Submission to the Australian Government's Department of Health

in regard to the

Electronic Health Records and Healthcare Identifiers: Legislation Discussion Paper

on behalf of:
Health Informatics Society of Australia
Health Information Management Association of Australia

Edited by: Peter Croll and Philip Robinson

June 2015

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Executive Summary

The professional societies of HISA and HIMAA are pleased to be able to provide the Department of Health with this submission which summarises the views of many professionals closely associated with e-health development, delivery and application.

Both societies have actively followed the evolution of the Healthcare Identifiers and the PCEHR. They have previously provided detailed submissions to government on these developments in order to provide relevant feedback from healthcare and IT professionals working in this field. The following submission has been derived from a detailed survey that asks for levels of agreement and comment on each of the proposals made in the 'Electronic Health Records and Healthcare Identifiers: Legislation Discussion Paper'.

The survey undertook by HISA and HIMAA attracted 350 respondents, many of whom have detailed knowledge of the HI and PCEHR developments, applications and related legislations. Over half of the survey respondents have signed up for the PCEHR with a further quarter aware of its potential and planning to do so.

In general, the survey shows widespread support for the proposals in the discussion paper. However, there are some areas of concern, notably secondary use and privacy. A number of pertinent comments have been made all of which are listed in this submission. All respondents remained anonymous yet supplied non-identifiable demographic information to highlight the direct connection they have with the healthcare and health IT professions.

With contributions from Dr Louise Schaper (CEO, HISA) and Richard Lawrance (CEO, HIMAA).

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HISA Board Member and Treasurer

About HIMAA

The Health Information Management Association of Australia Ltd (HIMAA) is **the peak body for health information management professionals in Australia**. It has been serving the health information management profession since 1949.

Health information management professionals apply their knowledge and skills to create, acquire, analyse and manage information to meet the medical, legal, ethical and administrative requirements of the health care system. ANZSCO recognised occupations include health information managers (HIMs) and clinical coders (CCs). They hold the information systems key to the integration of patient records and funding flow in efficiency as well as effectiveness improvements to patient care.

The Association promotes and supports health information management professionals as the universally recognised specialists in information management at all levels of the healthcare system. We do this through positioning and advocacy, accreditation, education and training, certification and credentialing, quality standards, publications and resources, and HIMAA membership networking activities at local and national levels, including an annual national conference of international standing.

HIMAA is committed to improving the health of all Australians through professional information management.

About HISA

With a 20+ year history, the Health Informatics Society of Australia Ltd (HISA) is **the peak body for health informatics & e-health in Australia**. We have a vested interest in growing workforce capacity and capability in heath IT and are passionate advocates for the e-health enabled transformation of healthcare.

HISA is a not-for-profit, member organisation with a broad and diverse stakeholder community with over 1000 active members and a database of over 13,000 committed participants in digital health, e-health and health informatics. We have access to the best minds in e-health nationally and globally including: IMIA (which links HISA to WHO & over 60 specialist health informatics organisations across the planet), APAMI (Asia Pacific Association for Medical Informatics) and HINZ (Health Informatics New Zealand).

HISA membership is open to individuals and organisations. The majority of HISA members are senior players and leaders in their fields. Together, our membership represents thousands of years of combined experience in health and in health-IT.

Survey Methods Used

This survey was conducted using an online application called SurveyMonkey and sent out as a web link to the respondents. No personal identifiable information was asked for or collected. Only limited demographic information relating to the respondent's profession, employment and use of the PCEHR was included.

