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Health Informatics Society of Australia

in conjunction with the
Australian Healthcare & Hospitals Association

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Submission on 'Healthcare Identifiers and Privacy'

Presented to the

Australian Government's Department of Health and Ageing

in response to the

'Discussion Paper on Proposals for Legislative Support'

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August, 2009

Health Informatics Society Australia Ltd.

This document has been reviewed and represents a formal submission from the Health Informatics Society of Australia	
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Healthcare identifiers and privacy: Discussion paper on proposals for legislative support

A Submission to Department of Health and Ageing

Introduction

The Health Informatics Society of Australia (HISA) in conjunction with the Australian Healthcare and Hospitals Association (AHHA), welcomes the opportunity to provide this submission in response to the discussion paper released by the Department of Health and Ageing (DoHA) on 'Health Identifiers and Privacy'.

Since 1993, HISA has taken a lead role in promoting eHealth and advancing the eHealth agenda across Australia. We recognise the importance of establishing a national approach to health identifiers that could lead to a safer and more efficient healthcare system. In fact, privacy and security of health information is one of our key specialist areas that we have been supporting through a number of HISA led initiatives to date. HISA recognises that advancement in a national eHealth agenda requires extensive consultation and collaboration. To gather responses from a wide range of stakeholders interested in eHealth we have broadened our consultation to include other relevant associations with whom we work closely, in particular, the Australian Healthcare and Hospitals Association and the association members of the Coalition for eHealth.

To meet the timeframe set by the discussion paper we chose to provide their members with an online survey that addressed all the questions raised. This submission analyses the results from the survey and provides the detailed comments from the participants to assist DoHA in achieving an acceptable and workable Health Identifier Scheme.

HISA's Online Survey

An online survey was produced by HISA based on the 40 Proposals and 41 related Questions in DoHA's discussion paper. For the 24 open ended questions, each survey participant had the option of providing free text. The majority of the questions were kept in their original form as found in the discussion paper although some required some modification to suit a standard question format. Both the original question and the related one used in the survey have been listed in the detailed breakdown for each question that follows. The full survey produced by Dr Brendan Lovelock, CEO of HISA, has been appended to this submission.

We had a good response considering the complexity of the topic. With about 450 participants signing in we achieved 100 full completions. Almost all the respondents were practitioners from either clinical or health IT management professions. They included 350 pertinent comments that have been listed in full for further information.

Overall

It was clearly evident from the responses that most are in agreement with what is being proposed in the discussion document. Some specific issues provoked stronger majority response, i.e. greater than 75% consensus, as follows:

a) *The need to apply specific penalties* [Q10]
81% of participants agreed that there is a need to apply specific penalties to unauthorised use or disclosure of healthcare identifiers by health sector or other participants who hold the healthcare identifier in association with health information. With 49% of the participants saying that they 'Strongly Agree' to this principle.

b) *The privacy of deceased persons* [Q25]
78% of the participants agreed that the privacy of health information about deceased persons should be treated the same as other personal information about them. With 45% of the participants saying that they 'Strongly Agree' to this principle.

c) *Consent for direct marketing* [Q33]
82% of the participants agreed that that the consent of the individual should be obtained for the use or disclosure of health information for direct marketing purposes. With 72% of the participants saying that they 'Strongly Agree' to this principle.

The start of the survey included questions about the participants' job titles and the type and size of their organisation. Cross Tab analysis was undertaken to establish if any particular job or organisation had a noticeable influence on the outcome. Results showed that the responses were uniform across the majority of questions. Where some differences were evident based on job or organisation status they have been reported against those questions. Once separated into different sections the sample size is considered too low (i.e. less than 10) to make any informed judgement as to whether this result would be consistently reproduced in further surveys. The main value comes from looking at the comments that were made in light of which sector indicated a more uniform or stronger response.

On analysis of the comments it is evident that although there is a general agreement with the proposals as they stand there is concern over the implementation details that is lacking from DoHA's discussion document. One interpretation is that the majority of participants would wish to see the proposed Health Identifiers and have sufficient confidence that the agencies concerned together with the proposed protections are adequate, provided the implementation issues are satisfactory addressed. That is, the benefits of national Health Identifiers as outlined in the document plus the strengthening of the Privacy laws as proposed by the Australian Law Reform Commission (i.e. the UPPs) outweighs the risks to privacy. This is based on an assumption we know what these privacy risks are but that cannot be determined from the level of detail that has been published to date. A Privacy Impact Analysis (PIA) for the proposed Health Identifiers has not been published and the discussion document does not provide that level of detail. The real risk will come from how each principle of the appropriate privacy act is handled and managed in practice by whoever implements the proposed Health Identifiers. While such questions remain unanswered there remains a risk to the whole project that fear of function creep, misunderstanding of how sensitive information is handled and its relationship to the identifiers, misunderstanding of technology or any technology compromise made to satisfy the implementers, etc., etc. could become ‘showstoppers’ for the necessary legislation. It is important that this is addressed through open consultation with the wider community as soon as possible. Our concern is that the discussion paper as it stands does not achieve this aim.

Overall Comments from the Survey

At the end of the survey, participants were asked if they wished to add any additional comments. Some are simply supportive while others are not. What is evident is the need for improved communication on these issues. Participants felt the discussion document was lacking in certain critical areas to include: high level issues; education to our health service providers; the exact relationship of the identifiers to sensitive medical information; the phased approach that will be taken; and, ease of reading for the non expert, as follows:

1. See my blog (http://aushealthit.blogspot.com/2009/07/commonwealth-department-of-health.html) for the high level issues that are just not addressed by the discussion document
2. Some health-related data sets, e.g., the ACAP MDS, already have de-identified individual codes. Are the proposed identifiers intended to replace these?
3. We absolutely need these identifiers now, and my comments are not meant to suggest delaying their introduction. I fully support using the existing arrangements until the new UPP can be implemented.
4. Great idea!
5. A national health Identifier is a critical issue in the provision of quality care in Australia. The Issue is quality of care - not privacy, the tail must not wag the dog.
6. No thank you
7. I believe the Commonwealth is mistaken in taking the opportunity to adjust so many health privacy principles to address perceived issues unrelated to the health identifiers
8. This survey is difficult to answer for a Swiss citizen and non English natives.
9. As laborious as it may be, there needs to be a layer of adjudication in addition to the health policies, always available to assist with variations on a theme which invariably surface.
10. Many unknowns have not been addressed, e.g. how is the data to be stored, and who or what have the exceptions to access.
11. Legislation issues need to be addressed but the next big challenge will be implementation.
12. Sooner done the better!!
13. Section A.3.1 of the discussion paper says that consumers will not need to declare their IHI. Also, in the discussion paper's introduction it states that providers do not have to use it. There are 2 problems here:
    1) Letting consumers choose whether or not they supply an IHI means providers' systems have to cater for that choice. In other words they would need to maintain 2 concurrent systems. I suggest that this is unrealistic.
    2) As the UHI becomes increasingly embedded within providers’ systems, increasingly decisions will be made to incorporate IHIs into work flows that assume an IHI is

available. Moreover, the use of the IHI will enable providers to provide better, or offer more, services. The pressure on the provider to push for an IHI will be great. Eventually consumers will be led to believe they have to provide their IHI. Which goes against the content of the discussion paper. This is the same as for electronic systems. Consumers concerned about privacy and consent may prefer a paper record. But, for the majority (or all) of health providers, that is simply not an option. So they are compelled to submit to the keeping of their records in electronic systems, without adequate privacy or consent safeguards/frameworks. We can see examples of this in other sectors such as the use of credit card details to register membership of a video rental outlet, or the requirement by airlines of a Medicare card to verify if children can travel interstate. Neither of these examples conform to the intended (or authorised) use of the cards.

I was unable to work out what legal frameworks the paper is suggesting regarding the choice of consumers to supply an IHI, but irrespective of how it is governed, there is a risk that this will be challenged by consumers in the future for the reasons outlined above (should they care enough - and some might).I'm not suggesting that it should be mandated, but that the government recognise that the suggestion that it won't be is unrealistic (in the real world) and therefore risks misunderstanding. Perhaps if it could be explained that this is an interim arrangement until we are fully electronic? This could head off potentially damaging criticism.

14. good luck
15. Lack of specific support for 'funding, management, planning, monitoring, improvement or evaluation of health services' will diminish the capacity of health information systems to improve healthcare Safety and Quality - which is the greatest potential benefit of e-health systems, a primary driver for clinician adoption and the key to healthcare reform. Why should legislation not be absolutely clear about supporting this?
16. Education on the identifiers to each Health Service would be imperative to an affective roll-out and use of this
17. People confuse the disclosure of the identifier with the disclosure of health information. The identifier in isolation contains no useful information and should be disclosed to healthcare providers who have the relevant information (this disclosure should be auditable and made available to the individual though).

    Disclosure of the identifier with health information should be regulated with the same level of scrutiny that it would if the identifier was not there.

Background

HISA

HISA (the Health Informatics Society of Australia) deals with science and practice around information that leads to informed and assisted healthcare. That is to say the resources, devices and methods required to optimize the acquisition, storage, retrieval and use of information and knowledge in health and biomedicine. HISA provides a national focus for this discipline, its practitioners, industry and users.

With over 500 members and a further 500 associates working with HISA through its Special Interest Groups, HISA represents a broad range of health practitioners (doctors, nurses and allied health care providers), IT specialists, health care management, technology suppliers and academics. As such, HISA is uniquely positioned to understand and provide comment on the issues surrounding information privacy in the health arena. HISA is in active discussion with its member base through a regular process of survey, evaluation and discussion. One of our core objectives is to stimulate the insightful analysis of the issues surrounding health information. Privacy legislation is key to HISA members, the majority of whom are directly responsible for handling sensitive health data in their capacity as data custodians, clinicians, health managers / administrators and health researchers. We encourage the Dept. of Health and Ageing to take further advantage of HISA as a reference resource, as it continues in supporting the development of workable solutions to critical eHealth issues.

What has HISA done in Health Privacy and Security?

Since 2006, consultation of our members on health privacy and security issues plus the wider health informatics community has been instigated through a number of avenues.

This included a national symposium in October 2006 on privacy and security of electronic health (ehPASS'06). At this event, attended by 60 delegates from across 5 states/territories, Professor Peter Croll (chair of ehPASS'06) announced that HISA would be making a submission to the Australian Law Reform Commission (ALRC) on behalf of the HISA members and wider community. To facilitate this, a national survey was conducted with HISA members and associate health organisations specifically focussed on the health sections of the ALRC issue paper 31.

The HISA board agreed in Nov 2006 to form a special interest group focusing on Privacy and Security issues known as HIPS with a committee formed from national experts in the area.

A further ehPASS workshop was conducted at the International Medinfo 2007 conference in August with representation from key international players specialising in health privacy. In September 2007, HISA initiated a national survey across both its members and across members of the consortium of professional society relating to health. One section was dedicated to Privacy and Security of Health information. These items were ranked as of the highest importance from the respondents and the detailed comments were included in the ALRC submission (an extract of the relevant vision statements are appended to this submission).

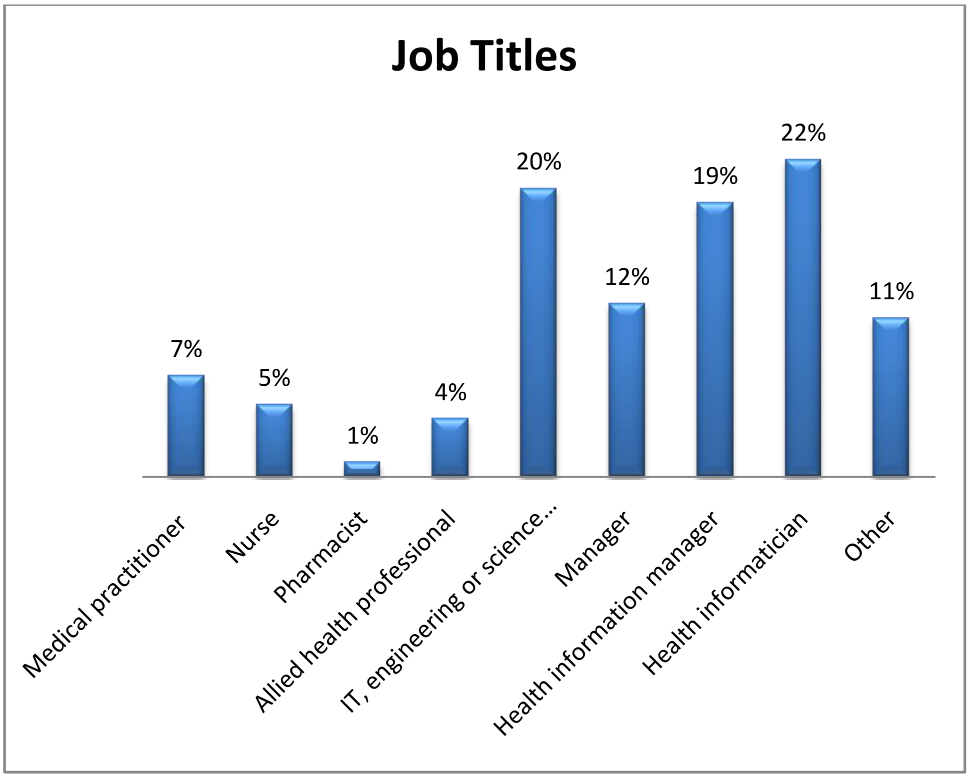
In November 2007, the HIPS group organised a national forum hosted by Microsoft in Sydney at which key national presenters were invited to include Professor Michael Frommer who was leading the NCRIS initiative to establish the national data linkage centre for population health studies. Members who attended this event were consulted on this submission at this event and invited to comment via the HIPS web forum pages (www.hisa.org.au/hips) set up for this purpose.

In November 2008, HISA organised the inaugural conference 'Health Privacy Futures' chaired by Prof Peter Croll, see www.healthprivacy.org.au. This was a highly successful event with over 100 participants of mainly professional practitioners from across the privacy spectrum. Featured speakers included Dr Bridget Bainbridge, Prof Bill Caelli AO, Malcolm Crompton, Megan Morris (DoHA), Prof Les McCrimmon, Christopher Public AM, Andrew Solomon (OPC), Jan Whitaker, etc. This event helped communicate the diversity of the topic and set foundations for ongoing discussion through the Health Informatics Privacy and Security forum (HIPS).

Details of the Responses to each question

Background of Survey Participants

Each participant was asked their job title from a selected range used in prior HISA surveys on workforce issues. The Managers, Health Information Managers and Health Informaticians made up the majority with 43% in total. It should be noted that many in this category may have prior training and experience in clinical professions as evident from HISA's workforce surveys. IT specialist, Engineers or Science professionals made up 20%. The remaining 37% were mainly clinical professionals who have significant IT exposure or dependency in their job.



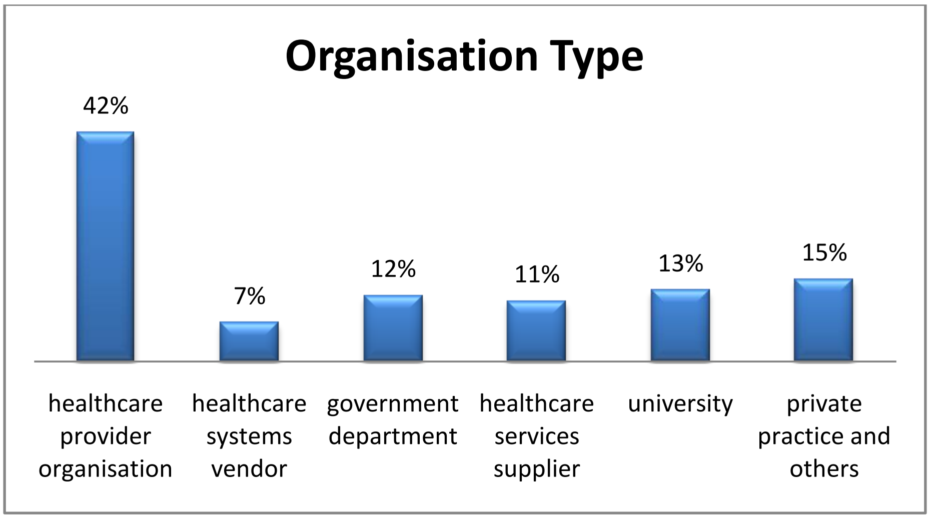
Survey participants who selected the job title of **'Other'** included:

- Researcher
- Nurse Academic
- Health Librarian and Medical Education Officer
- Consumer
- Business Analyst
- Nurse, Information Sys Developer,
- Community Director, GP Division, information system
- Clinical Coder
- Professor
- Health policy developer
- Peak Body & Industry Representation

Organisation Type of Survey Participants

Each participant was asked to select their organisation type from six categories. A Healthcare Provider Organisation was the main category at 42%. The remainder was more evenly spread across

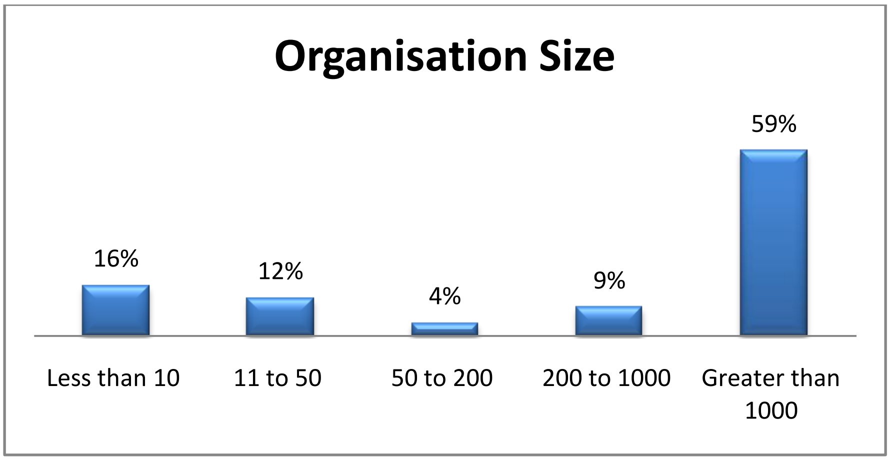
7% to 15%. The other section at 15% included Private Practice of which one third were from General Practice.



Survey participants who selected the job title of **'Private Practice and Other'** included:

- Division of General Practice
- Retired
- Private Practice
- Consumer Advocacy
- Health informatics consultancy
- Management consultant
- Healthcare network (non direct provider)
- National health policy body
- Support Peak Body by Aged Care Industry IT Council

Organisation Size of Survey Participants



Each participant was asked to select the size of their organisation from one of five size categories. For the majority (59%) they are in large organisations of over 1000 staff. This would include Government Agencies, State Health and Universities. It should be noted that a significant percentage (32% +) are also employed by Small to Medium Enterprises (SME). Concern over how the proposed Health Identifiers would affect business was raised in the discussion document. Their responses to this are included in the participant's comments from the survey.

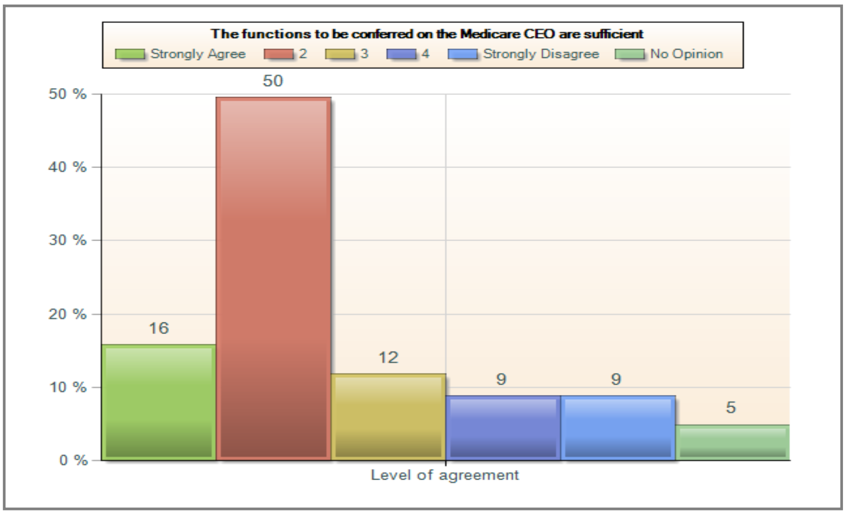
PART A: NATIONAL HEALTHCARE IDENTIFIERS AND REGULATORY SUPPORT PROPOSALS

Proposals for the Medicare Functions to Operate the Health Identifier Service

Proposal 1: Provide Medicare Australia with functions, in or under Commonwealth legislation, to establish and operate the HI Service for the purpose of accurately and uniquely identifying healthcare individuals, healthcare providers and provider organisations and enable communication between individuals, healthcare providers and provider organisations.
The functions would be conferred on the Chief Executive Officer of Medicare Australia and cover:

- assigning, collecting and maintaining identifiers to individuals, individual healthcare providers and organisations including by using information it already holds for existing purposes
- developing and maintaining mechanisms for users to access their own records and correct or update details
- collecting information from individuals and other data sources
- use and disclosure of these identifiers and associated data, including personal information, for the purposes of operating the HI Service.

