no impact" and "don't know" are not included and are presented in a separate graph below.

Figure 22: The impact of Commonwealth privacy legislation upon protecting individual privacy

Q. Overall, how would you rate the impact of the Commonwealth privacy legislation upon protecting the privacy of individuals in Australia?



Base: All respondents
 ST3 = 203 ST4 = 112 ST5 = 37 ST6 = 80 ST7 = 51
 Note: Sample sizes require caution when generalising to populations.