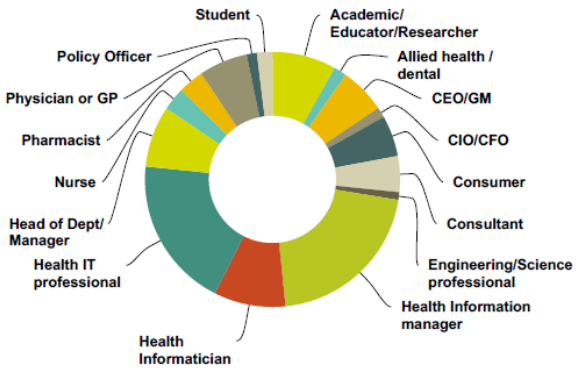
The survey was divided into sections to allow the respondents to choose their area of expertise. These sections closely followed the Department of Health's discussion paper. The respondents were free to answer as many questions as they wished. A total of 40 survey questions were provided that directly related to the proposals put forward in the discussion paper. Respondents were advised to read the discussion paper prior to responding in order to understand the context of the questions. All the questions relating to the proposals allowed the respondent to add free text comments. These are listed in full in the appendix.

Only two questions, Q8 and Q9, had extra options added. These were included at the discretion of the survey writer who was aware of some alternative viewpoints in the respective professional societies. These have been commented on in the analysis. No other deviation from the discussion paper was made. The questions attempted to be a true representation of each proposal in the discussion paper, allowing for some reordering and simplification of the wording to suit the survey style. The full survey is listed in the appendix.

About the Survey Respondents

Q1 With which title do you most closely identify from the following list?

Answered: 308 Skipped: 35

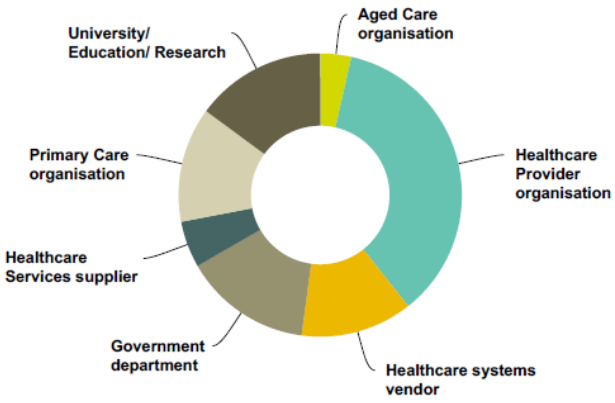


Answer Choices	Responses	
Academic/ Educator/Researcher	8.12%	25
Allied health / dental	1.62%	5
CEO/GM	5.84%	18
CIO/CFO	1.30%	4
Consumer	5.19%	16
Consultant	4.55%	14
Engineering/Science professional	0.97%	3
Health Information manager	20.78%	64
Health Informatician	9.09%	28
Health IT professional	19.16%	59
Head of Dept/ Manager	7.79%	24
Nurse	2.92%	9
Pharmacist	3.25%	10
Physician or GP	6.17%	19
Policy Officer	1.30%	4
Student	1.95%	6
Total		**308**

The majority of survey respondents (just under half) work as Health Information Managers, Health Informaticians or Health IT Professionals. Survey respondents were permitted to give an alternative job title when the above selection did not apply, with a further 32 listed in the comments section of the appendix. The main other job title included: Project Officers and Liaison Officers/Advisors. The vast majority, if not all, respondents worked in a health related profession or as health IT professionals.

Q2 What type of organisation do you work for?

Answered: 282 Skipped: 61

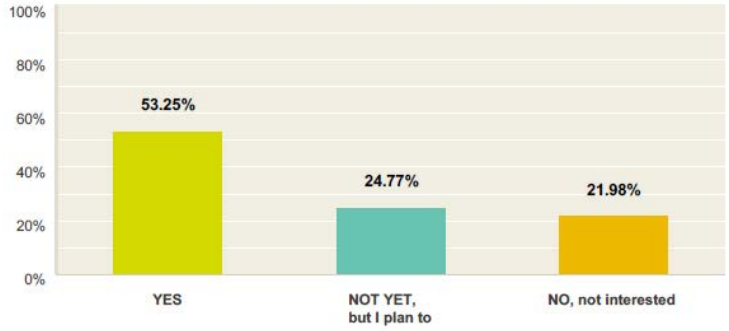


Answer Choices	Responses	
Aged Care organisation	3.55%	10
Healthcare Provider organisation	35.82%	101
Healthcare systems vendor	12.77%	36
Government department	14.54%	41
Healthcare Services supplier	5.32%	15
Primary Care organisation	13.12%	37
University/ Education/ Research	14.89%	42
Total		**282**

Survey respondents work for a range of organisations, including healthcare provider organisations, vendors and academia. Other organisation types are listed in the comments section of the appendix. The main other organisation types include: Consultancies, Medicare Local and Not for Profits. The majority of organisations the respondents worked for are healthcare related.