Q1. Do you agree that the functions to be conferred on the Medicare CEO are sufficient?



In regard to proposal [1] the majority (66%) agreed that that 'sufficient' function was being conferred on the Medicare CEO to operate the Health Identifier Service. The comments below raise concern over the amount of responsibility, the CEO's misuse of this power, their understanding of medical needs over that of business, the infrastructure that will be put in place to protect Privacy etc.

Comments on the Proposals for the Medicare Functions

1. Should specifically mention protect privacy
2. There should be appropriate procedure to make sure the CEO does not misuse these powers
3. Where is the alternative that TOO MUCH is conferred on the Medicare CEO
4. I don't regard the document as providing sufficient detail about the functions is proposing to perform. There has been insufficient consultation with consumers.

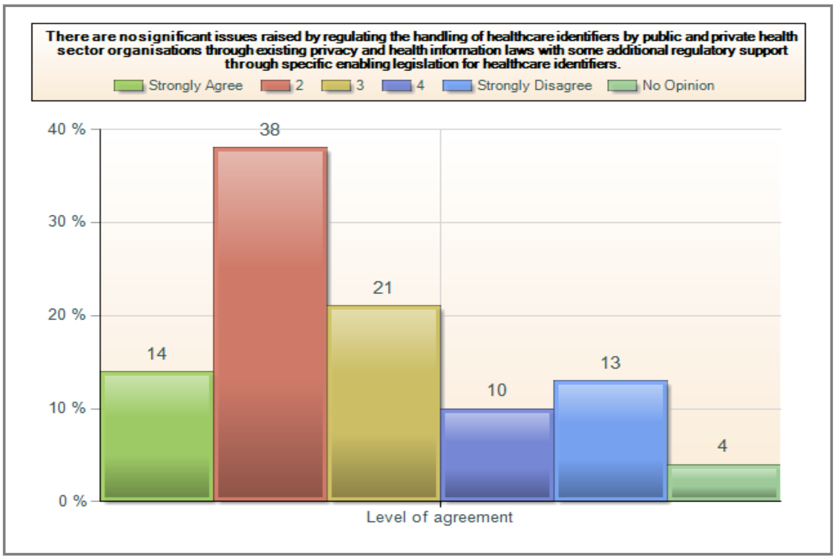
5. is the CEO of Medicare a health related professional with some business knowledge and not someone with just finance and business interest to understand healthcare needs
6. The CEO of MA should be accountable to independent governance arrangements. There is insufficient accountability by the CEO of MA for existing services such as MBS, PBS, ACIR including a lack of accountability to DoHA as the policy maker - which is exacerbated now MA reports through Human Services.
7. Insufficient structural attention is being paid to how identifiers will be put into action, how they will be interfaced to IT systems, how they will be safeguarded against unauthorised use. The technology neutral stance has left the identifiers concept vulnerable to fraud and abuse.
8. Also needs to be able to refer identified breaches in privacy and inappropriate use of identifiers to appropriate regulatory authorities.
9. Medicare already have the information about individuals so it is not a great step to expand their role.
10. While I can't think of anything else, there is probably something (I know that's hedging my bets). Perhaps one area is power to direct that providers inc organisations/individuals use the national Identifiers it can't be optional/opt in. Do that and you have failed.
11. From my understanding of the discussion points it appears the proposed functions should be sufficient
12. Wrong model, the chief good-protector. No such animal exists. Established laws has to how medical information is to be used and by whom.
13. Needs to be responsible/accountable for data quality - and this should be expressly stated
14. Medicare need to clean up its act big time in regards data quality.
15. It is logical for Medicare to undertake this responsibility based on its current accessibility to relevant info but do have concerns of its accuracy.
16. individuals need the option of viewing who has accessed their health record
17. the provider should be separate from a user such as Medicare
18. Medicare is seen as a "trusted" agency by the majority of the Australian population - functions proposed would seem sufficient at this point in time, but an annual review of the efficacy of these proposed powers may be worthwhile.
19. Requirements for proper eHealth functionality should override privacy fears.
20. I question Medicare being the appropriate agency for these functions. These should be services that are allowed to proliferate out to other agencies to execute.

Proposals for the Application of General Privacy and Other Laws

Q2. Are there significant issues raised by regulating the handling of healthcare identifiers by public and private health sector organisations through existing privacy and health information laws with some additional regulatory support through specific enabling legislation for healthcare identifiers?

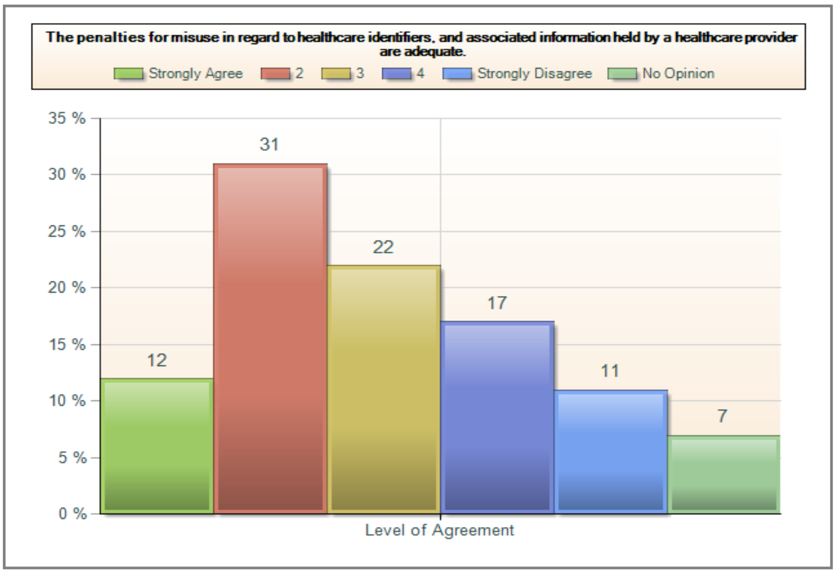
Proposal 2: Where an IHI or HPI-I is associated with health information about an individual, the collection, use and disclosure of an IHI or an HPI-I will be subject to the privacy and health information laws applicable to that health information.

Misuse of an IHI or HPI-I by a healthcare provider will be able to be pursued as a breach of privacy in jurisdictions with privacy laws or will be subject to other penalties set out in relevant health records or health service legislation.



In regard to proposal [2] on existing privacy laws the majority (52%) were in agreement while (23%) disagreed.

Q3. Are there circumstances where penalties for misuse of a healthcare identifier and associated information that is held by a healthcare provider will be inadequate?



Overall the results were positive (43%) although a significant number disagreed (28%) or were neutral (22%) or had no opinion (7%). Cross tabulation of Question 3 showed that Medical Practitioners and Nurses mostly disagreed. The IT, Engineering and Science professionals were across board on this issue while the Health Informaticians and Health Information Managers mostly agreed.

Comments on the Proposals for the Application of General Privacy and Other Laws

1. Need formal National Framework and Ministerial Accountability
2. Measures to track access to and use/misuse of HI are poorly defined and their auditing unplanned.

   > 20 years of experience managing sensitive patient data in a WAN shows that misuse is not uncommon and can be detected if there is a will.

3. Another unnecessarily draconian threat to doctors who seem to be presumed guilty unless proven innocent and likely at any time to do the wrong thing
4. One will need to examine the proposed covering legislation before finalising an opinion.
5. Will extent of harm suffered by someone whose privacy is breached influence penalties?
6. There needs to be national consensus on privacy and health information. Privacy "principles" are inadequate as they are just principles.
7. Must be stronger than general privacy legislation
8. The problem of abuse of identifiers has only been examined through the lens of regulations and penalties. It's not a balanced approach. In a world without borders, the potential for abuse and fraud to occur offshore, beyond the reach of Australian law enforcement renders the purely legal approach very limited.
9. General penalties for breaches of privacy and health information laws are inadequate, not specifically for HI.
10. The great issue here is that privacy is viewed as the 99% issue about a national EMR. Privacy is the 0.5% issue - patient outcomes is the critical component - 99.5%
11. There must be a regulation and penalties for misuse of the data. But there must be a possibility to use the data for emergency. The health care prof could access to data in case of emergency and then give a report to the authority why it was done.
12. What about other government agencies, e.g. Federal Police, ATO, and for "national security" the latest buzz word for violation of individual rights.
13. Need to be sure that third parties (acting on behalf of providers) are also covered by the 'rules & penalties'
14. ongoing/expanded education on what constitutes an abuse and what the penalties are. Perhaps de-identified examples distributed on an ongoing basis of misuse of identifiers/information which appear justifiable but are not followed by the reason why. It appears to be a valid reason to do something but here is why you actually broke the law and the actual consequences.
15. Identifiers should not be used until uniform legislation (Commonwealth) is in place to safeguard privacy
16. Stats on the quantum of penalties imposed on persons/bodies who have misused information under current laws does not engender confidence in the use of these for new identifier
17. While laws at the moment seem adequate, an increase in penalties for misuse may be warranted, if only to achieve a better comfort level from consumers.
18. There needs to be more clarity in State and commonwealth privacy legislation relating to the longitudinal health record. This goal is to facilitate sharing between sectors: Acute, Community, Primary. Current interpretations of Victorian legislation make it impossible to share between Acute and Community.
19. Monitoring and reporting of privacy breaches does not seem to be adequately publically accessible on a National level - the proposals seem to suggest individual organisations report and act transparently, but National monitoring systems do not seem to be proposed.
20. Use commonwealth not state jurisdictional powers wherever possible
21. The identifiers alone are useless bits of information, other information such as clinical information and identifiable information has always have always had the potential for

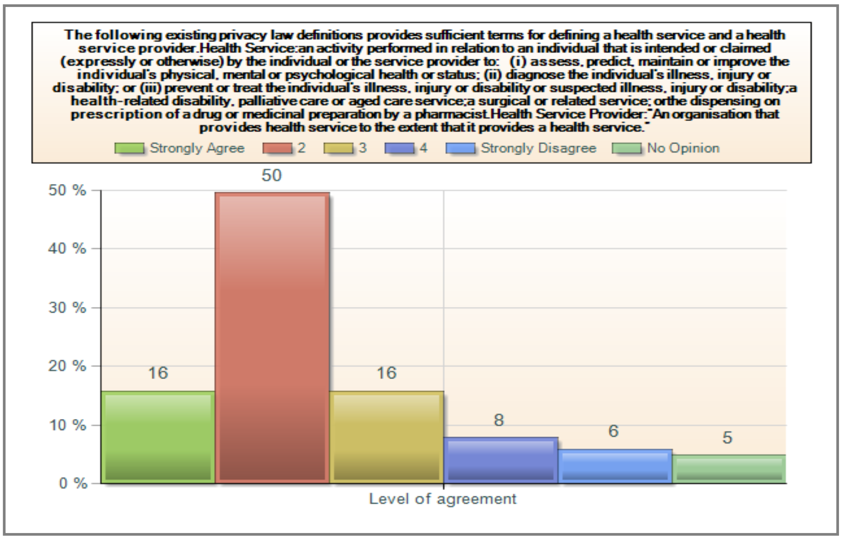
misuse. The important thing to monitor is that the identifier cannot be used to facilitate breaches.
22. This will be completely unworkable and will leave providers of ICT services to health care providers in a completely untenable position.
23. Identifiers are key in the proposal. Misuse should therefore carefully monitored.
24. A strong message needs to be sent to those that this is serious if breached
25. Review of Health Privacy Principle 15 is required.

Proposals for Healthcare Service Definitions

Proposal 3: Definitions of healthcare service and healthcare service provider will be included in the legislation.

Q4. Is it appropriate that definitions contained in privacy law are adopted?

Q5. Are there other specific terms that should be defined?



The following existing privacy law definitions provides sufficient terms for defining a health service and a health service provider.Health Service:an activity performed in relation to an individual that is intended or claimed (expressly or otherwise) by the individual or the service provider to: (i) assess, predict, maintain or improve the individual's physical, mental or psychological health or status; (ii) diagnose the individual's illness, injury or disability; or (iii) prevent or treat the individual's illness, injury or disability or suspected illness, injury or disability;a health-related disability, palliative care or aged care service;a surgical or related service; orthe dispensing on prescription of a drug or medicinal preparation by a pharmacist.Health Service Provider:"An organisation that provides health service to the extent that it provides a health service."

In regard to the proposal [3] on including healthcare service definitions, the majority (66%) of participants gave a positive response with only 14% giving a negative response that the terms provided were sufficient. The comments below reflect some of the deficiencies of the definition. In particular, services and businesses that handle health records but are not necessarily viewed as providing a health care service. Examples quoted below include insurance companies, genomic sequencing services, home services for the aged, health information managers, etc. Concern has previously been raised in the HIPS forums about businesses that provide IT services for healthcare and would not necessarily be regarded as a healthcare service provider. Normally they are covered under contractual arrangements between the IT service provider and the healthcare organisation but this arrangement can be insufficient with SME's that are non healthcare providers being exempt from some privacy legislation (e.g. NPPs).

Comments on the Proposals for Healthcare Service Definitions

1. The HSP needs to cover all staff of the HSP
2. What status is assigned to, say, a business that provides genome sequencing for an individual?

   a. What status is assigned to an insurance company that assembles health information about an individual not covered in the above statement?
   b. What do the providers of that health data do about privacy in their dealings with the other businesses?
3. Looks like a preamble to subdivide levels of access thereby depriving GP of full and total picture of patient, illness and previous or other care
4. This is a complex issue which will need wide community consultation before its acceptability can be properly assessed.
5. Health Information Managers and other service providers within the health service will require authorised medical record access as well. Is this covered?
6. Too vague - need to exclude unqualified individuals and organisations offering unproven and unreviewed services.
7. The boundaries around aged care services are interesting. For example, if someone receives a home maintenance service as part of HACC, is this well-described as a health service?
8. Separately we must beware that there are plenty of other services that fall outside the definition of health service that nevertheless deal with health information. Increasingly, the availability of pharmaceuticals and alternative remedies at otherwise regular e-shopping sites give retail organisations outside the health system detailed insights into customers' state of health.
9. Is there anything else? Sounds like it's covered
10. jargon - doesn't really describe anything!
11. Bordering on legalese.
12. What about an individual health service provider?
13. Very narrow definitions
14. Health Service Provider may need to cover the transmission and storage of information pertinent to providing a service
15. You mean..
    An Organisation that provides a Health Service is defined as a Health Service Provider.
16. Whilst anyone may be able to find an exception to this rule. This is sufficient initially to cover the providers that will most likely be using the identifiers. There is no benefit in debating this at this time as the definition can be augmented in the future as required
17. This seems a bit vague to me. The phrase "provides health service to the extent that it provides a health service" could be interpreted in many vague ways.
18. "Organisation" needs clarification. If it means one hospital for example it is insufficient.
19. There are a number of service providers who could be seen not to fit this definition, such as home help, meals delivery, personal care the definition should be changed so that it is clear that they are included.
20. A health service provider can be an individual
21. The definitions need to be sufficiently broad so as to not exclude organisations, etc. with a legitimate need.
22. It is necessary to make difference between:
    - Health service provider (a person) and
    - Service provider organisation

    The subject of health care (service) can be also a group of persons (e.g. a family).

Prediction is a big question mark. I am not sure that prediction can be classified to be health care service in most of cases.

Proposals for the Secondary Use of Information

Proposal 4: The HI Service Operator will only disclose an individual's IHI and the minimum personal information required to identify an individual to an authorised healthcare provider. Requests for an IHI must be supported by a minimum set of personal information.

Proposal 5: Healthcare providers will be authorised to use or disclose an individual's name, date of birth, sex and address details in order to request an IHI from the HI Service Operator.

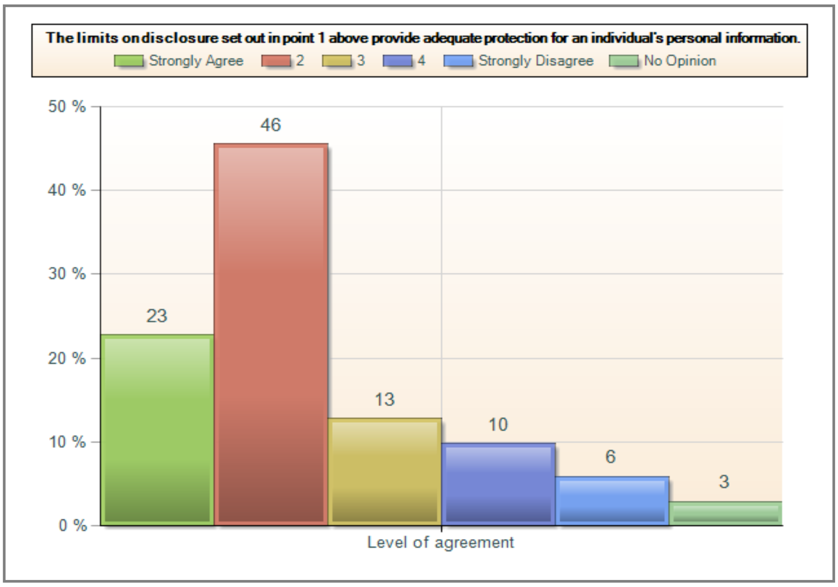
Proposal 6: The HI Service Operator will disclose information held in the Service only to authorised users. The term 'authorised user' will be defined in the legislation.

Proposal 7: The HI Service Operator will be authorised to disclose the HPI-I and relevant data fields for professional registration and other purposes to bodies set up in legislation establishing the NRAS.

Proposal 8: Secrecy provisions similar to those set out in the Health Insurance Act or the National Health Act would apply to the disclosure of information by staff in undertaking the HI Service Operator function.

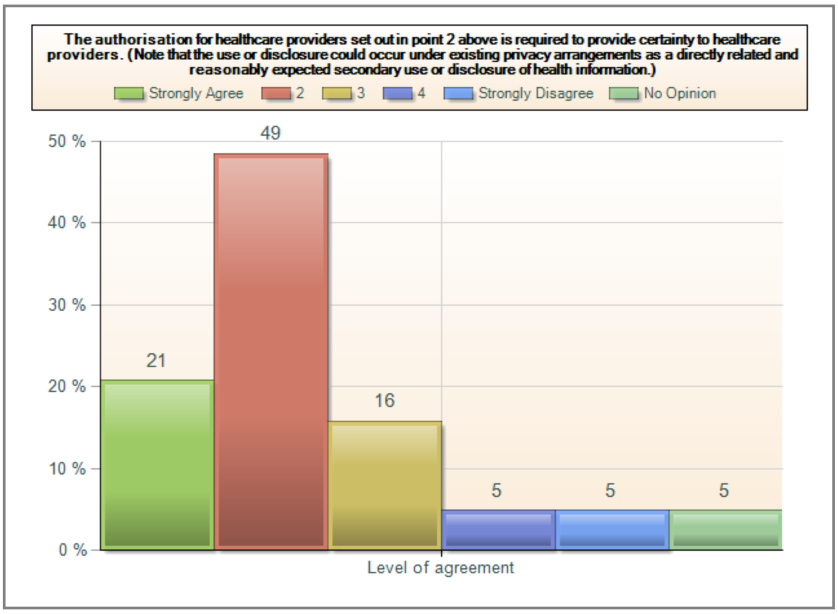
Proposal 9: Existing Commonwealth, state and territory health information regulation and administrative arrangements will apply to secondary uses and disclosures of HI Service information.

Q6. Do the limits on disclosure set out in Proposal 4 provide adequate protection for an individual's personal information?



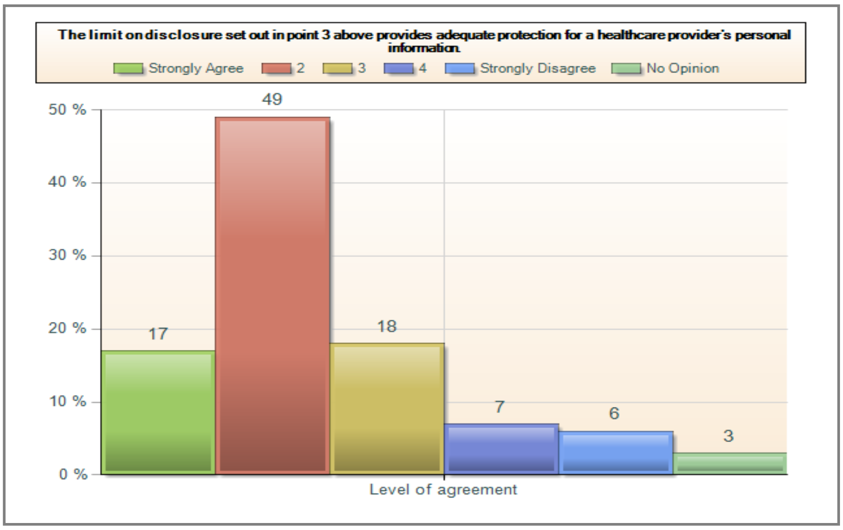
The majority agree (69%) that the limits on disclosure in proposal [4] provide adequate protection. 16% disagree.

Q7. Is the authorisation for healthcare providers set out in Proposal 5 required to provide certainty to healthcare providers, noting that the use or disclosure could occur under existing privacy arrangements as a directly related and reasonably expected secondary use or disclosure of health information?



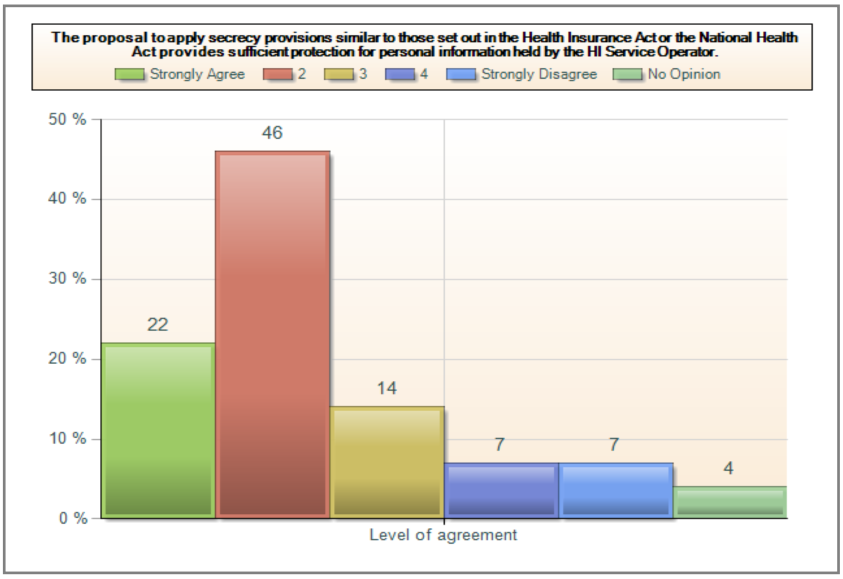
The majority (70%) agree that authorisation as set out in proposal [5] is required. Only 10% disagree here.

Q8. Does the limit on disclosure set out in Proposal 6 provide adequate protection for a healthcare provider’s personal information?



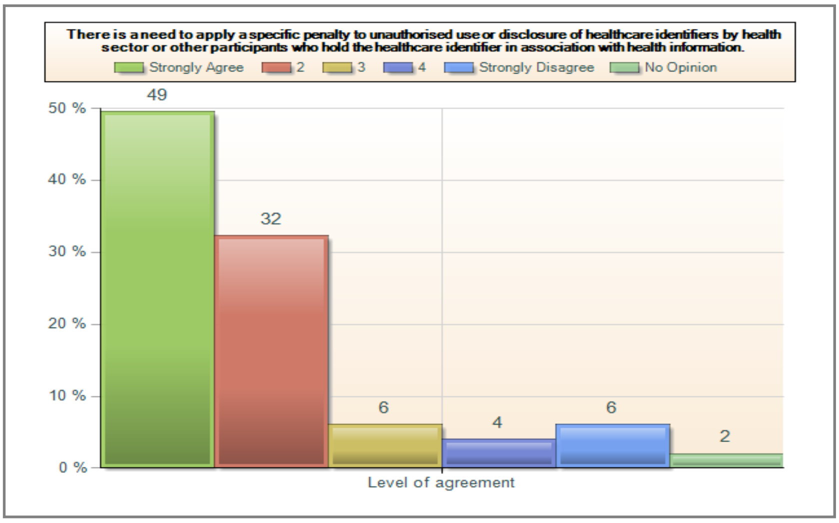
The majority (66%) agree that proposal [6] provided adequate protection with 13% disagreeing.

Q9. Does the proposal to apply secrecy provisions similar to those set out in the Health Insurance Act or the National Health Act provide sufficient protection for personal information held by the HI Service Operator?



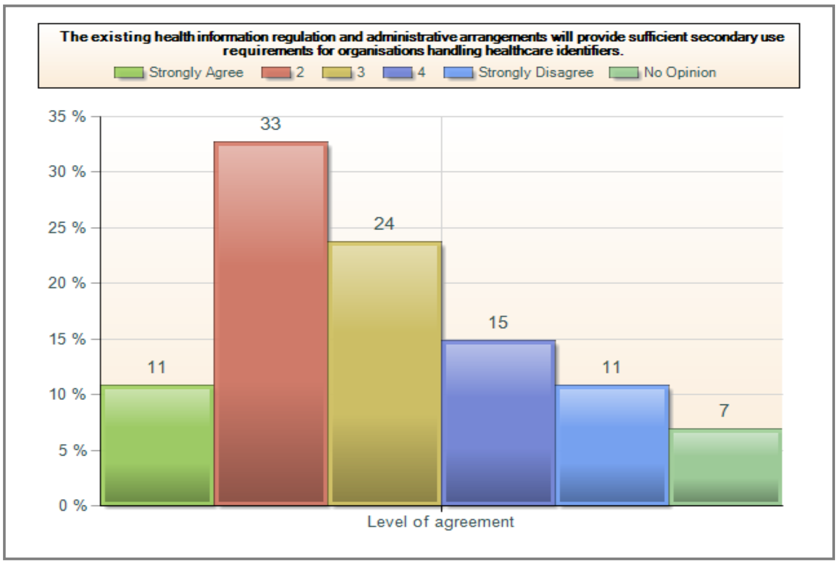
The majority (68%) agree that the proposal to apply secrecy provision provides adequate protection while 14% disagree.

Q10. Is there a need to apply a specific penalty to unauthorised use or disclosure of healthcare identifiers by health sector or other participants who hold the healthcare identifier in association with health information?



Almost half (49%) strongly agree for the need to apply a specific penalty to unauthorised use or disclosure with a total of 81% agreeing to this.

Q11. Do you agree that existing health information regulation and administrative arrangements will provide sufficient secondary use requirements for organisations handling healthcare identifiers?



Although the majority agreed (44%) a significant number (26%) disagreed with the existing administrative arrangements being sufficient for secondary use requirements.

It is evident from the comments on the secondary use proposals [4-9] that clarification is still needed on this complex issue. For example, confusion exists over whether these proposals are addressing the secondary use of the Health Identifiers or secondary use of a patient‘s medical data. A number of comments address the governance arrangements and who the wider community would trust with administrative and regulation issues. Calls for wider consultation is made.

Comments on the Proposals for the Secondary Use of Information

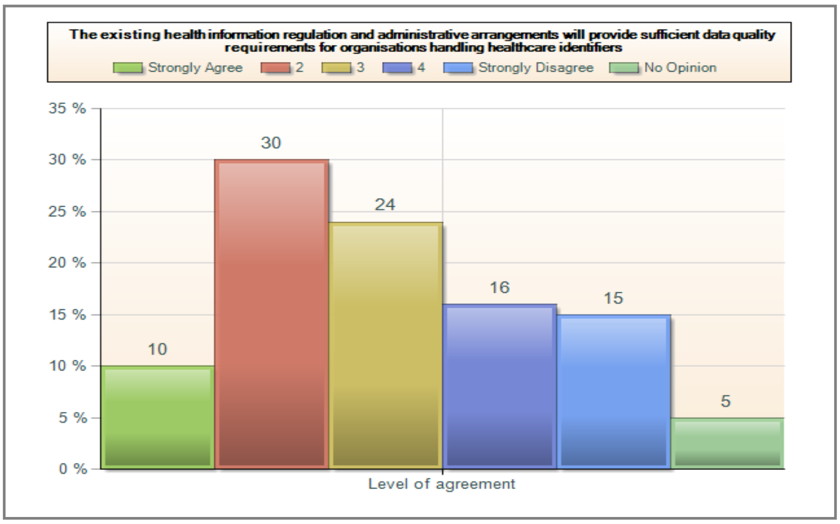
1. In some way limit transfer/downloading of bulk files containing patient information where FOI requests are made. There have been a number of recent incidence in this area....unrelated to health information, but from other departments.
2. It is not clear how the secondary use will be regulated. It is extremely important that the IHI can be used in research and record linkage to be able to evaluate service provision and treatment outcome. It is not clear whether you are assessing agreement to this secondary use.
3. There is not good reason for secondary use or disclosure to anybody at any time
4. The circumstance relating to this proposal would appear to be quite different from those envisaged in the existing regulation and administrative arrangements. This issue has not been adequately discussed with consumer community for whom it has the major interest.
5. A problem is that some health information is very sensitive while other is not. The fact that someone has consulted a sexual health clinic, for example, may be viewed as sensitive and should not be made available to, say, HACC agencies providing minimal service
6. Need formal submission and approval processes, independent governance and protection for small sample size resulting in identification of individuals

7. There will be incentives and opportunities for third parties to illicitly obtain IHIs which are not anticipated by the concepts of authorised use. There is insufficient attention given to preventing exposure (leakage/loss/theft) of IHIs as opposed to reacting to disclosure.
8. Current secondary use arrangements are confusing and need clarification.
9. I believe current limitations/law on privacy cover the situation.
10. Processes for those individuals who do not want any information to be share between health care providers/or a particular health care provider. eMR to have developed ways to better identify and protect and comply with these person's wishes.
11. Most government institutions are very laissez-faire concern individual health information.
12. As before the provision of information for the treatment/management of the patient/client across the range of Health Service providers requires more clarity.
13. Re Q17 there must be a reasonable and equitable enquiry process with regard to potential breaches.
    Re Q18 Existing arrangements are not adequate and consistent - are they not to be replaced/supported by the new UPPs and an inter-governmental agreement?
14. The identifier should not be considered any different to other health information. The identifier in isolation should be a useless piece of information.
15. The proposal to have this occur under existing jurisdictional legislation is unworkable
16. It is important that data are available for scientific and adequate regulations for this purpose should be implemented.
17. Need to define how HI will be used in secondary data use
18. Need to ensure that the ALRC recommendation 63.9 on monitoring, etc. is supported by the secondary use provisions.

Proposal on Data Quality

Proposal 10: Existing Commonwealth, state and territory health information regulation and administrative arrangements will apply to data quality.

Q12. Do you agree that existing health information regulation and administrative arrangements will provide sufficient data quality requirements for organisations handling healthcare identifiers?



In regard to proposal [10] on data quality more agreed (40%) than disagreed (31%) and with a significant percentage (29%) neutral or no opinion. It is evident that there is a broad cross section of opinion here. Cross tab analysis showed that in response to this question, healthcare systems venders were the most positive (71%) and government departments were the most negative (50%). It is evident from the comments that data quality is regarded as a critically important issue and many participants have firsthand experienced of the problems poor data quality can cause.

Comments on the Proposal on Data Quality

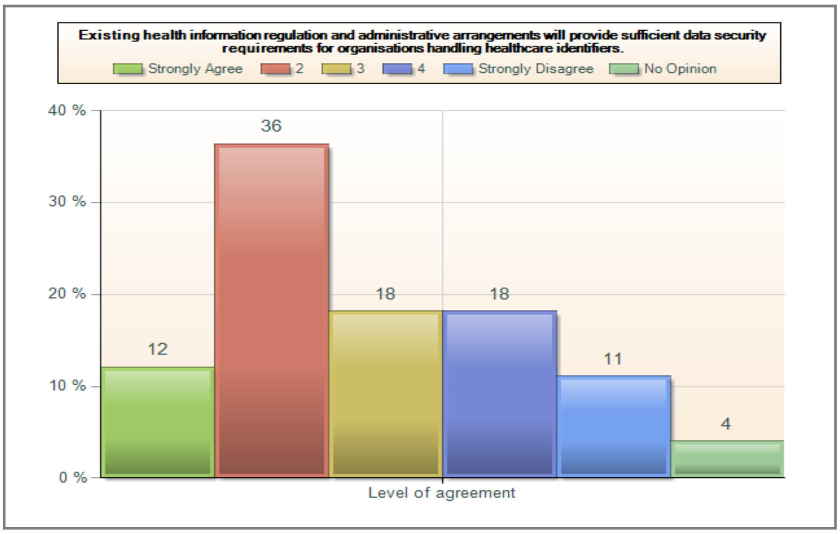
1. I expect that there is a lot to say about QC of stored data. Both demographic data and clinical findings will be subjects of these regulations. The will and ability of service providers to confirm that their data is stored with the correct patient and in ts the correct data is suspect.
2. Soft ware systems are different in each state and each state has a different capacity to collect data. Each state also has their own definition of terms and can override National standards on an ad hoc basis. The lack of qualified health staff with tertiary qualifications or post grad qualifications is of concern. We rely on these unqualified staff to make decisions about data quality when there is no clinical knowledge. Looking at information on the internet to gain knowledge is a poor method of making decisions. Western Australia often gets overridden in any decision making and this is a concern as the state is so large and there are multiple disparate systems in place.
3. So far, NSW Health IT and Commonwealth IT as I have experienced it is utterly devoid of MEDICAL WISDOM
   The interests of other possible users, demographers, accountants, overseers etc are glaringly obvious when the structure and functionality is examined
4. The issues go well beyond the matter of regulation and administrative arrangements and both service providers and consumers will need to be involved in the design of data both content and format relative to its suitability for the type of distribution possibility which this proposal seems to encompass.
5. OK as long as it continues to be Medicare & it's policies/procedures applicable to IHI's.
6. jurisdictional patient identification mechanisms are not sufficiently robust currently. If Hospitals are able to update the IHI Service with patient address details more robust mechanisms will be required.
7. health information and administrative arrangements in SA are a 'dogs breakfast'. The medical records standards are outdated and relate to paper based records - no acknowledgement of e-health. Administrative arrangements differ widely with no consistency in definitions of codes for numerous record keeping functions in client records. Much work to be done to achieve uniform standards necessary for interoperability.
8. Not sure that it does - I work in an area where we do data matching etc and it's a struggle.
9. These regulation in the private sector with the possible exception of Pathology are not particularly oriented to data quality as far as I am aware
10. Human resourcing around these quality requirements needs to be reviewed to ensure compliance
11. Poor data quality, GIGO

12. There is still no effective way in ensuring that a healthcare provider will assign the correct identifier to an individual, as there is no requirement for proof of identity when receiving healthcare
13. Experienced previous data quality issues when dealing with Medicare and Health records. Needs good data matching and built in data cleansing work flows along with ongoing data validation. Data quality cannot be an afterthought.
14. There is not a clear set of collection rules for all sectors (including private). This is required to be able to use demographics to support patient identity.
15. Data Quality is extremely important in health information; this is generally underestimated and processes for managing and monitoring data quality are vague and provide no concrete standards, however the proposal as outlined suggests a framework for a suitable standard of data quality for IHIs will be developed.
16. Transition period where existing/historical data must be matched is the greatest risk area
17. photo are required as mix up happen frequently
18. Medicare Data is often of much lower quality then that of healthcare agencies actively providing care to an individual. It is important that the IHI services are proliferated out to other healthcare agencies to improve the quality.
19. Are we talking about the quality of the demographic data linked with the HI? If so, it is difficult to know how regulation and administration will impact on data quality until it is implemented, given that information on data quality under existing Medicare regulations is not easy to obtain.
20. The nature of data quality is often poorly understood (every database, how well maintained, by default has errors). Safeguards should be instituted to mitigate the effects of errors.
21. Stronger requirements for compliance by organisations handling healthcare identifiers to data standards and quality are required. Organisations also need some way to enforce vendors (health care IT system suppliers such as PAS, EMR systems) to build and deliver systems that align with data standards at no cost.

Proposal on Data Security

Proposal 11: Existing Commonwealth, state and territory health information regulation and administrative arrangements will apply for data security.

Q13. Do you agree that existing health information regulation and administrative arrangements will provide sufficient data security requirements for organisations handling healthcare identifiers?



Nearly half (48%) agree that the security arrangements in proposal [11] are sufficient, although 29% disagree. Cross tab analysis showed that removing the participants that work for larger organisations (i.e. >1000) and the result would be more evenly split over agree (40%) and disagree (35%) to this question. This is significant since the data security arrangements will differ considerable between SMEs and larger enterprises.

Comments on the Proposal on Data Security

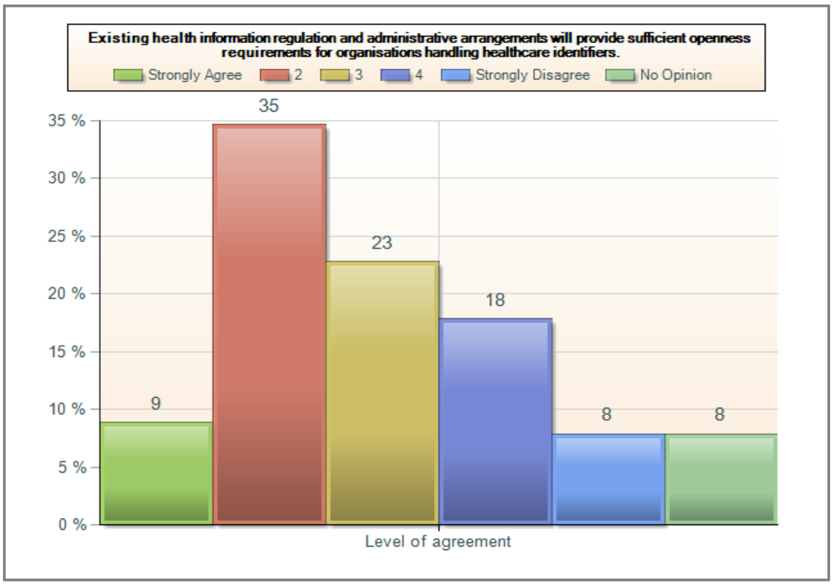
1. IT security is mythical - fanciful - a farce
   Microsoft, the Pentagon, the Palace and the CIA have all been hacked
2. It is most unlikely that the existing regulation and administrative arrangements which were designed for manual records will be suitable for electronic security requirements. This will need very close consultation across the consumer community.
3. Currently there is inconsistency, with some data sets being de-identified, while others are identified. Needs to be consistently applied across all jurisdictions.
4. I fear that health identifiers are not capable of being secured as currently conceptualised merely as numbers. Banks are taking greater care to prevent replay of account numbers than NEHTA/Medicare are taking with replay of IHIs.
5. some data security functions imposed are too restrictive and may impeded the delivery of informed health care because of existing data security provisions.
6. While I don't understand all current regulation, my experience is that current security is adequate
7. However there needs to be better understanding in some sectors as to what the existing arrangements are. Some re-education with the introduction of identifiers would be appropriate
8. absolutely NOT

9. Building foolproof systems (organisational and/or technical) is difficult, and we have to assume that breaches of regulations are inevitable (of both the deliberate and the unintended type). Judicial penalties for breaches should be sufficient to drive improvements, but should we also allocate a funding pool to recompense those whose rights are illegally breached? Depending on the circumstances, a breach of privacy can be personally and professionally devastating. On the other hand, total privacy can never be a guaranteed right.
10. Needs to be reviewed to ensure the achievement of the desired outcome i.e. availability of patient information at the time of treatment.
11. There is a major gap between security policy, systems audit capability and actual auditing for appropriate use. Significant investment required to bring this into line with other government departments e.g. Tax, police, Centrelink.
12. The identifier is no more sensitive than other health information. Access to health information with only an identifier should not be allowed
13. Multiple jurisdictions and confusing regulatory environment is unworkable.

Proposal on Openness

Proposal 12: Existing Commonwealth, state and territory health information regulation and administrative arrangements will apply to openness.

Q14. Do you agree that existing health information regulation and administrative arrangements will provide sufficient openness requirements for organisations handling healthcare identifiers?



With regard to the openness proposal [12], more participants (44%) gave a positive response in agreement over the negative disagreement (26%), although almost one third (31%) were neutral or had no opinion. Cross tab analysis showed that IT, Engineering and Science professionals were the most positive (45%) while Nurses (60%) were the most negative. Participants who worked for a healthcare systems vendor were strongly in agreement (85%) as were University staff (61%).

Comments on the Proposal on Openness:

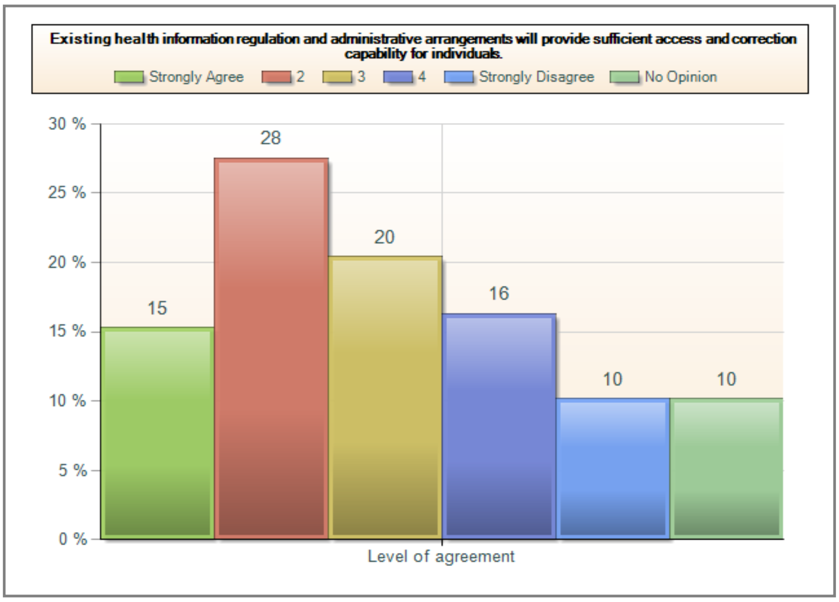
1. What can be meant by this?
    Concept is opaque

2. I note that the proposal intends to provide authorised access to parties accredited by PKI technology. I strongly doubt whether this technology is suitable to be applied to the situation involving wide cross communication between an excess of 600,000 health service providers requiring to be authorised to exchange information across such a "many to many" type system which in its next step is connected to 22 million patients.
3. Accountability of MA needs to be increased.
4. I think needs work to become more open.
5. While I don't understand all current regulation, my experience is that current security is adequate
6. Does the individual client receive notification as to who has accessed their health records?
7. Still not clear.
8. The jurisdictions already have mature release of information, privacy and data security policies
9. Ditto

Proposal on Access and Correction

Proposal 13: Existing Commonwealth, state and territory health information regulation and administrative arrangements will apply to access and correction. No additional legislative requirements will be developed for access and correction.