Q3 Have you registered for a PCEHR?

Answered: 323 Skipped: 20

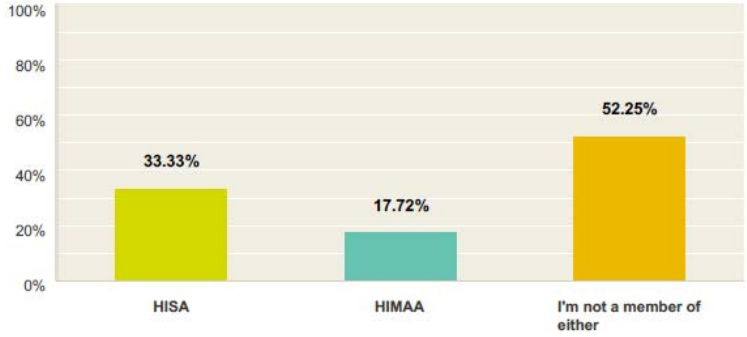


Answer Choices	Responses	
YES	53.25%	172
NOT YET, but I plan to	24.77%	80
NO, not interested	21.98%	71
Total		323

Survey respondents were asked if they have registered for the PCEHR. Just over half have done so with another quarter planning to. Those respondents claiming that they are not interested was 22%. Only 12 respondents made comments, for example: “I didn’t know I could”, “Tried too but it failed”, “Website was rubbish”, “Required me to call. That's more effort than I wish to give”. One respondent stated they were not an Australian resident and one claimed they had registered but now cancelled their PCEHR. The full list of comments on registration status can be found in the appendix.

Q4 Are you a member of...?

Answered: 333 Skipped: 10



Answer Choices	Responses	
HISA	33.33%	111
HIMAA	17.72%	59
I'm not a member of either	52.25%	174
Total Respondents: 333		

Both HISA and HIMAA have substantial non-member networks throughout the sector. Approximately half of survey respondents were members of either HISA or HIMAA.

Analysis

The following pages present the results of the survey, section by section, with graphs, tabulated data and brief analysis, including the most pertinent comments.

Please note that the term 'survey respondents' is used in the description of results, but as the table for each question shows, the number of individuals who responded to each question varies. In each case we report the data from the number of responses to that question.

The survey and the following analysis is separated into the following sections:

Section 1: Names and Definitions

Section 2: Governance

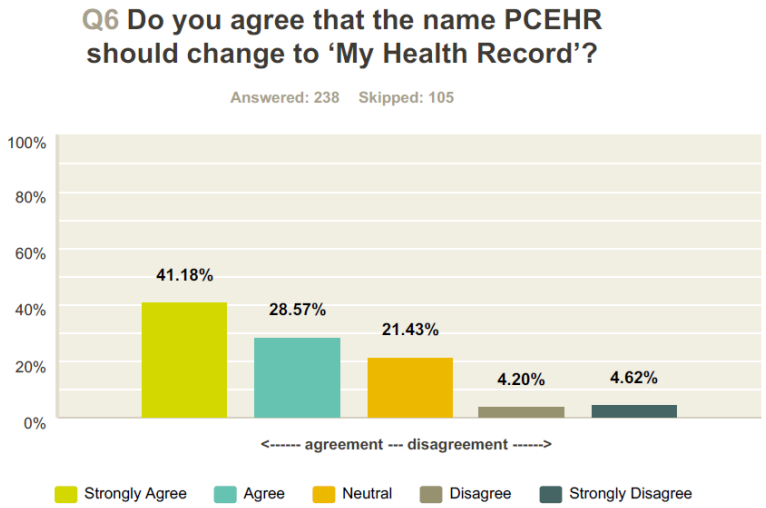
Section 3: Individual's Participation

Section 4: Obligation of Parties

Section 5: Privacy

NOTE questions to do with navigation around the survey have been excluded, e.g. Q5, Q13, Q20, Q29, Q40 and Q54