Q15. Do you agree that existing health information regulation and administrative arrangements will provide sufficient access and correction capability for individuals?



43% of participants agreed that proposal [13] regarding existing health information regulation and administrative arrangements will provide sufficient access and correction capability for individuals while 26% did not. 30% were neutral or had no opinion.

Comments on the Proposal on Access and Correction

1. I just don't see the existing methods working in a National environment.
2. Do the current arrangements really work?

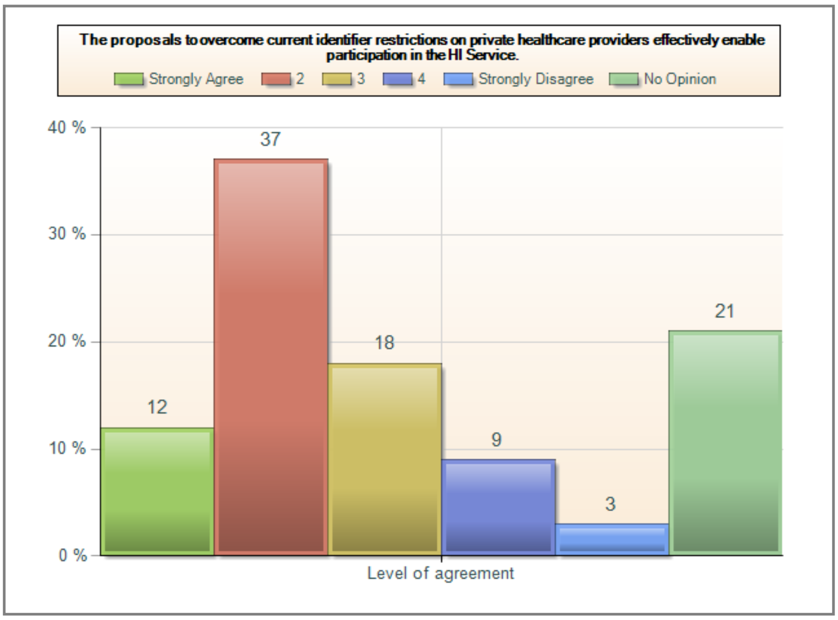
3. What regs and arrangements are these?
4. It is difficult to imagine how the existing regulations which relate to manual records are likely to be sufficient in an eHealth environment. To propose such measures without adequate consultation with community is not acceptable.
5. Medicare's current processes clearly ok and superior to most health services.
6. jurisdictional patient identification mechanisms are not sufficiently robust currently. If Hospitals are able to update the IHI Service with patient address details more robust mechanisms will be required.
7. Medicare appear more advanced in this area than existing state based channels to access client records and / or make corrections.
8. Again, I think the privacy security legislation is adequate to restrict and allow access. Note: putting logging on IT systems is a really well understood these days. By adequately logging the access - so there is a trail - current legislation could easily cover the situation. NB: Adobe Acrobat for Government allows data to be displayed on a computer screen, but be so locked down you can't even screen print it. You would need to photograph the screen
9. Will the corrections be the main source of health information, and what happens to the erroneous information?
10. A wrong allocation of an identifier to an individual will cause major issues as it permeates (sent to other providers) through the health system.
11. Person must be able to query but medical corrections must be approved by medically qualified professionals.
12. Recommend overarching C'th regulation and mgt
13. Currently individuals are more likely to update their data more frequently at healthcare agencies currently providing services to them than update their data at Medicare. Access to IHI data should be easily facilitated via existing methods at the healthcare provider or through Medicare
14. What kind of information will they able to access and correct. Should be able to update address, but details such as name change or dob change should require supporting documentation to avoid fraud situations. Corrections should take form of amendments or addendums from a point in time with an audit trail still available to see previous information. Information should not just be able to be overwritten.
15. Ditto
16. Since it is about sensitive data, regulations and procedures should be examined for adequacy.
17. I think that existing administration arrangements may not be sufficient for online access and correction.

Proposal on Identifiers

Proposal 14: It is proposed that Commonwealth legislation provide that NPP 7 does not apply to the adoption, use and disclosure of the IHI or the HPI-I by private sector healthcare provider organisations for the purposes of accurately and uniquely identifying individuals and individual healthcare providers respectively for health information management and to enable communication between individuals, healthcare providers and provider organisations.

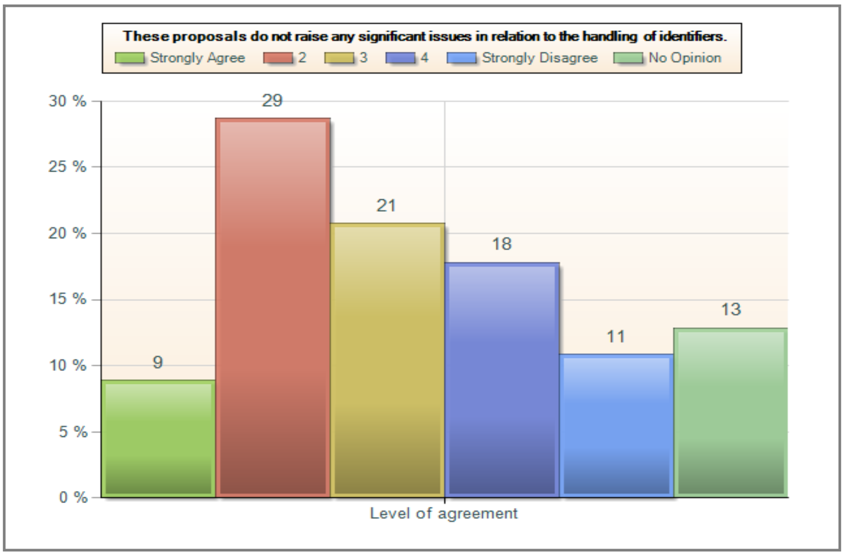
Proposal 15: It is proposed that Commonwealth legislation will provide that NPP 7 does not apply to the use and disclosure of Medicare numbers to Medicare Australia by private sector healthcare provider organisations for the purposes of the retrieval of individual identifiers.

Q16. Will the proposals to overcome current identifier restrictions on private healthcare providers effectively enable participation in the HI Service?



Almost half (49%) agreed with the proposals [14] and [15] relating to current restriction on private health providers with only (12%) disagreeing. 39% were neutral or had no opinion.

Q17. Do these proposals raise any significant issues in relation to the handling of identifiers?



In regard to the proposals [14] and [15] more agreed (38%) than disagreed (29%) that these proposals did not raise any significant issues. Cross tab analysis showed that the Medical Practitioner disagreed (57%) while the IT, Engineering and Science professionals were neutral and the Health Informaticians were general positive (45%). Also participants who claimed to work for the Health Systems Vendors strongly agreed (71%).

Comments on the Proposal on Identifiers

1. It is not possible to sensibly comment on this issue without the specific detail what is intended to be proposed.
2. Need to ensure greater accountability for inappropriate use by all providers.
3. I predict that there are other issues, perhaps technological issues, that impact "participation in the HI service" that fall outside the purview of the legislation. To borrow a phrase, there are unknown unknowns. It is not even remotely possible to state with confidence that "These proposals do not raise any significant issues". As things stand, almost nothing prevents IHIs from being replayed by unauthorised parties (including cyber criminals). It is a worry that around the world, banks are taking greater care to mitigate replay attack than is NEHTA/Medicare.
4. private sector buy in important - need to ensure full access to IHI and HPI-I for private sector
5. Unless the private sector providers are fully involved in the use of the National identifiers, we don't need to proceed any further at all, the whole national ID system will have failed.
6. If NPP 7 does is not to apply to Medicare numbers, why not just use the Medicare number as the UHI?
7. In the above paragraphs what is the reference to "It is proposed". Who or what is "It".
8. A single identifier across public and private health service organisations and providers must be available to all Australians to ensure this system is functional. Otherwise this process will not enable continuity of health care across Australia which is the aim. Private health service organisations must be able to access pertinent previous health care provided to the individual in order to provide adequate safe care. Medical and nursing practitioners require access to all information. Allied health and complementary and alternative medicine

practitioners should only have the ability to enter data against the identifier but not have access to all the individuals health information unless specifically given permission by the individual person seeking health care.

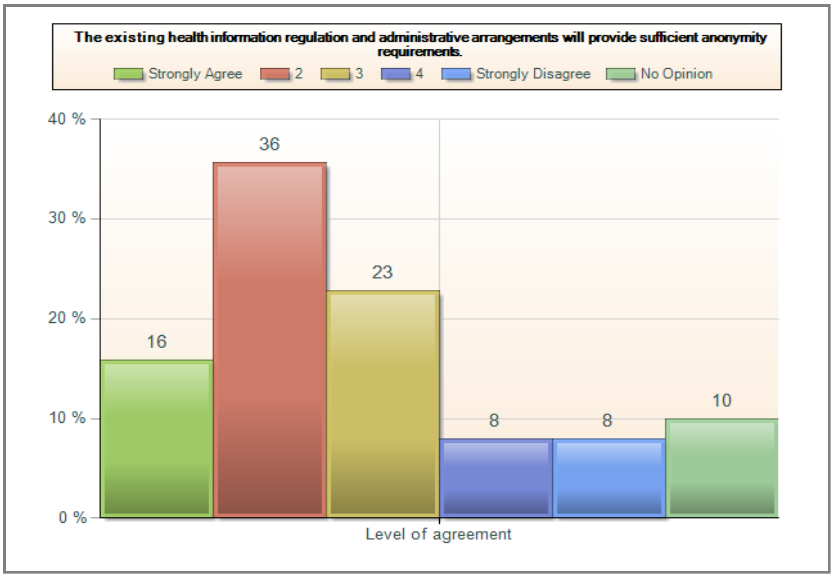
9. My private research amongst consumers of medical services indicates no resistance to the issuing or management of unique identifiers
10. Except in house systems that will require updating if we need to link information.
11. Disclosure of the identifier should not be of concern when it is done in isolation. i.e. without other information.

    When it is disclosed with other information than the NPP's should apply as they would have in the past when the information was disclosed. The presence of the identifier should not change this
12. Multiple jurisdictions mean uncertainty will rule
13. Allowing the use of HIs is to be welcomed - and should enable safety and quality benefits to be realised in both short and longer terms.

Proposal on Anonymity

Proposal 16: Existing Commonwealth, state and territory health information regulation and administrative arrangements will apply to anonymity.

Q18. Do you agree that existing health information regulation and administrative arrangements will provide sufficient anonymity requirements?



The majority of participants (52%) were in agreement that the requirements for anonymity were sufficient for proposal [16]. Cross tab analysis showed that Health service managers and Health Informaticians were the most positive both at 63% with Mangers 58% positive and Medical Practitioners 57% positive in agreement.

Comments on the Proposal on Anonymity

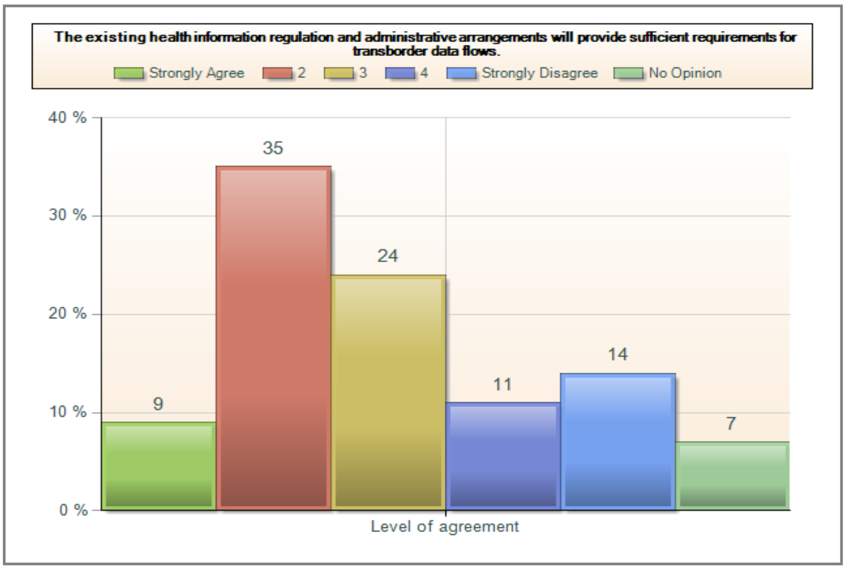
1. A personal health record has no need to be anonymous
2. Insufficient detail and lack of communication prevent proper consideration of this item.
3. Need to protect against identification due to small sample size.

4. As far as I can see, the IHI is very rarely able to be used to identify a patient without additional demographic info (personal communications). Ergo, it isn't even intended to be used anonymously. Deriving IHIs from Medicare numbers when the uniqueness of the latter is so uncertain leads to (a) huge importance on data cleansing (with unexamined privacy implications??), and (b) the obvious need for redundancy over an long period of time; i.e. IHIs on their own won't be reliable, so anonymity suffers.
5. This may be true but will require careful attention to detail during implementation
6. Not enough information known to present an opinion. Would need to see provisions being developed.
7. Anonymity mechanism must be tied to best practice e.g. Aust standard for pseudonym EHR.
8. A completely different approach is required to allow people to be sure that they can receive services anonymously. An alternative approach would be to allow people to create multiple identifiers and would require significant public education and understanding of the implications, risks and benefits of doing so.
9. 1You must have a common national privacy protection legislation and privacy protection principles. The continuum of care and services is the major question and it cannot be proved without common rules. Best solution is a unique ID.

Proposal on Trans-Border Data Flows

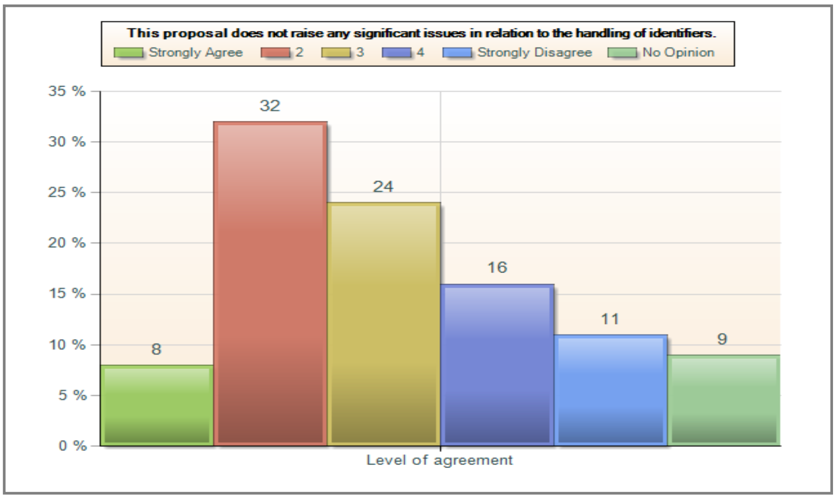
Proposal 17: Existing Commonwealth, state and territory health information regulation and administrative arrangements will apply to transborder data flows.

Q19. Do you agree that existing health information regulation and administrative arrangements will provide sufficient requirements for transborder data flows?



Although more agreed (44%) with the proposal [17] on transborder data flows, 28% disagreed with 14% strongly disagreeing. Analysis showed that the Mangers were the group to most disagree as were those from the Health Service Supplier organisations.

Q20. Does this proposal raise any significant issues in relation to the handling of identifiers?



In regard to significant issues on proposal [17] there was less overall agreement (40%) than with question 19.

Comments on the Proposal on Trans-Border Data Flows

1. I am not sure how this will overcome transborder flow of data. Hopefully it will as the current situation is spaghetti.
2. It seems current conditions forbid "cloud computing" - utterly absurd
3. Insufficient detail and lack of communication prevent proper consideration of this item.
4. I'm not sure about this. Presumably some other countries have very poor security for health data or are vulnerable to corrupt practice
5. Need to ensure consistency for all data sets shared between jurisdictions - some are identified and some are not. Identification should occur to support better health policy development but needs to be accompanied by legislation that ensures appropriate use
6. Private sector PHRs (like Google Health) will be compelling. Many will be offshore. I cannot see any effective way to quarantine IHIs. Is it proposed that private sector PHRs simply undertake not to gather IHIs?
7. Variations between states and territories within Australia regarding their privacy laws need to be removed. The existing arrangements should not impact on HI arrangements.
8. Federal laws should be passed to enable free transborder data flow on health information. All States and Territories must be required to bring their privacy protection laws up to the same high standard before the identifier is put into action. It will create an entire level of bureaucracy just to allow data transfer if we leave the current system in place. We are one country. This issue is perpetrating a poor health care system and putting Australians at risk.
9. If there are different privacy laws from state to state this will be unnecessarily cumbersome. One federal law would be better
10. This is a complete nightmare for online services with national coverage.
11. Also in trans-border communication this issue should be considered as sensitive.

Proposals on the Functions of Medicare

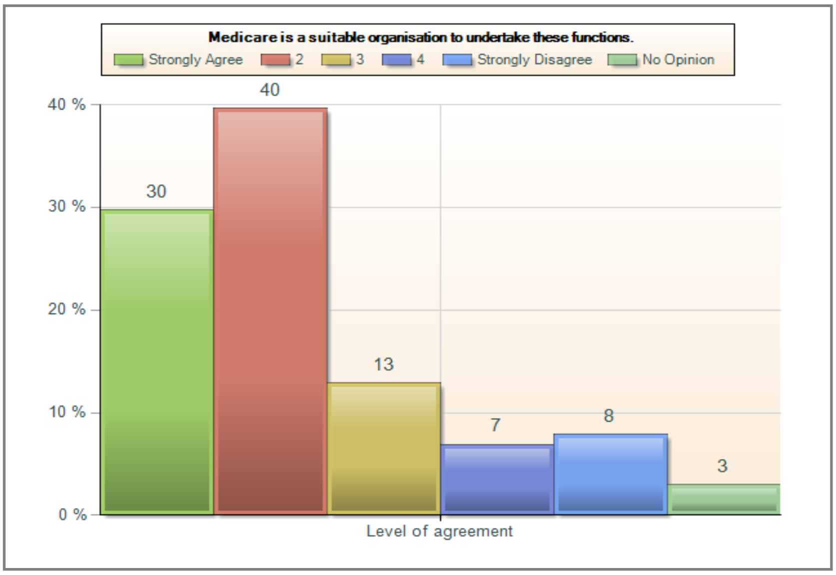
Proposal 18: The role of the Ministerial Council would be set out in an intergovernmental agreement. Key elements would be set out in legislation, including any processes for future consideration by the Ministerial Council about the operation or expansion of functions of the HI Service.

Proposal 19: Establish a process for controlling the expansion of the future uses of the HI Service. This could be done by:
- providing for the Minister who is responsible for the legislation to determine future operation or expansion of the service subject to a requirement to undertake a privacy impact assessment and seek agreement from all state and territory Health Ministers.

Guidelines for the steps to be undertaken would be expected to be set out in the legislation.

Proposal 20: It is proposed that these functions would be undertaken by Medicare Australia in its role as the initial HI Service Operator (see Proposal 1 above).

Proposal 20: It is proposed that these functions would be undertaken by Medicare Australia in its role as the initial HI Service Operator.