Section 1: Names and Definitions

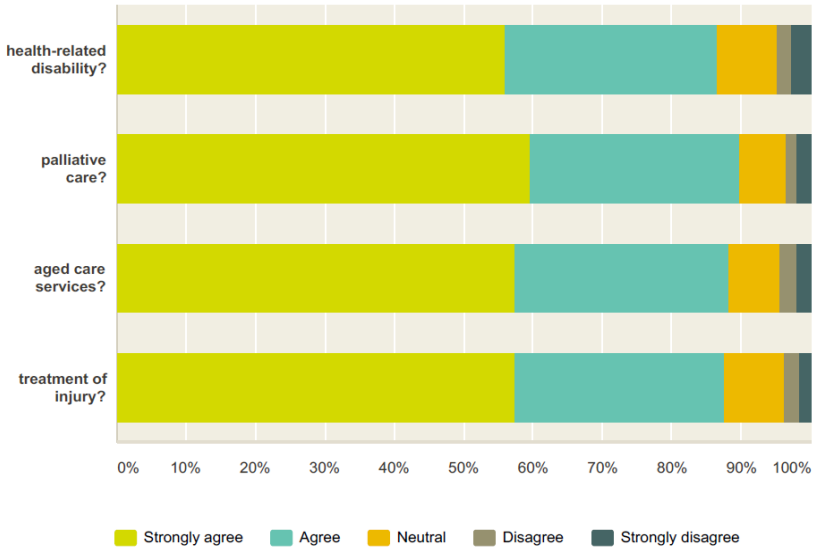


	Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree	Total	Weighted Average
<------ agreement --- disagreement ------>	41.18% 98	28.57% 68	21.43% 51	4.20% 10	4.62% 11	238	2.03

Comment - there is general agreement to the proposed name change to "My Health Record" with almost 70% in favour of the change. Perhaps more significantly, under 9% of respondents disagreed with the proposed change with just over 20% being neutral. Alternative names and comments are provided in the appendix.

Q7 Do you agree that the definition of "healthcare" in both the HI Act and the PCEHR Act be expanded to include the following:

Answered: 246 Skipped: 97

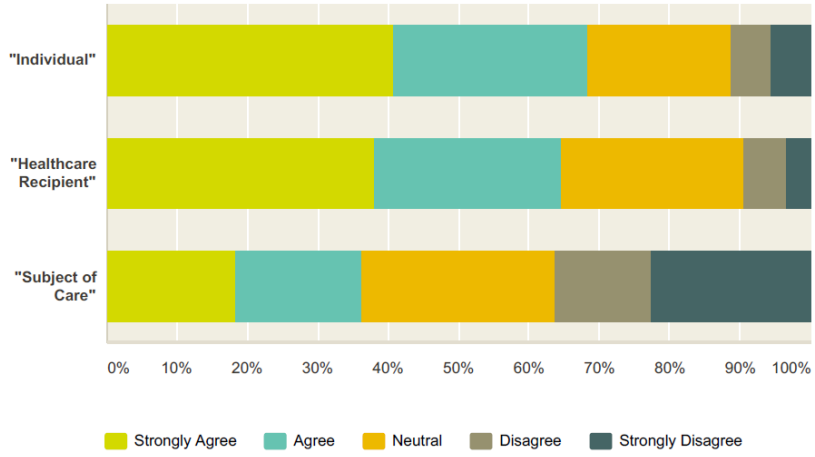


	Strongly agree	Agree	Neutral	Disagree	Strongly disagree	Total	Weighted Average
health-related disability?	55.92% 137	30.61% 75	8.57% 21	2.04% 5	2.86% 7	245	1.65
palliative care?	59.59% 146	30.20% 74	6.53% 16	1.63% 4	2.04% 5	245	1.56
aged care services?	57.38% 140	30.74% 75	7.38% 18	2.46% 6	2.05% 5	244	1.61
treatment of injury?	57.26% 138	30.29% 73	8.71% 21	2.07% 5	1.66% 4	241	1.61