This question on the suitability of Medicare to undertake the Health Identifiers function was not directly asked in the discussion paper. An extra question was included in the survey to address proposal [20]. The response from the participants was very positive toward Medicare (80%). Some of the reservations are listed below:

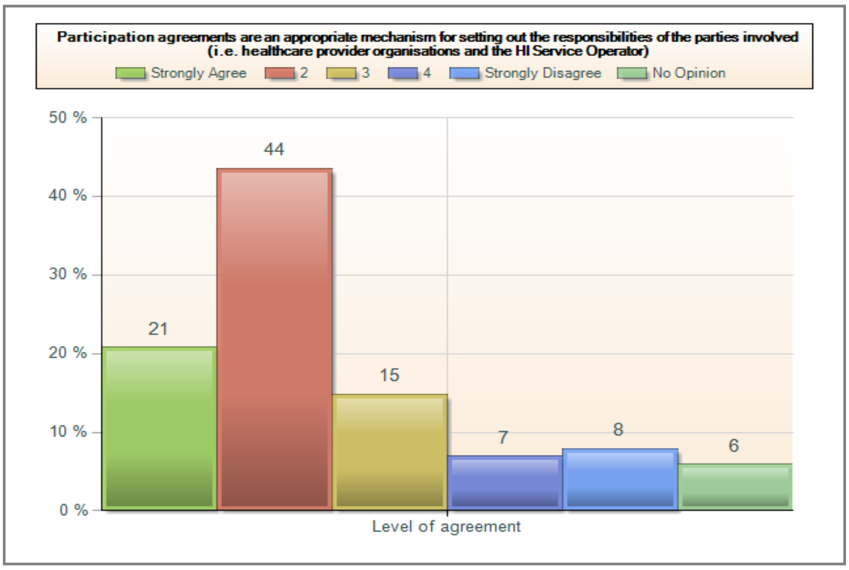
Comments on the Proposals on the Functions of Medicare

1. Medicare is so bureaucratic and restrictive - all data goes in and none comes out. There is a need for national research and quality monitoring - the organisation must facilitate this.
2. Medicare does a bad job with its current duties and responsibilities
3. The principles involved are agreed however the management of the system will require inclusive involvement in the operation of the system so that its complexity and mistakes which will inevitably arise can be quickly and effectively managed. Without such governance, poor performance will surely be widespread.

4. I can't think of an alternative
5. Subject to appropriate accountability including independent governance - not just MA CEO to Human Services Minister
6. AS long as they are suitably resourced for this new function
7. Based on their track record of maintaining Medicare numbers I am concerned we will end up with multiple IHI and the system will lose integrity. Their will need to be a major change in identification protocols and maintenance of identifiers.
8. With review and appropriate restructure and human resourcing to ensure that the Functions of Medicare are carried fully.
9. provided given additional resources (i.e. funding and suitably qualified/experienced/trained personnel)
10. appropriate organisation but must be able to automate or web enable data access/corrections from approved health providers with adequate security.
11. This is a cost saving device
12. Attention must be paid to usability (in all its aspects, e.g. forms, UIs, and effectiveness of communication). Education and training are important, but the more usable and effective the systems are, the less training is needed. Spend extra money at the beginning to save at the end.
13. If Medicare On Line is an example, then a better organised group will need to be implemented.
14. Medicare should be managing the service and the support of the service. It should then proliferate the service out to other agencies
15. This function is significantly different from current Medicare functions. This work is crucial to the acceptance of the need for identification and should be undertaken in the context of a broader public education campaign about the transformation of health care with IT.
16. Not sure - might be better to be an independent national health agency separate to Medicare - avoids potential conflicts of interests.

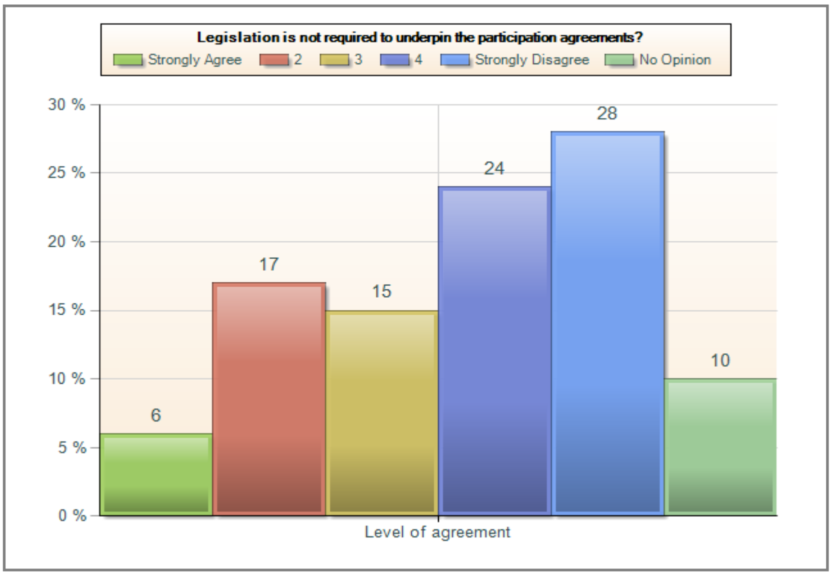
Proposal on Participation Agreements

Q21. Do you think participation agreements are an appropriate mechanism for setting out the responsibilities of the parties involved (i.e. healthcare provider organisations and the HI Service Operator)?



The majority of participants (65%) thought that participation agreements were an appropriate mechanism. Only 15% disagreed.

Q22. If so, do you consider that legislation is necessary to underpin the participation agreements?



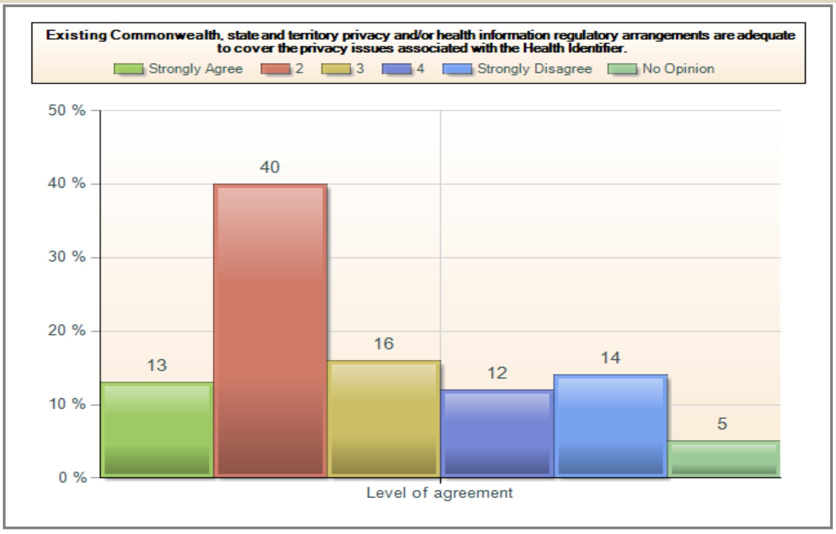
The negative response to this question indicates that the majority (52%) believe that legislation is required to underpin participation agreements. Those groups that felt the strongest were the Medical Practitioners and the Health Service Suppliers.

Comments on the Proposal on Participation Agreements

1. Again - barriers and stumbling blocks
2. This is a complex question about which no effective consultation with consumers has occurred. We consider that this oversight needs to be corrected in regard to such vital issue.
3. Some small aged care agencies are very unsophisticated regarding IT and data security
4. Intuitively it seems very unlikely that no legislation is required here, when specific amendments are required to remove existing restrictions on identifiers etc.
5. Yet another stand alone agreement should be dismissed as yet more red tape for each organisation and hence discarded as unnecessary. It should be assumed as part of functioning as a healthcare organisation in Australia that these standards are met, not another separate bit of paper to be completed and hoops to be jumped through for this particular issue! Hence, overriding legislation about health information management in general should cover this.
6. This is not a voluntary situation - clear adherence is required. I would expect some legislative support is required
7. Medicare's track record with similar vendor agreements for Medicare online and PBS online is poor. Medicare use them as to justify non standards based implementations and to change them at will. Organisations entering into such agreements with Medicare have an unequal power relationship making negotiation of "reasonable" conditions very difficult. There should either be legislation of an independent third party who oversees these agreements.
8. Would define requirements/responsibilities formally.
9. Minimum participation agreement criteria should be legislated.
10. Legislated and very strong penalties will send a positive message to both provider organisations and consumers
11. Should define the collection, storage, access and transmission of sensitive information as National standards.
12. choice will slow down the uptake
13. The scope of participation agreements needs to be clear and well defined in National legislation. That this approach is being considered at all is due to the failure to achieve any agreement on a single national legislative environment.

Proposal on Independent Regulation

Proposal 21: It is proposed that existing Commonwealth, state and territory privacy and/or health information regulatory arrangements will apply.



The majority (53%) were in agreement with independent regulatory arrangements in regard to proposal [21]. 26% disagreed and alternative suggestions are included in the comments that follow:

Comments on the Proposal on Independent Regulation

1. Current health information arrangements are user unfriendly, atrociously administered and completely out of time with modern professional IT systems
2. same comments as comments 38.
3. As a short term arrangement they are but in the longer term we need one unified regulatory arrangement, not one that varies between jurisdictions.
4. A commissioner specifically empowered to deal with UHI issues may be advantageous
5. If the points covered in A.6.2.3 Independent regulation are within current legislation then I agree. If they are not they should all be employed. The discussion paper extract does not make this point clear.
6. They are confused, contradictory and do not set out to achieve the same objectives. There should be a National standard.
7. NPP appear to be adequate to cover general ID needs. State health regulations should ensure adequate privacy coverage in relation to transfer of information
8. Disclosure of the identifier should not be any more regulated than disclosure of other health information
9. We certainly need devolution of the application of regulations to local levels, but there should be a single consistent national regulatory environment.
10. I would suggest health privacy authority.
11. Uniform national privacy principles, as advocated by the ALRC, are desirable and should be pursued with some haste.

Part B: Proposed National Privacy Reforms

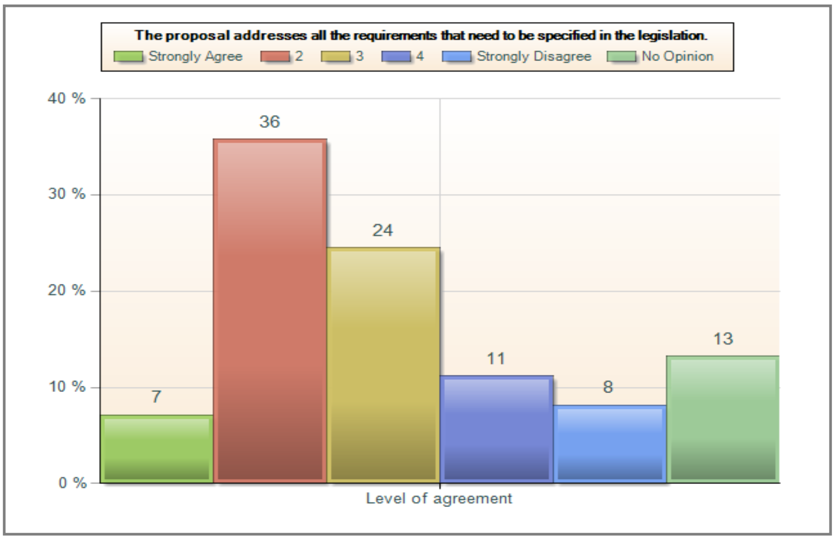
Proposal on Administration

Proposal 22: National legislation include requirements such as: conciliation being a critical element in the approach to resolving complaints; an independent administrative or judicial mechanism; the length of time consumers have to lodge a complaint; powers of regulators; and sanctions for breaches of the law by agencies or organisations.

Guidelines including minimum standards be developed and agreed to by regulators to ensure that there is a consensus in the way in which privacy laws are to be applied across Australia.

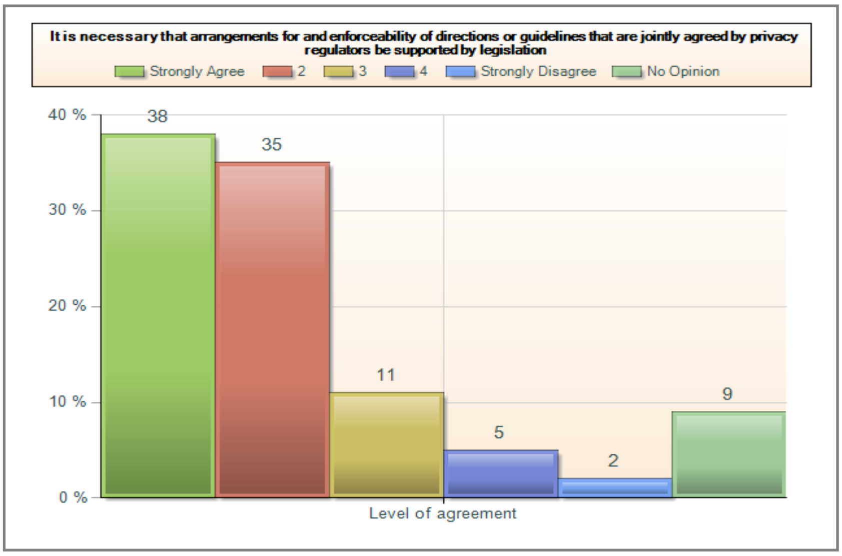
Jurisdictional regulators be empowered to jointly determine a common approach to applying these minimum standards.

Q23. Are there any other requirements that should be specified in legislation?



43% were in agreement that all the requirements relating to proposal [22] are addressed with 19% disagreeing.

Q24. Is it necessary that arrangements for and enforceability of directions or guidelines that are jointly agreed by privacy regulators to be supported by legislation?



The majority (73%) response here agreeing that legislation is required and jointly agreed as outlined in proposal [22] shows a strong agreement from many (38%) on this issue. The IT, Engineers and Scientist was the group that gave the highest strong positive agreement (50%).

Comments on the Proposal on Administration

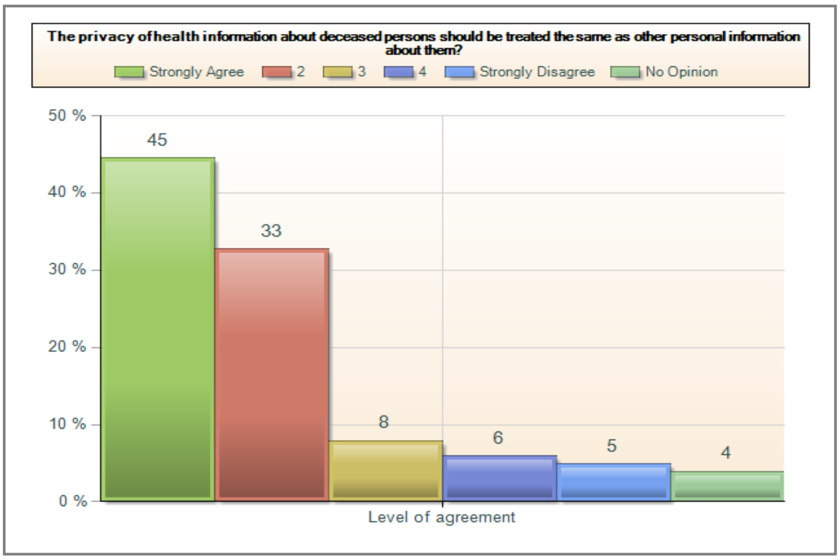
1. Force, coercion

   Recipe for yet another tier of dead wood administrators, bureaucrats, supervisors, red-tape, user time wasting
2. Action beyond broad agreement will require quality consultation with all stakeholders.
3. There also needs to be very severe penalties for breaches to deter inappropriate acts.
4. Yes, however guidelines are better as flexible standards (e.g. guidelines thru the Privacy Commissioners office) that are able to be adjusted outside of legislative amendment process - which is slow to respond to identified difficulties in practical application and seems to lead to convoluted and difficult to follow legislation.
5. It is not good enough to have baseline standards embodied in national legislation. We need a uniform national legislative and regulatory environment.
6. How about included health providers and consumers in the discussion?

Proposal on Coverage

Proposal 23: Health information of deceased individuals should be subject to the same protection as other personal information about deceased persons whether this is through privacy law or other arrangements.

Q25. Are there any reasons for the privacy of health information about deceased persons to be treated differently to other personal information about them?



The majority of participants agreed (78%) with almost half strongly agreeing (45%) in regard to proposal [23] about the privacy of the deceased. The Medical Practitioners agreed strongly (71%) on this issue.

Comments on the Proposal on Coverage

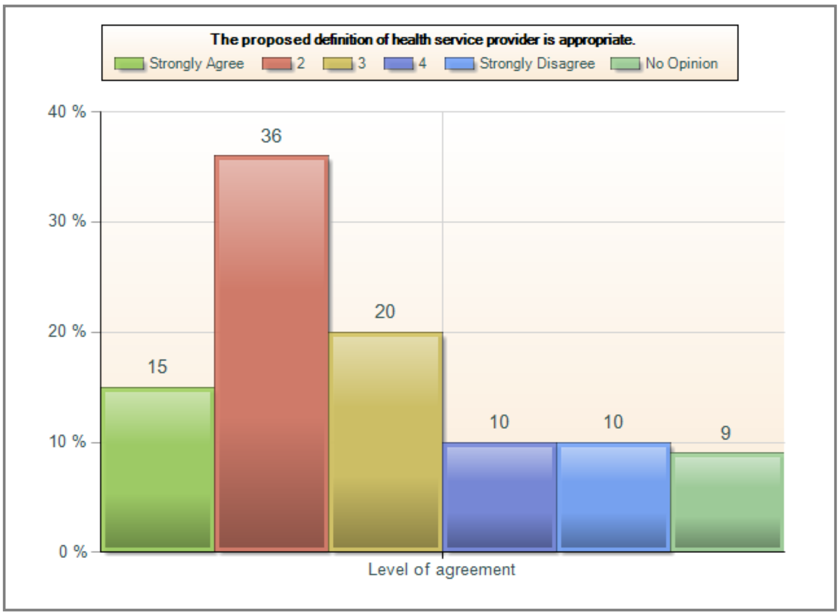
1. Need to learn from death to improve health for the living.
2. same as comments made on Q42.
3. What I mean is that deceased persons' health information should continue to be strongly protected. I think the question is poorly and ambiguously framed because when it says 'the same as other personal information', my understanding is that privacy protection in general disappears after death because a dead person is not a "natural person".
4. Need caution where a deceased person's health information has the potential to impact other living family members (e.g. familial diseases)
5. Differing levels of protection required for different classes of information
6. Bearing in mind that health information is also sensitive information rather than just personal information and that provisions for access for Organ transplantation medicine are provided for by appropriate legislation.
7. As per current policies
8. There may be good reasons that such data becomes available for post-mortem assessment.
9. Note that retention of information about deceased persons - and the care they had received - can be very important in monitoring safety and quality of care. Also note that many health providers may not be aware of the individual's death and may not be aware they are holding information about a deceased person. Should there be a distinction between living and dead person's data and the way it should be treated?

Proposal on Key Definitions

Proposal 24: Include a definition of ‘health service provider’ as ‘an organisation that provides a health service to the extent that it provides a health service’.

Q26. Is the proposed definition of health service provider appropriate?

Q27. Are there any other terms that need to be defined to support a health information privacy protection as part of a national framework?



The majority (51%) agreed that the definitions were appropriate for health service providers in relation to proposal [24].

Comments on the Proposal on Key Definitions

1. Needs to make sure of management accountability for staff within providers
2. Farce
3. I may have missed something - but from what I've read the definition is too broad.
4. The description needs to ensure inclusivity (including out-of-hospital sector providers and alternative therapy providers - so long as they adhere to the administrative arrangements) without specificity so that new types of provider can be accommodated over time
5. A provider can be an individual not working within an organisation
6. Don't understand why the last bit "to the extent that it provides a health service". Sounds like Yes Minister or Legalese to me. Of no sense to the average population. Why not just the first bit; an organisation that provides a health service?
7. I don’t understand the meaning of the "to the extent that it provides a health service" Can you be a little bit of a "Health service provider"?
8. jargonistic.
9. what about individuals?
10. it is circular

11. Not sure if this adequately covers all organisations who may have a "touchpoint" to health information (e.g. it's carriage/storage)
12. Confused (noted previously)
13. It can always be modified as required
14. Can be an individual
15. Definition needs to be broad enough so as to not to exclude legitimate parties.
16. See my previous comment

Proposal on Unified Privacy Principles (UPP's): 2

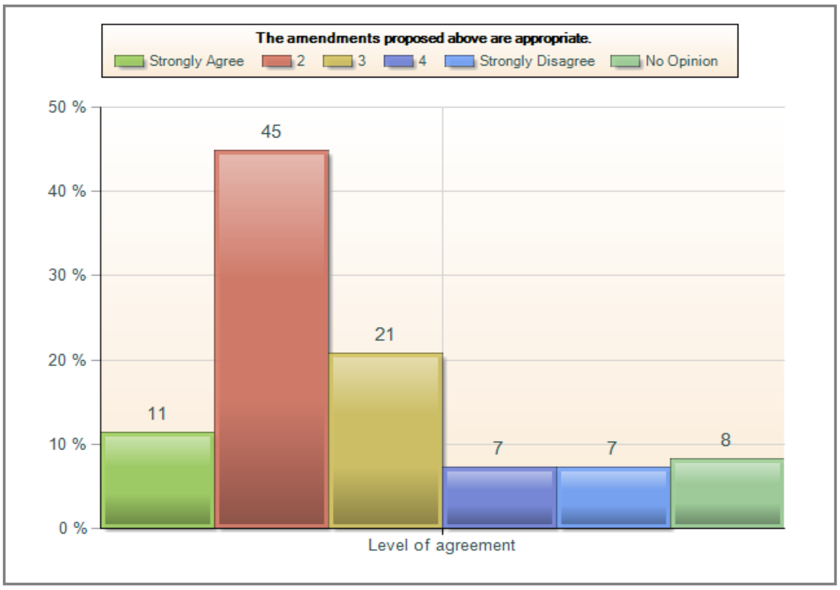
Proposal 25: Amendment of 2.5(c) to allow the collection of sensitive information where there is a serious threat to an individual's welfare.