There is broad agreement from the respondents to expansion of the definition of healthcare. In fact, the results are remarkably consistent, with between 85% and 90% in agreement and very low levels of disagreement (less than 5%). There is therefore strong support for this expansion.

Q8 Do you agree that the different definitions of "consumers" in the PCEHR Act and "healthcare recipients" in the HI Act should be aligned by using the following in both Acts:

Answered: 244 Skipped: 99



	Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree	Total	Weighted Average
"Individual"	40.77% 95	27.47% 64	20.60% 48	5.58% 13	5.58% 13	233	2.08
"Healthcare Recipient"	38.03% 89	26.50% 62	26.07% 61	5.98% 14	3.42% 8	234	2.10
"Subject of Care"	18.14% 41	18.14% 41	27.43% 62	13.72% 31	22.57% 51	226	3.04

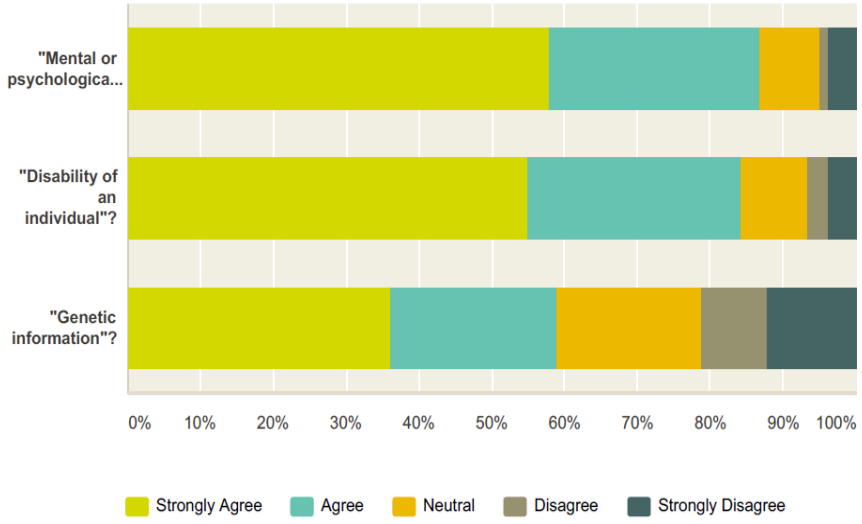
There is strong agreement, with around two thirds of respondents either strongly agreeing or agreeing, to the alignment by the use of the words "Individual" and "Healthcare recipient" in both Acts.

An additional term 'Subject of Care" was introduced in this survey. The reasoning was that in a recent publication by HISA: "The 2015 Australian Guidelines for the Protection of Health Information" this term was used for the following reasons: "'*Subject of care' is a term recognised and used by the International Organization for Standardization (ISO) to refer to patients, clients, and residents of healthcare organisations. While not an elegant term, it is currently accepted internationally as the best one to use at this time*".

However, use of the term "Subject of Care" was much less supported with just over one third of respondents in favour of the term and over 20% strongly disagreeing to the term. The passive nature of the term is what people opposed. For example, one response stated that "subject of care' implies a passive role - which jars with the idea of active control of the PCEHR/MyHR by the individual" and another that "I (also) don't like "subject of care", because it implies that this person is completely passive when in fact it's the consumer who is in charge of their health. I prefer "consumer" or "healthcare consumer".