Proposal 26: Deletion or modification to 2.5(d) to exclude the right for non-profit organisations to collect health information about their members.

Proposal 27: Amendment of 2.5(f) to provide that any guidance issued by the Privacy Commissioner in relation to the collection of sensitive information necessary for research purposes be required to be developed in conjunction with input from other appropriately qualified individuals or organisations in the field of research.

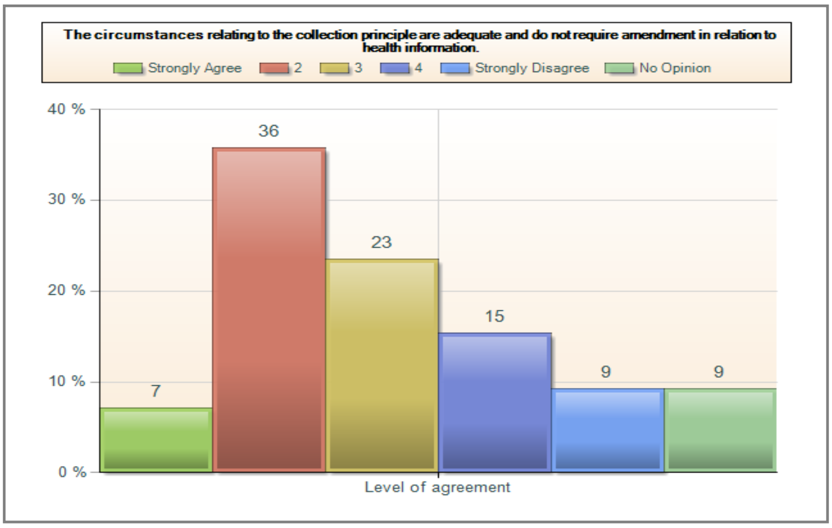
Proposal 28: Any rules or guidelines issued by the Privacy Commissioner in relation to the collection of identifying health information where it is necessary for the funding, management, planning, monitoring or evaluation of a health service be developed in conjunction with input from other appropriately qualified individuals or organisations in the health service management field.

Q28. Do you agree that the amendments proposed above are appropriate?



The majority (56%) agreed that the amendments proposed were appropriate in relation to proposals [25-28].

Q29. Are there any other circumstances where the collection principle might require amendment in relation to health information?



Although more agreed (43%) than disagreed (24%) that the circumstances relating to the collection principle are adequate in relation to proposals [25-28] the response would have been more even if we excluded the IT, Engineers and Scientists. For the Medical Practitioners and Nurses they disagreed (50%) more than agreed (25%) on this issue.

Comments on the Proposal on Unified Privacy Principles (UPP's):

1. Additional sensitive information has no place in the IHI service. International research indicates that linking sensitive information to identifiers increases objections to the service and destruct of the service. The service should remain purely an identification service.
   NFP organisations should not be treated differently.
2. Use of information for research needs to be made easier so long as it is de-identified and cannot be re-identified. Consent should be discarded from the discussion in this situation.
3. I believe that coupling these changes to Health privacy principles to the UHI is unnecessary and possibly will derail or delay the UHI introduction
4. define "an individual's welfare"
5. The role of consent in treatment needs to be clear (i.e. the extent to which consent is required for the treatment of the patient)
6. The exception for 'Funding, management, planning, monitoring or evaluation of health services' should include "improvement" and must be added as a clause with extra guidance to be provide by the PC similar to the framing of the exception for Research 2.5(f)
7. These changes should be made in relation to the handling of health information in general. They actually have nothing to do with the identifiers
8. Uniform legislation/regulation again
9. need to include consumers, plus have right to opt off.
10. Need to ensure that monitoring and evaluation is not curtailed by nebulous claims of privacy.
11. Definition "the collection is necessary for research in the public interest (or public good" is to open. Who defines " the public interest"? There should be a specific purpose for data collection even in the case of "public interest". Subjects of care should be always informed and they should have right to reject data collection for research purposes.

Proposal on UPP 5: Use and Disclosure of Information

Proposal 29: Amendment of 5.1(c) to allow the use or disclosure of sensitive information where there is a serious threat to an individual's welfare.

Proposal 30: Amendment of 5.1(f) to provide that any guidance issued by the Privacy Commissioner, in relation to the use or disclosure of sensitive information is necessary for research purposes, be required to be developed in conjunction with input from other appropriately qualified individuals or organisations in the field of research.

Proposal 31: Rules or guidelines issued by the Privacy Commissioner in relation to the collection of identifying health information where it is necessary for the funding, management, planning, monitoring or evaluation of a health service be developed in conjunction with input from other appropriately qualified individuals or organisations in the health service management field.

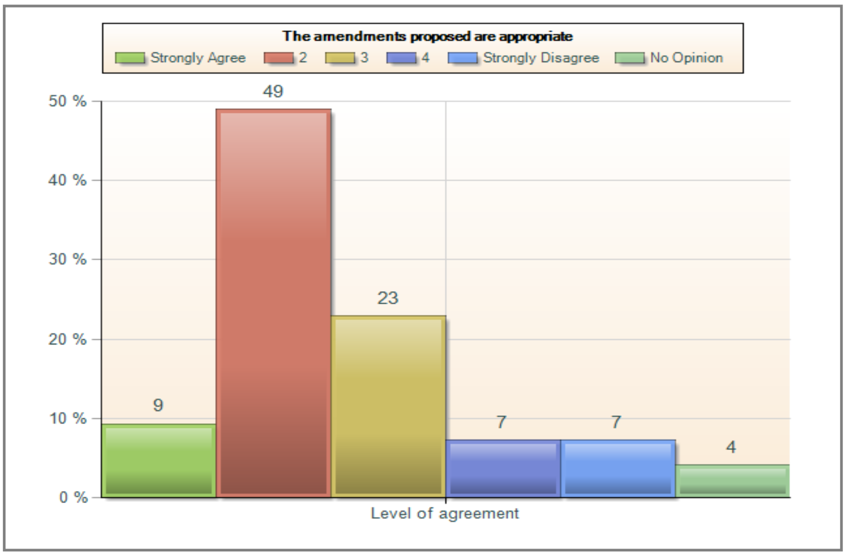
Proposal 32: An exception is proposed to allow personal information to be used or disclosed by an agency or organisation where an individual is known or suspected to be missing or deceased, subject to this not being contrary to any wishes expressed by the individual before they went missing or became incapable of consenting, with disclosure limited to a law enforcement officer for the purposes of ascertaining the whereabouts of the person.

Proposal 33: It is proposed that the definition of a 'person responsible for an individual' be altered to provide for:

- any person who has a personal relationship with the individual rather than only a person who has an intimate relationship, or
- a person who is responsible for providing support or care to the individual rather than only the person who is primarily responsible.

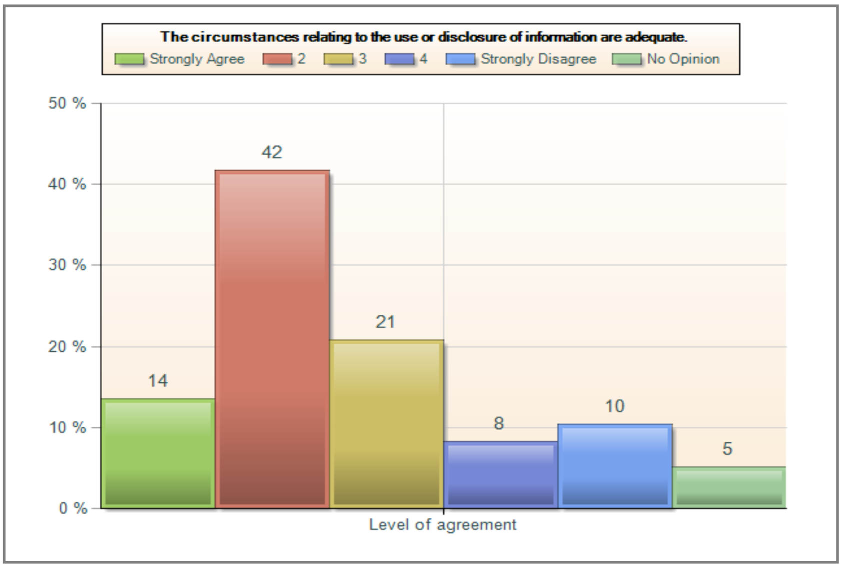
Guidelines could identify the grounds on which a personal relationship exists or that a person is responsible. These would include such things as whether there is a sufficient degree of intimacy or level of responsibility. Another alternative would be to set the list up as an inclusive rather than an exclusive list.

Q30. Do you agree that the amendments proposed above are appropriate?



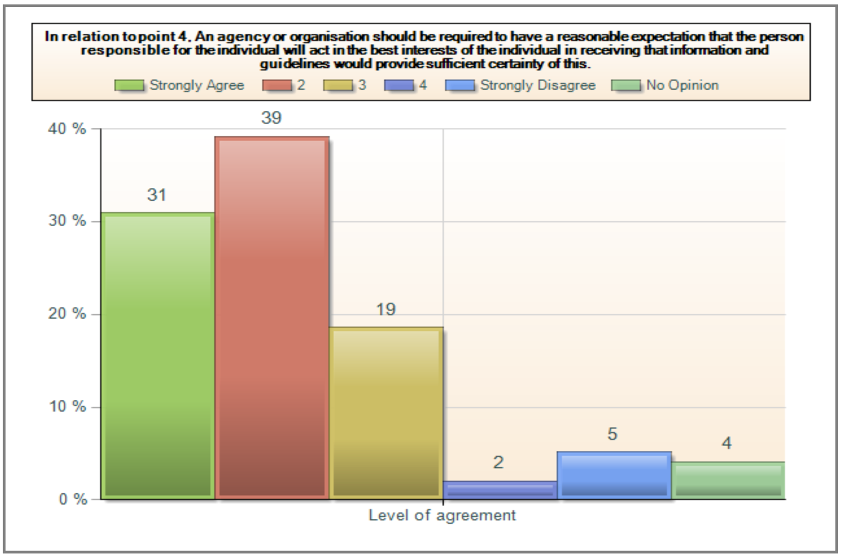
The majority (58%) agreed that the amendments proposed were appropriate in relation to proposals [29-33] while only 14% disagreed.

Q31. Are there any other circumstances where additional guidance about the use or disclosure of information would be helpful?



The majority (56%) agreed that the amendments proposed were appropriate in relation to proposals [29-33].

Q32. In relation to Proposal 32, should an agency or organisation be required to have a reasonable expectation that the person responsible for the individual will act in the best interests of the individual in receiving that information? Would guidelines provide sufficient certainty?



The majority (70%) agreed that guidelines would be sufficient for organisation in relation to proposals [29-33].

Comments on the Proposal on UPP 5:

1. I'm yet to be convinced on points 48 to 50. Perhaps a rethink is needed here.
2. pt consent or consent from their proxy is paramount
3. Elder abuse is a concern

4. Relating to point 5, while I do agree with the pragmatic approach here, sufficient caution would need to be exercised. What of the abusive (ex)husband who successfully convinces the clerk that his wife is his wife; thus finding out her new address?

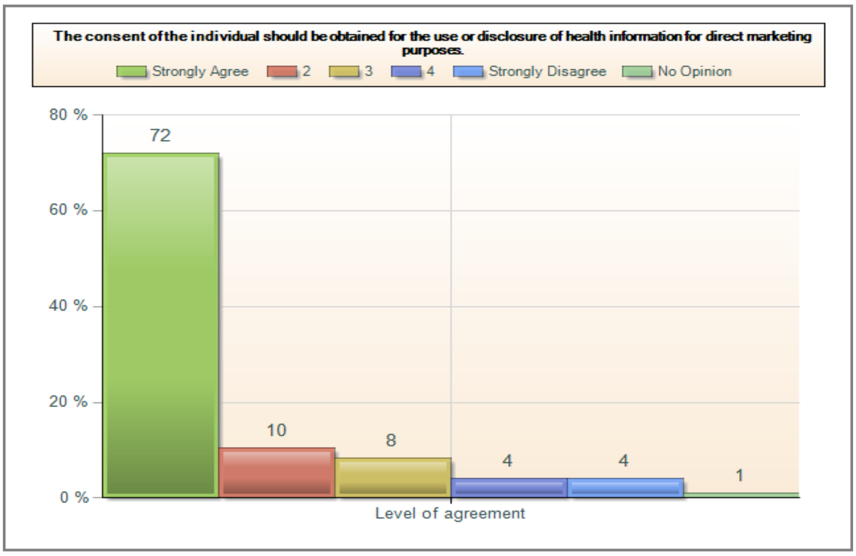
    If an inclusive rather than exclusive list of representatives, also need a specific 'excluded' sub-list to list those who should NOT be considered representatives (see separated or ex husband example above).
5. These issues need to be worked through BEFORE legislation. It really isn’t good enough to push through with this without these important issues being addressed in the legislation
6. There should be an amendment to protect the welfare of the healthcare providers. If it is known that an individual poses a serious risk to health providers, then this information should be allowed to be shared. There is an amendment to protect the individual's personal risk, but not the provider. We have already lost too many providers through actions of individuals seeking healthcare. We need protection too. Perhaps the amendment could read "a serious risk to an individual's or healthcare provider's welfare"?
7. These changes I believe would allow governments to routine breach patient confidentiality by declaring it was "A serious threat to the individual".
    a. I believe these proposed changes should be removed
8. "Amendment of UPP 5.1(c) to allow the use or disclosure of sensitive information where there is a serious threat to an individual’s welfare."
    a. This section is ripe for abuse. This entire section is open for massive abuse.
9. Guidelines are inappropriately low level of enforcement of privacy
10. The exception for 'Funding, management, planning, monitoring or evaluation of health services' should include "improvement" and must be added as a clause with extra guidance to be provided by the PC similar to the framing of the exception for Research 5.1(f)
11. As long as it is clear about the penalties for breaches
12. These changes should be made in relation to the handling of health information in general. They actually have nothing to do with the identifiers
13. Need to ensure that monitoring and evaluation is not curtailed by nebulous claims of privacy.
14. Reasonable belief is to week and open term. You can always say that there was a reasonable belief.

    Here you are speaking about "serious threat to an individual’s welfare". Welfare is not same as health. It is much more and depends of personal settings. It can be any kind of professional, political, economical or even religious opinion.

Proposal on UPP6: Direct Marketing

Proposal 34: The consent of individuals is required to the use or disclosure of health information for direct marketing purposes.

Q33. Do you agree that the consent of the individual should be obtained for the use or disclosure of health information for direct marketing purposes?



The issue of gaining consent for direct marking in relation to proposal [34] had the greatest positive agreement (82%) of any question. Of all the groups the Health Informaticians felt the strongest on this issue and only 1% overall had no opinion.

Comments on the Proposal on UPP6:

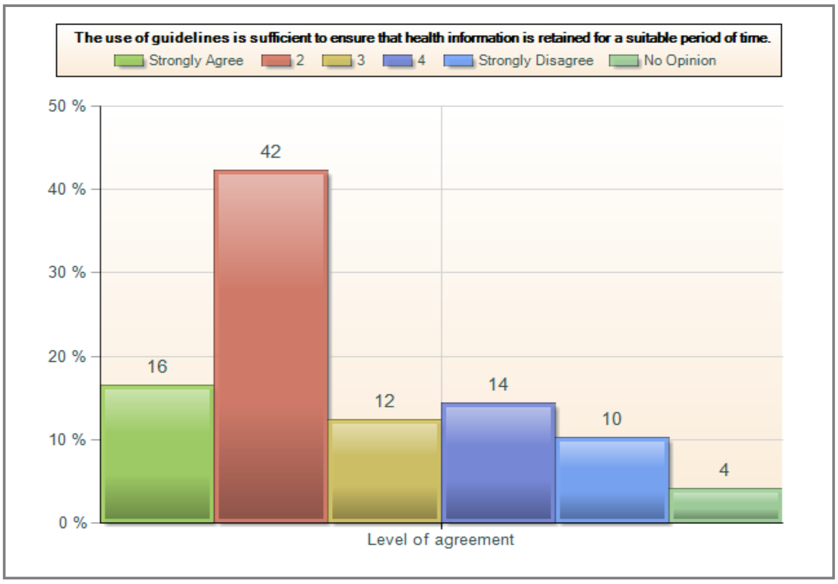
1. In general, I believe that no direct marketing access to ANY private health information should be allowed.
2. So - financial or commercial use peeps into view already
3. This is essential if direct marketing is undertaken/purposed.
4. Health information should not be discloses to any party for direct marketing purposes without the express consent of the individual concerned.
5. I'm not sure that any direct marketing is a good idea
6. There should be no provision for direct marketing. The IHI service is being established for the identification of individuals in order to provide health services ONLY
7. Properly handled, carefully targeted health promotions might be OK subject to implied consent. If we truly believe that PHRs are important to patient centric care, and if we are comfortable with these being private sector based, then we will probably need to think more about implied consent to marketing.
8. I do not believe health information should be allowed to be used for direct marketing under any circumstances, even with patient consent as often the power relationships where such consent is obtained are too disparate.
9. The default should be non-participation - not the requirement to "Opt out"
10. Spam - please NO. General peak body (e.g. Diabetes Australia) general information and choice to join things like NDSS. NO Drug company marketing their latest cholesterol lowering drug because you have a high cholesterol reading!!!

11. I have some very strong reservations about the use of direct marketing in healthcare. Other than for health promotion activities (which should not, in my opinion, be under the guise of direct marketing), I cannot see any role for marketing in this legislation other than for the legislation to enforce a prohibition. I don't think the general populous would be happy with this aspect of the proposal.
12. Absolutely vital
13. People tend to say no if they don't understand the consequences. Most people don't understand statements by Government organisations.
14. Also when the media request information via FOI. There needs to be written consents and acknowledgement of the use of the data,
15. These changes should be made in relation to the handling of health information in general. They actually have nothing to do with the identifiers
16. If identifiable
17. Should this be explicit or written consent?
18. There are many level of consent. Consent must be informed and signed be subject of information.

Proposal on UPP 8: Data Security

Proposal 35: Guidelines be developed by the Privacy Commissioner outlining key requirements for retaining health information (e.g. minimum retention periods and obligations owed by a healthcare provider to an individual where a healthcare service has been sold, amalgamated or closed).

Q34. Are guidelines sufficient to ensure that health information is retained for a suitable period of time?



The majority (58%) agreed that the use of guidelines to ensure health information is retained as appropriate in relation to proposal [35].

Comments on the Proposal on UPP 8:

1. Should be a legislatively defined and enforced

2. All data should go to the individual.
3. This should be a matter of national policy covering all stakeholders by enforceable legislation. Guidelines are inadequate to deal with such situations.
4. But guidelines should be reviewed to ensure they are adequate.
5. NHMRC guidelines should be used for research information
6. I think precedent dictates that if there are any gaps, specific legislation would be required.
7. Needs to be worked through prior to legislation not passed to the PC.
8. Guidelines are not strong enough - should be legislated
9. Security of health information in general gets very short shrift in Australia. Health information tends to be under-classified. Guidelines are generally policy and management process focussed and very light on actual preventative measures.
10. Required retention times need to be stated. Not vague recommendations.

    Also, needs to be some statement about the author being able to access the records written by them for medico legal defence purposes-e.g. medical centres where they no longer work denying access.
11. This is not the case in the pathology sector and there needs to be uniformity across the entire sector and all domains otherwise managing electronic data will become extremely difficult. Changes will potentially be extremely expensive for industry to implement so it would be much better for it to be legislated
12. Recommend a strict retention schedule, based on content class, and not merely guidelines.
13. Requires review at National Level and applied out nationwide
14. Will always be complex given the different requirements between States and services types for minimum retention periods.
15. education on records maintenance, included/checked as part of certification
16. This should be law
17. Guidelines not sufficient - only legislated requirements are enforceable and then the penalty has to deter bad practice
18. If for any reason the Guidelines prove inadequate, legislation should be enacted
19. These changes should be made in relation to the handling of health information in general. They actually have nothing to do with the identifiers
20. Uniform legislation/regulation
21. I would argue for a reasonable long period of retaining data.
22. Need legislation
23. May need to be driven by clinical need/relevance. Some data may be of value for decades.
24. Privacy commissioner is typically not well familiar with health care specific security questions (privacy is NOT same as security). Security principles should be set by legislation (e.g. a degree).

Proposal on UPP 9: Access and Correction

Proposal 36: It is proposed that the exception from providing access to health information where providing access would reveal the intentions of the organisation in relation to negotiations with the individual in such a way as to prejudice those negotiations does not include negotiations about provision of health services.

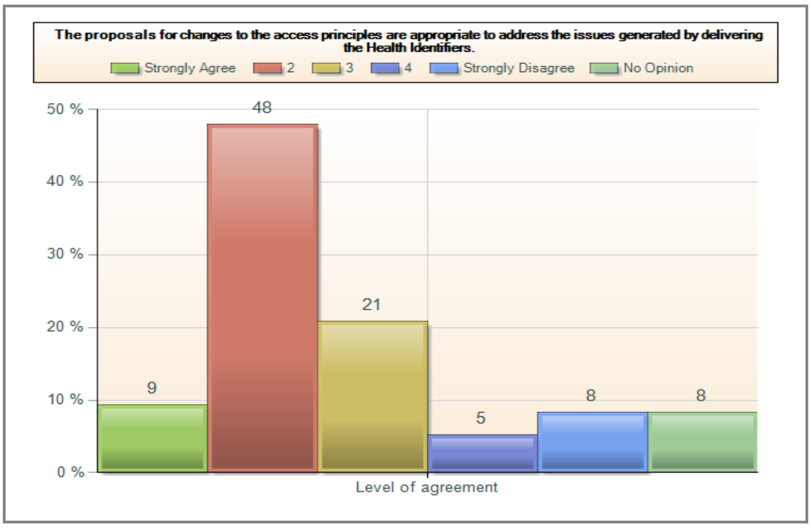
Proposal 37: A note be inserted into the Access and Correction Principle explaining that nothing in the principle compels an organisation to refuse to provide an individual with access to his or her health information.

Proposal 38: Guidelines be developed by the Privacy Commissioner that include detailed information about the process which should be followed to gain access to personal information, including guidance on requests for access, responses to those requests, how information is provided and fees.

Q35. Do you agree with these proposals?

Q36. Are guidelines sufficient to ensure processes for access to health information are understood by agencies and organisations?

Q37. Are any other amendments to the access principle required?



The majority (57%) agreed that the proposed changes for access principles are appropriate in relation to proposals [36-38].

Comments on the Proposal on UPP 9:

1. Researchers (especially overseas organisations like drug companies) should pay for access to information and payment should be made into the patients Medicare Fund. I would like to know if research information is being requested and transmitted to overseas organisations as correcting requesting information from overseas (about yourself) is ?difficult and probably not covered in this legislation.
2. The DOHA discussion paper doesn't seem to address the central issue of who owns the data. The proposal does not define the format of the data which this system is intended to provide as a conglomerate of information derived from a range of cooperating service providers. Without this detail it is difficult to address the question but also difficult to imagine how the end result would be covered by what have been proposed.

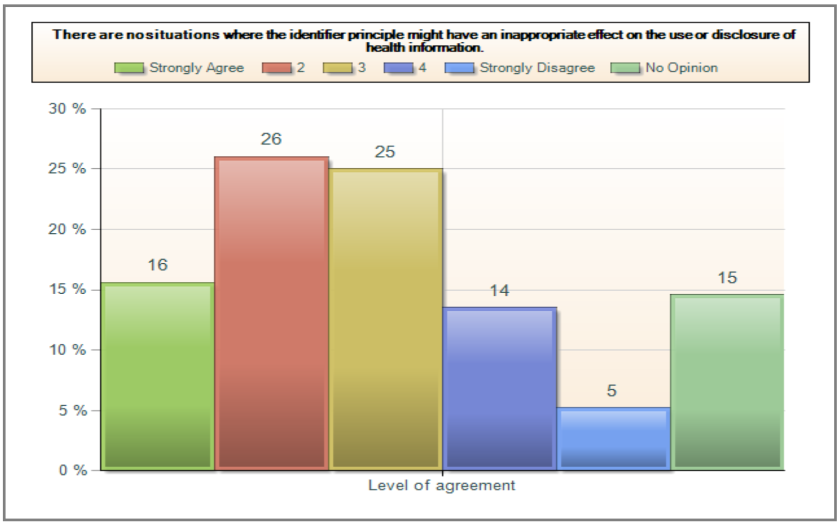
3. Wholehearted agree with the 'nothing in the principle compels an organisation to refuse to provide information' note.
4. Needs to be worked through prior to legislation not just passed to the PC
5. Fees for access should not be legislated, nor fixed as they will become quickly dated. They should be determined by the actual costs involved in access (e.g. costs in time of clinician being present to explain records and ensure no access to other individuals' records at the time), not dreamed up by some bureaucrat who does not understand the costs involved. Also, clarity over lawyers claiming access on behalf of their patients as a cheaper way of getting medical reports.
6. I do not believe these issues are specifically related to the health identifiers at all
7. This should be resolved in legislation
8. Would this override Breen v Williams? Don't we first need to wait for a legal definition of what constitutes "health information"?
9. While access is required for correction of information, the issues relating to the actual correction of the data would be more logically included under UPP7: data quality. Poor quality data can cause patient harm- the Pc should develop guidelines regarding standards of data quality to support UPP7 (which is very vague)
10. These changes should be made in relation to the handling of health information in general. They actually have nothing to do with the identifiers
11. See my previous comment.

Proposal on UPP 10: Identifiers (Organisations Only)

Proposal 39: The identifier principle should permit the use or disclosure of information that includes an identifier for funding, management, planning, monitoring, improvement or evaluation of health services and for research purposes in the public interest subject to the same limits that apply to health information being used or disclosed for those purposes.

Q38. Do you agree with this proposal?

Q39. Are any other situations where the identifier principle might have an inappropriate effect on the use or disclosure of health information?



In relation to proposal [39] on ‘Identifiers’ UPP10 the more agreed (42%) than disagreed (19%) although a significant number of participants (40%) had no opinion or were neutral.

Comments on the Proposal on UPP 10:

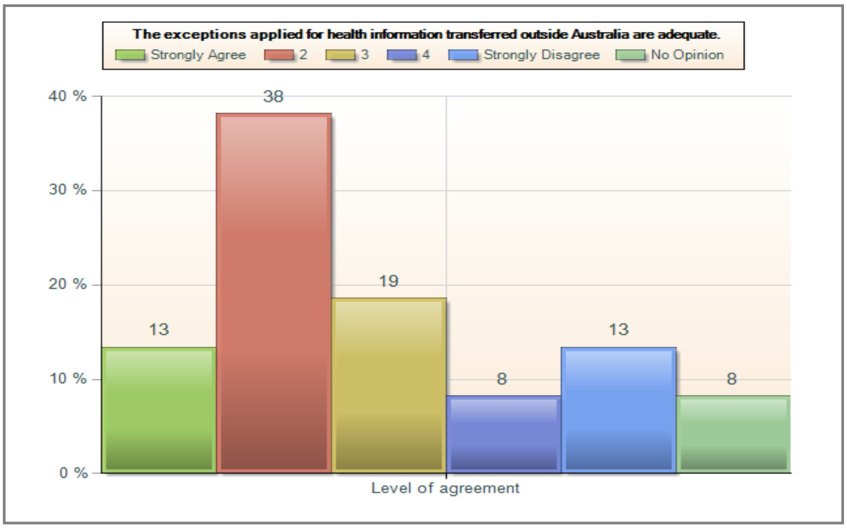
1. In all cases the public should know why there information is being used and should consent to the same. The whole research area requires review.
2. Action beyond broad agreement will require quality consultation with all stakeholders.
3. Perhaps this is the area where protection of the healthcare provider from individuals known to pose a risk could be allowed by allowing information to be shared by organisations in this situation.
4. Disclosure of an identifier will automatically make this identified Health information. Disclosure of such information other than for direct patient care or research approved by an appropriate ethics committee should not be permitted
5. Consider the case of emigration, where insured cohorts could enter a public/private system that might blacklist them, based upon identified risk factors that are exclusory for existing insurance plans. It may work flawlessly in Australasia, but not map as elegantly to the rest of the world.
6. The above statement is a double negative.
7. Use of Health Identifiers makes it possible to do far better research through data linkage. We need to ensure this retains an adequate firewall. Any risks must be fed back to primary care giver to discuss with patient.
8. This is far too broad
9. Just the initial set-up and linking with current data systems
10. provided controls are in place to prevent data matching
11. A vital step.

Proposal on UPP 11: Cross-Border Data Flows

> Proposal 40: An agency or organisation should be allowed to use or disclose information outside Australia to lessen or prevent a serious risk to life, health, safety or welfare without continuing to be accountable for any misuse.

Q40. Do you agree with this proposal?

Q41. Are there any other exceptions for health information transferred outside Australia?



The majority (52%) agreed that the exemptions for transferring health information outside Australia in regard to proposal [40] are adequate.

Comments on the Proposal on UPP 11:

1. Absolutely not appropriate as the laws are different in each country.
2. Accountability for miss-use is required
3. There should be mention of storage of health data overseas as this is becoming an issue with servers hosted overseas, and needs to be clarified.
4. This should only occur with patient (or their legal delegates) consent. In its current form this would allow disclosure in almost all circumstances as the Australian organisation would have little capacity to test a statement from overseas such as "serious risk to welfare". This would allow health information to be transmitted overseas to domains with much less regulation about health information and its subsequent retransmission back to Australia where it could be freely used.
5. Consider the statement: "where there is a reasonable belief that the recipient of the information is subject to a similar privacy law" It is wildly optimistic to think that an accurate adjudication could be carried out in all instances in a timely fashion, based on an exception clause alone. What is needed is a board of review, available on a 24/7 basis, to consider all emergent requests for release of information internationally.
6. Current expectations are adequate. Accountability must be maintained by the source in the absence of these.
7. Accountability is fundamental to ensuring ongoing responsibility
8. These changes should be made in relation to the handling of health information in general. They actually have nothing to do with the identifiers
9. Can’t be help responsible for what happens outside of Australia but controls need to be in place to prevent unauthorised release of information to outside Australia.
10. n you are speaking about prevent a serious risk to welfare. Privacy principles are different in different countries (e.g. Europe vs. USA). Therefore is necessary to know rules the data processor or any secondary user is following. In USA by Patriot Act CIA can use cross-border data for its own proposes.

Extract from:
‘A Vision for an Australian Healthcare System Transformed by Health Informatics’

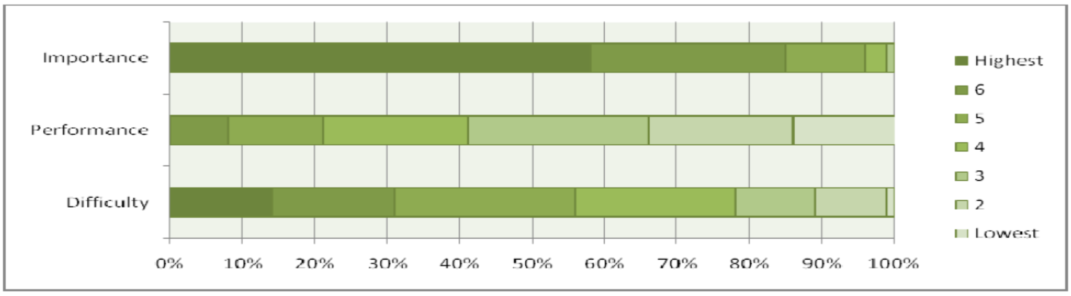
Full text available on www.hisa.org.au

Managing Privacy, Security and Confidentiality

- **In Australia's fully-enabled electronic information environment designed to engage consumers, transform care delivery and improve population health, consumers have confidence that their personal health information is private, secure and used with their consent in appropriate, beneficial ways.**
- **Technological developments have been adopted in harmony with policies and business rules that foster trust and transparency.**
- **Organisations that store, transmit or use personal health information have internal policies and procedures in place that protect the integrity, security and confidentiality of personal health information.**
- **Policies and procedures are monitored for compliance, and consumers are informed of existing remedies available to them if they are adversely affected by a breach of security.**
- **Consumers trust and rely upon the secure sharing of healthcare information as a critical component of high quality, safe and efficient healthcare.**

Transparency

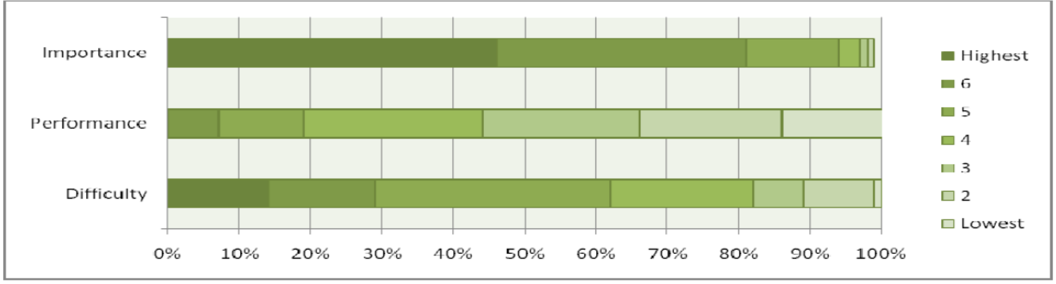
a. **Transparency -** *Policies for the permissible use of personal health information by those other than the patient are clearly defined, accessible, and communicated in an easily understood format. In addition individuals have the right to know how their personal health information has been used and who has access to it.*



Importance = 6.3, Performance = 3.2, Difficulty = 4.7 [20]

Collection and Use of Personal Health Information

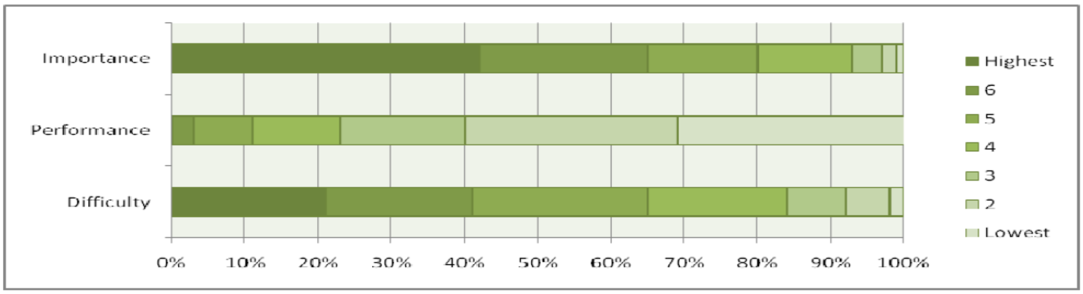
b. **Collection and Use of Personal Health Information** - *Personal health information of the individual consumer is obtainable consistent with applicable federal and state law. It is accurate, up-to-date, and limited to what is appropriate and relevant for the intended use. Consumers have a right to the privacy of their personal health information, taking into account existing exceptions under law. Consumers are apprised when they have a choice in how their personal health information is used and shared and when they can limit uses of their personal health information.*



Importance = 6.2, Performance = 3.2, Difficulty = 4.8 [20]

Individual Control

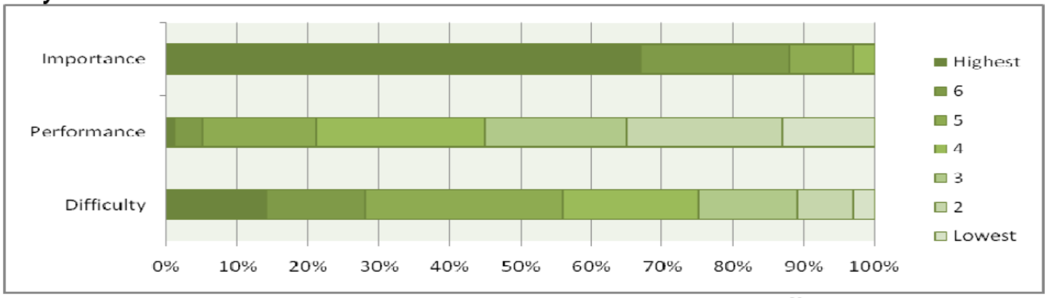
c. **Individual Control** - *Individuals are able to limit when and with whom their identifiable personal health information is shared. Individuals are able to delegate these responsibilities to another person. Individuals are able to readily obtain an audit trail that discloses by whom their personal health information has been accessed and how it has been used.*



Importance = 5.8, Performance = 2.4, Difficulty = 5.0 [20]

Security

d. **Security** - *Measures are implemented to protect the integrity, security, and confidentiality of each individual's personal health information, ensuring that it cannot be lost, stolen, or accessed or modified in an inappropriate way. Organisations that store, transmit, or use personal health information have in place mechanisms for authentication and authorization of system users.*



Importance = 6.5, Performance = 3.2, Difficulty = 4.6 [20]

Individual Health Identifier Consultation Survey

Created: July 23 2009, 6:04 AM
Last Modified: July 23 2009, 6:04 AM
Design Theme: Basic Blue
Language: English
Button Options: Labels
Disable Browser “Back” Button: False

Health Identifiers and Privacy Survey

Page 1 - Heading

About the Survey - HISA’s Privacy and Security forum (HIPS) has developed this survey to provide feedback on the Australian Department of Health and Ageing’s discussion paper on the proposed Individual Health Identifiers (Click here to download a copy of the paper)The survey is in two parts. Part A contains 23 multiple choice questions and is related to the Individual Health Care Identifiers (IHI’s) and their supporting regulations. If you have a casual interest in the IHI’s then this is the section you should complete. Part B contains 14 multiple choice questions and is related to the privacy regulations around the IHI’s. If you have an interest in information privacy it is important that you also complete this section. We have included cross reference (hyperlinks) to the original text to make things easier. We suggest that you answer as many questions as time permits. It is important to note that no identifying information will be used in the delivery of the analysis from this survey. We look forward to your contribution

Page 1 - Heading

Tell us about yourself - In this section we will ask you a few short questions about yourself which will allow us to better analyse the data. At the end of this section you can optionally tell us your name and email address. This will enable us to send you the survey report when it is completed and to involve you with discussions around the survey when they occur. All identifying information will be removed in the analysis of this survey.

Page 1 - Question 1 - Choice - One Answer (Bullets)

With which title do you most closely identify from the following list?

○ Medical practitioner
○ Nurse
○ Pharmacist
○ Allied health professional
○ Other healthcare provider
○ IT, engineering or science professional
○ Support worker
○ Manager
○ Health information manager
○ Health informatician
○ Other, please specify

Page 1 - Question 2 - Choice - One Answer (Bullets)

Organisation Type
Could you now tell us about the type of organisation that you work for. Click on the box which best fits your organisation:

○ I work for a healthcare provider organisation

- ○ I work for a healthcare systems vendor
- ○ I work for a government department
- ○ I work for a healthcare services supplier
- ○ I work for a university
- ○ Other, please specify

____

Page 1 - Question 3 - Choice - One Answer (Bullets)

Organisation SizeClick on the box which best describes the number of staff in your organisation:

- ○ Less than 10
- ○ 11 to 50
- ○ 50 to 200
- ○ 200 to 1000
- ○ Greater than 1000

Page 1 - Question 4 - Open Ended - One Line

Name (optional)

____

Page 1 - Question 5 - Open Ended - One Line

Email (optional)

Providing us with your email address will allow us to send you a copy of the final report.

____

Page 1 - Heading

Part A: National Healthcare Identifiers and Regulatory Support Proposals:

This section has 23 multiple choice questions relating to specific proposals put forward with the discussion document. All the questions are framed in the terms of a statement and you are asked how much you agree with that statement. There is also a "no opinion" option that you can choose when you do not want to make a comment.

You will be provided with a copy of the proposal followed by the multiple choice questions associated with that proposal. At the end of each proposal there is a hyperlink that will allow you to download the specific section of the report relating to that proposal.

There is a comments box at the end of each set of questions that will allow you to add any further information that you consider important to your survey response.

Page 1 - Heading

Proposals for the Medicare Functions to Operate the Health Identifier Service
Provide Medicare Australia with functions, in or under Commonwealth legislation, to establish and operate the HI Service for the purpose of accurately and uniquely identifying healthcare individuals, healthcare providers and provider organisations and enable communication between individuals, healthcare providers and provider organisations. The following functions would be conferred on the Chief Executive Officer of Medicare Australia and cover:

- assigning, collecting and maintaining identifiers to individuals, individual healthcare providers and organisations including by using information it already holds for existing purposes
- developing and maintaining mechanisms for users to access their own records and correct or update details
- collecting information from individuals and other data sources
- use and disclosure of these identifiers and associated data, including personal information, for the purposes of operating the HI Service.

(Link to related discussion paper extract)

Page 1 - Question 6 - Rating Scale - Matrix

The functions to be conferred on the Medicare CEO are sufficient

	Strongly Agree	2	3	4	Strongly Disagree	No Opinion
Level of agreement	○	○	○	○	○	○

Page 1 - Question 7 - Open Ended - Comments Box

Additional Comments

Page 1 - Heading

Proposals for the Application of General Privacy and Other Laws
Where an IHI (individual health identifier) or HPI-I (a healthcare provider's identifier) is associated with health information about an individual, the collection, use and disclosure of an IHI or an HPI-I will be subject to the privacy and health information laws applicable to that health information.
Misuse of an IHI or HPI-I by a healthcare provider will be able to be pursued as a breach of privacy in jurisdictions with privacy laws or will be subject to other penalties set out in relevant health records or health service legislation.
(Link to related discussion paper extract)

Page 1 - Question 8 - Rating Scale - Matrix

There are no significant issues raised by regulating the handling of healthcare identifiers by public and private health sector organisations through existing privacy and health information laws with some additional regulatory support through specific enabling legislation for healthcare identifiers.

	Strongly Agree	2	3	4	Strongly Disagree	No Opinion
Level of agreement	○	○	○	○	○	○

Page 1 - Question 9 - Rating Scale - Matrix

The penalties for misuse in regard to healthcare identifiers, and associated information held by a healthcare provider are adequate.

	Strongly Agree	2	3	4	Strongly Disagree	No Opinion
Level of Agreement	○	○	○	○	○	○

Page 1 - Question 10 - Open Ended - Comments Box

Additional Comments

Page 1 - Heading

Proposals for Healthcare Service Definitions
Definitions of healthcare service and healthcare service provider will be included in the legislation.
(Link to related discussion paper extract)

Page 1 - Question 11 - Rating Scale - Matrix

The following existing privacy law definitions provides sufficient terms for defining a health service and a health service provider.

Health Service:

- an activity performed in relation to an individual that is intended or claimed (expressly or otherwise) by the individual or the service provider to: (i) assess, predict, maintain or improve the individual's physical, mental or psychological health or status; (ii) diagnose the individual's illness, injury or disability; or (iii) prevent or treat the individual's illness, injury or disability or suspected illness, injury or disability;
- a health-related disability, palliative care or aged care service;
- a surgical or related service; or
- the dispensing on prescription of a drug or medicinal preparation by a pharmacist.

Health Service Provider:
"An organisation that provides health service to the extent that it provides a health service."

	Strongly Agree	2	3	4	Strongly Disagree	No Opinion
Level of agreement	○	○	○	○	○	○

Page 1 - Question 12 - Open Ended - Comments Box

Additional Comments

Page 1 - Heading

Proposals for the Secondary Use of Information

The HI Service Operator will only disclose an individual's IHI and the minimum personal information required to identify an individual to an authorised healthcare provider. Requests for an IHI must be supported by a minimum set of personal information.
Healthcare providers will be authorised to use or disclose an individual's name, date of birth, sex and address details in order to request an IHI from the HI Service Operator.
The HI Service Operator will disclose information held in the Service only to authorised users. The term 'authorised user' will be defined in the legislation.
The HI Service Operator will be authorised to disclose the HPI-I and relevant data fields for professional registration and other purposes to bodies set up in legislation establishing the NRAS.
Secrecy provisions similar to those set out in the Health Insurance Act or the National Health Act would apply to the disclosure of information by staff in undertaking the HI Service Operator function.
Existing Commonwealth, state and territory health information regulation and administrative arrangements will apply to secondary uses and disclosures of HI Service information.
(Link to related discussion paper extract)

Page 1 - Question 13 - Rating Scale - Matrix

The limits on disclosure set out in point 1 above provide adequate protection for an individual's personal information.

	Strongly Agree	2	3	4	Strongly Disagree	No Opinion
Level of agreement	○	○	○	○	○	○

Page 1 - Question 14 - Rating Scale - Matrix

The authorisation for healthcare providers set out in point 2 above is required to provide certainty to healthcare providers. (Note that the use or disclosure could occur under existing privacy arrangements as a directly related and reasonably expected secondary use or disclosure of health information.)

	Strongly Agree	2	3	4	Strongly Disagree	No Opinion
Level of agreement	○	○	○	○	○	○

Page 1 - Question 15 - Rating Scale - Matrix

The limit on disclosure set out in point 3 above provides adequate protection for a healthcare provider's personal information.

	Strongly Agree	2	3	4	Strongly Disagree	No Opinion
Level of agreement	○	○	○	○	○	○

Page 1 - Question 16 - Rating Scale - Matrix

The proposal to apply secrecy provisions similar to those set out in the Health Insurance Act or the National Health Act provides sufficient protection for personal information held by the HI Service Operator.

	Strongly Agree	2	3	4	Strongly Disagree	No Opinion
Level of agreement	○	○	○	○	○	○

Page 1 - Question 17 - Rating Scale - Matrix

There is a need to apply a specific penalty to unauthorised use or disclosure of healthcare identifiers by health sector or other participants who hold the healthcare identifier in association with health information.

	Strongly Agree	**2**	**3**	**4**	**Strongly Disagree**	**No Opinion**
Level of agreement	○	○	○	○	○	○

Page 1 - Question 18 - Rating Scale - Matrix

The existing health information regulation and administrative arrangements will provide sufficient secondary use requirements for organisations handling healthcare identifiers.

	Strongly Agree	**2**	**3**	**4**	**Strongly Disagree**	**No Opinion**
Level of agreement	○	○	○	○	○	○

Page 1 - Question 19 - Open Ended - Comments Box

Additional Comments

Page 1 - Heading

Proposal on Data Quality
Existing Commonwealth, state and territory health information regulation and administrative arrangements will apply to data quality.
(Link to related discussion paper extract)

Page 1 - Question 20 - Rating Scale - Matrix

The existing health information regulation and administrative arrangements will provide sufficient data quality requirements for organisations handling healthcare identifiers

	Strongly Agree	**2**	**3**	**4**	**Strongly Disagree**	**No Opinion**
Level of agreement	○	○	○	○	○	○

Page 1 - Question 21 - Open Ended - Comments Box

Additional Comments

Page 1 - Heading

Proposal on Data Security
Existing Commonwealth, state and territory health information regulation and administrative arrangements will apply for data security.
(Link to related discussion paper extract)

Page 1 - Question 22 - Rating Scale - Matrix

Existing health information regulation and administrative arrangements will provide sufficient data security requirements for organisations handling healthcare identifiers.

	Strongly Agree	2	3	4	Strongly Disagree	No Opinion
Level of agreement	○	○	○	○	○	○

Page 1 - Question 23 - Open Ended - Comments Box

Additional Comments

Page 1 - Heading

Proposal on Openness
Existing Commonwealth, state and territory health information regulation and administrative arrangements will apply to openness.
(Link to related discussion paper extract)

Page 1 - Question 24 - Rating Scale - Matrix

Existing health information regulation and administrative arrangements will provide sufficient openness requirements for organisations handling healthcare identifiers.

	Strongly Agree	2	3	4	Strongly Disagree	No Opinion
Level of agreement	○	○	○	○	○	○

Page 1 - Question 25 - Open Ended - Comments Box

Additional Comments

Page 1 - Heading

Proposal on Access and Correction
Existing Commonwealth, state and territory health information regulation and administrative arrangements will apply to access and correction. No additional legislative requirements will be developed for access and correction.
(link to related discussion paper extract)

Page 1 - Question 26 - Rating Scale - Matrix

Existing health information regulation and administrative arrangements will provide sufficient access and correction capability for individuals.

	Strongly Agree	2	3	4	Strongly Disagree	No Opinion
Level of agreement	○	○	○	○	○	○

Page 1 - Question 27 - Open Ended - Comments Box

Additional Comments

Page 1 - Heading

Proposal on Identifiers

It is proposed that Commonwealth legislation provide that NPP 7 (National Privacy Principals 7 of the Privacy Act) does not apply to the adoption, use and disclosure of the IHI or the HPI-I by private sector healthcare provider organisations for the purposes of accurately and uniquely identifying individuals and individual healthcare providers respectively for health information management and to enable communication between individuals, healthcare providers and provider organisations.
It is proposed that Commonwealth legislation will provide that NPP 7 does not apply to the use and disclosure of Medicare numbers to Medicare Australia by private sector healthcare provider organisations for the purposes of the retrieval of individual identifiers.

(Link to related discussion paper extract)
(Link to National Privacy Principals 7 of the Privacy Act)

Page 1 - Question 28 - Rating Scale - Matrix

The proposals to overcome current identifier restrictions on private healthcare providers effectively enable participation in the HI Service.

	Strongly Agree	2	3	4	Strongly Disagree	No Opinion
Level of agreement	○	○	○	○	○	○

Page 1 - Question 29 - Rating Scale - Matrix

These proposals do not raise any significant issues in relation to the handling of identifiers.

	Strongly Agree	2	3	4	Strongly Disagree	No Opinion
Level of agreement	○	○	○	○	○	○

Page 1 - Question 30 - Open Ended - Comments Box

Additional Comments

Page 1 - Heading

You are half way through the survey. Just one more page to go.
Click on the "submit" button below to go to the final page of the survey.

Page 2 - Heading

Proposal on Anonymity
Existing Commonwealth, state and territory health information regulation and administrative arrangements will apply to anonymity.
(Link to related discussion paper extract)

Page 2 - Question 31 - Rating Scale - Matrix

The existing health information regulation and administrative arrangements will provide sufficient anonymity requirements.

	Strongly Agree	2	3	4	Strongly Disagree	No Opinion
Level of agreement	○	○	○	○	○	○
✎ Additional Comme						

Page 2 - Heading

Proposal on Trans-Border Data Flows
Existing Commonwealth, state and territory health information regulation and administrative arrangements will apply to trans-border data flows.
(Link to related discussion paper extract)

Page 2 - Question 32 - Rating Scale - Matrix

The existing health information regulation and administrative arrangements will provide sufficient requirements for transborder data flows.

	Strongly Agree	2	3	4	Strongly Disagree	No Opinion
Level of agreement	○	○	○	○	○	○

Page 2 - Question 33 - Rating Scale - Matrix

This proposal does not raise any significant issues in relation to the handling of identifiers.

	Strongly Agree	2	3	4	Strongly Disagree	No Opinion
Level of agreement	○	○	○	○	○	○

Page 2 - Question 34 - Open Ended - Comments Box

Additional Comments

Page 2 - Heading

Proposals on the Functions of Medicare

In accordance with national policies, priorities and strategic directions, key functions to be undertaken by Medicare in relation to the HI Service include:

- managing the issue and assignment of national identifiers
- managing access to and use/disclosure of national identifiers
- maintaining records of national identifiers
- managing relationships with participants and relevant data sources
- providing advice and information to the strategic oversight body on the performance of the system
- educating, training and informing healthcare providers and consumers about how the service operates
- responding to system/service complaints and enquiries (in the first instance).

(Link to the related discussion paper extract)

Page 2 - Question 35 - Rating Scale - Matrix

Medicare is a suitable organisation to undertake these functions.

	Strongly Agree	2	3	4	Strongly Disagree	No Opinion
Level of agreement	○	○	○	○	○	○

Additional Comme

Page 2 - Heading

Proposal on Participation Agreements
It is proposed that as part of operating the HI Service participation agreements may be put inplace between healthcare provider organisations and the HI Service Operator. It is envisaged that participation agreements would set out the responsibilities of the parties involved in theHI Services. This may include:

defining the rules of participation, such as setting minimum I.T. security, equipment and data management standards
establishing the consequences of breaching business rules.

(Link to related discussion paper extract)

Page 2 - Question 36 - Rating Scale - Matrix

Participation agreements are an appropriate mechanism for setting out the responsibilities of the parties involved (i.e. healthcare provider organisations and the HI Service Operator)

	Strongly Agree	2	3	4	Strongly Disagree	No Opinion
Level of agreement	○	○	○	○	○	○

Page 2 - Question 37 - Rating Scale - Matrix

Legislation is not required to underpin the participation agreements?

	Strongly Agree	2	3	4	Strongly Disagree	No Opinion

Level of agreement	○	○	○	○	○	○

Page 2 - Question 38 - Open Ended - Comments Box

Additional Comments

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Page 2 - Heading

Proposal on Independent Regulation
It is proposed that existing Commonwealth, state and territory privacy and/or health information regulatory arrangements will apply.
(Link to related discussion paper extract)

Page 2 - Question 39 - Rating Scale - Matrix

Existing Commonwealth, state and territory privacy and/or health information regulatory arrangements are adequate to cover the privacy issues associated with the Health Identifier.

	Strongly Agree	2	3	4	Strongly Disagree	No Opinion
Level of agreement	○	○	○	○	○	○
Additional Comme						

Page 2 - Heading

Part B: Proposed National Privacy Reforms
This section contains 14 multiple choice questions and is related to the privacy regulations around the IHI's.

Page 2 - Heading

Proposal on Administration
National legislation include requirements such as: conciliation being a critical element in the approach to resolving complaints; an independent administrative or judicial mechanism; the length of time consumers have to lodge a complaint; powers of regulators; and sanctions for breaches of the law by agencies or organisations.
Guidelines including minimum standards be developed and agreed to by regulators to ensure that there is a consensus in the way in which privacy laws are to be applied across Australia.
Jurisdictional regulators be empowered to jointly determine a common approach to applying these minimum standards.
(Link to related discussion paper extract)

Page 2 - Question 40 - Rating Scale - Matrix

The proposal addresses all the requirements that need to be specified in the legislation.

	Strongly Agree	2	3	4	Strongly Disagree	No Opinion
Level of agreement	○	○	○	○	○	○

Page 2 - Question 41 - Rating Scale - Matrix

It is necessary that arrangements for and enforceability of directions or guidelines that are jointly agreed by privacy regulators be supported by legislation

	Strongly Agree	2	3	4	Strongly Disagree	No Opinion
Level of agreement	○	○	○	○	○	○

Page 2 - Question 42 - Open Ended - Comments Box

Additional Comments

Page 2 - Heading

Proposal on Coverage
Health information of deceased individuals should be subject to the same protection as other personal information about deceased persons whether this is through privacy law or other arrangements.
(Link to related discussion paper extract)

Page 2 - Question 43 - Rating Scale - Matrix

The privacy of health information about deceased persons should be treated the same as other personal information about them?

	Strongly Agree	2	3	4	Strongly Disagree	No Opinion
Level of agreement	○	○	○	○	○	○
Additional Comme						

Page 2 - Heading

Proposal on Key Definitions
Include a definition of ‘health service provider’ as ‘an organisation that provides a health service to the extent that it provides a health service’.
(Link to related discussion paper extract)

Page 2 - Question 44 - Rating Scale - Matrix

The proposed definition of health service provider is appropriate.

	Strongly Agree	2	3	4	Strongly Disagree	No Opinion
Level of agreement	○	○	○	○	○	○
Additional Comme						

Page 2 - Heading

Proposal on Unified Privacy Principles (UPP's): 2

Amendment of UPP 2.5(c) to allow the collection of sensitive information where there is a serious threat to an individual’s welfare.
Deletion or modification to UPP 2.5(d) to exclude the right for non-profit organisations to collect health information about their members.
Amendment of UPP 2.5(f) to provide that any guidance issued by the Privacy Commissioner in relation to the collection of sensitive information necessary for research purposes be required to be developed in conjunction with input from other appropriately qualified individuals or organisations in the field of research.
Any rules or guidelines issued by the Privacy Commissioner in relation to the collection of identifying health information where it is necessary for the funding, management, planning, monitoring or evaluation of a health service be developed in conjunction with input from other appropriately qualified individuals or organisations in the health service management field.

(Link to related discussion paper extract)

Page 2 - Question 45 - Rating Scale - Matrix

The amendments proposed above are appropriate.

	Strongly Agree	**2**	**3**	**4**	**Strongly Disagree**	**No Opinion**
Level of agreement	○	○	○	○	○	○

Page 2 - Question 46 - Rating Scale - Matrix

The circumstances relating to the collection principle are adequate and do not require amendment in relation to health information.

	Strongly Agree	**2**	**3**	**4**	**Strongly Disagree**	**No Opinion**
Level of agreement	○	○	○	○	○	○

Page 2 - Question 47 - Open Ended - Comments Box

Additional Comments

Page 2 - Heading

Proposal on UPP 5: Use and Disclosure of Information

Amendment of UPP 5.1(c) to allow the use or disclosure of sensitive information where there is a serious threat to an individual's welfare.
Amendment of UPP 5.1(f) to provide that any guidance issued by the Privacy Commissioner, in relation to the use or disclosure of sensitive information is necessary or research purposes, be required to be developed in conjunction with input from other appropriately qualified individuals or organisations in the field of research.
Rules or guidelines issued by the Privacy Commissioner in relation to the collection of identifying health information where it is necessary for the funding, management, planning, monitoring or evaluation of a health service be developed in conjunction with input from other appropriately qualified individuals or organisations in the health service management field.
An exception is proposed to allow personal information to be used or disclosed by an agency or organisation where an individual is known or suspected to be missing or deceased, subject to this not being contrary to any wishes expressed by the individual before they went missing or became incapable of consenting, with disclosure limited to a law enforcement officer for the purposes of ascertaining the whereabouts of the person
It is proposed that the definition of a 'person responsible for an individual' be altered to provide for any person who has a personal relationship with the individual rather than only a person who has an intimate relationship, or a person who is responsible for providing support or care to the individual rather than only the person who is primarily responsible. Guidelines could identify the grounds on which a personal relationship exists or that a person is responsible. These would include such things as whether there is a sufficient degree of intimacy or level of responsibility. Another alternative would be to set the list up as an inclusive rather than an exclusive list.

(Link top related discussion paper extract)

Page 2 - Question 48 - Rating Scale - Matrix

The amendments proposed are appropriate

	Strongly Agree	2	3	4	Strongly Disagree	No Opinion
Level of agreement	○	○	○	○	○	○

Page 2 - Question 49 - Rating Scale - Matrix

The circumstances relating to the use or disclosure of information are adequate.

	Strongly Agree	2	3	4	Strongly Disagree	No Opinion
Level of agreement	○	○	○	○	○	○

Page 2 - Question 50 - Rating Scale - Matrix

In relation to point 4, An agency or organisation should be required to have a reasonable expectation that the person responsible for the individual will act in the best interests of the individual in receiving that information and guidelines would provide sufficient certainty of this.

	Strongly Agree	2	3	4	Strongly Disagree	No Opinion
Level of agreement	○	○	○	○	○	○

Page 2 - Question 51 - Open Ended - Comments Box

Additional Comments

Page 2 - Heading

Proposal on UPP6: Direct Marketing

The consent of individuals is required to the use or disclosure of health information for direct marketing purposes.
(link to related discussion paper extract)

Page 2 - Question 52 - Rating Scale - Matrix

The consent of the individual should be obtained for the use or disclosure of health information for direct marketing purposes.

	Strongly Agree	2	3	4	Strongly Disagree	No Opinion
Level of agreement	○	○	○	○	○	○
Additional Comme						

Page 2 - Heading

Proposal on UPP 8: Data Security

Guidelines be developed by the Privacy Commissioner outlining key requirements for retaining health information (e.g. minimum retention periods and obligations owed by a healthcare provider to an individual where a healthcare service has been sold, amalgamated or closed).
(Link to related discussion paper extract)

Page 2 - Question 53 - Rating Scale - Matrix

The use of guidelines is sufficient to ensure that health information is retained for a suitable period of time.

	Strongly Agree	2	3	4	Strongly Disagree	No Opinion
Level of agreement	○	○	○	○	○	○

Page 2 - Question 54 - Open Ended - Comments Box

Additional Comments

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Proposal on UPP 9: Access and Correction

It is proposed that the exception from providing access to health information where providing access would reveal the intentions of the organisation in relation to negotiations with the individual in such a way as to prejudice those negotiations does not include negotiations about provision of health services.
A note be inserted into the Access and Correction Principle explaining that nothing in the principle compels an organisation to refuse to provide an individual with access to his or her health information.
Guidelines be developed by the Privacy Commissioner that include detailed information about the process which should be followed to gain access to personal information, including guidance on requests for access, responses to those requests, how information is provided and fees.

(Link to related discussion paper extract)

Page 2 - Question 55 - Rating Scale - Matrix

The proposals for changes to the access principles are appropriate to address the issues generated by delivering the Health Identifiers.

	Strongly Agree	2	3	4	Strongly Disagree	No Opinion
Level of agreement	○	○	○	○	○	○

Additional Comme

Page 2 - Heading

Proposal on UPP 10: Identifiers (Organisations Only)
The identifier principle should permit the use or disclosure of information that includes an identifier for funding, management, planning, monitoring, improvement or evaluation of health services and for research purposes in the public interest subject to the same limits that apply to health information being used or disclosed for those purposes.
(Link to related discussion paper extract)

Page 2 - Question 56 - Rating Scale - Matrix

There are no situations where the identifier principle might have an inappropriate effect on the use or disclosure of health information.

	Strongly Agree	2	3	4	Strongly Disagree	No Opinion
Level of agreement	○	○	○	○	○	○

Additional Comme

Page 2 - Heading

Proposal on UPP 11: Cross-Border Data Flows
An agency or organisation should be allowed to use or disclose information outside Australia to lessen or prevent a serious risk to life, health, safety or welfare without continuing to be accountable for any misuse.
(Link to related discussion paper extract)

Page 2 - Question 57 - Rating Scale - Matrix

The exceptions applied for health information transferred outside Australia are adequate.

	Strongly Agree	2	3	4	Strongly Disagree	No Opinion

Level of agreement	○	○	○	○	○	○
✎ Additional Comme						

Page 2 - Question 58 - Open Ended - Comments Box

Any Additional Comments
Thank you for your important contribution to the Individual Health Identifiers survey. Are there any further comments that you would like to make about the privacy aspects of the Health Identifiers.

Thank You Page

Thank you for participating in the HISA's feedback on DOHA's Individual Health Identifier Discussion Document. Your information will make an important contribution to the development of the feedback report.

If you have included your email address with your survey response then we will send you a copy of the report and keep you involved with any ongoing discussions.

Screen Out Page

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Over Quota Page

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Survey Closed Page

The survey is now closed, please contact Brendan Lovelock at HISA on 03-9388-0555 (email brendan.lovelock@hisa.org.au) for further details