Q9 Do you agree that definition of "health information" in both the PCEHR Act and the HI Act should expanded to include the following:

Answered: 242 Skipped: 101



	Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree	Total	Weighted Average
"Mental or psychological health"?	57.85% 140	28.93% 70	8.26% 20	1.24% 3	3.72% 9	242	1.64
"Disability of an individual"?	54.81% 131	29.29% 70	9.21% 22	2.93% 7	3.77% 9	239	1.72
"Genetic information"?	35.98% 86	23.01% 55	19.67% 47	9.21% 22	12.13% 29	239	2.38

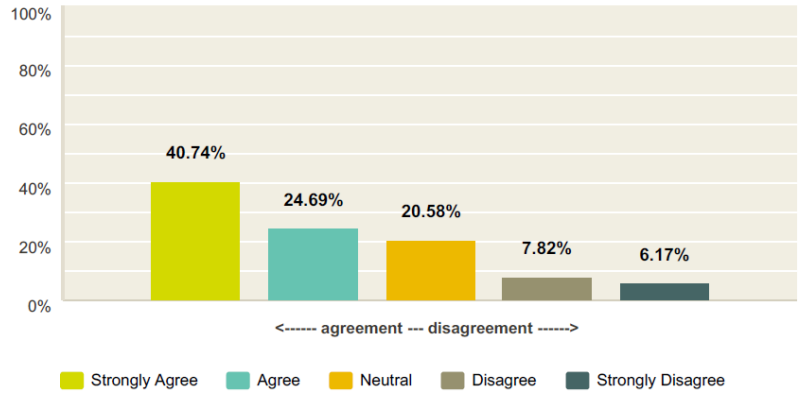
There is broad agreement from the respondents to expand the definition of health information. Again, the results are remarkably consistent with between 85% and 90% in agreement that "mental and psychological health" and "disability of an individual" are considered to be health information. There is strong support for this expansion.

An additional term 'Genetic Information' was introduced in this survey. The reasoning was that previous surveys undertaken by HISA showed a general approval to include genetic information when defining health information, given rapid advances in genomics and personalised medicine. Hence it was included as an alternative to consider.

59% of respondents agreed with the inclusion of genetic information, however, there was also a strong disagreement (12%). Comments from respondents who disagreed with its included concerns such as "genetic and HIV results should at all times require counselling of patient to truly understand what the information means, otherwise can cause more harm to patient's wellbeing" and "I think genetic information should be considered separately - unlike symptoms of illness and state of health, genetic information is an identifier of an individual".

Q10 Do you agree that regulations under the Acts should exclude activities from being defined as "healthcare" which are performed for reasons other than care or treatment (e.g. for the purpose of life insurance, health insurance etc.).

Answered: 243 Skipped: 100



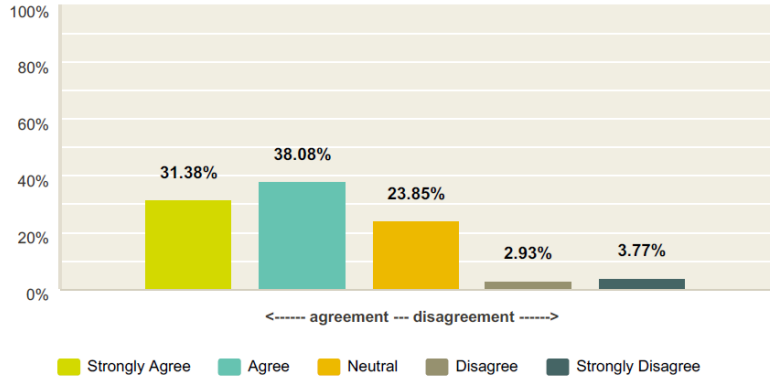
	Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree	Total	Weighted Average
<------ agreement --- disagreement ------>	40.74% 99	24.69% 60	20.58% 50	7.82% 19	6.17% 15	243	2.14

There is general agreement from the respondents, with over 65% either agreeing or strongly agreeing, that activities performed other than for care or treatment should be excluded from the regulations. In addition, just over 20% of respondents were neutral on this question.

Commentary from respondents included concerns about the potential misuse of health insurance and life insurance information and the "potential for consumer backlash if this type of information is included by default".

Q11 The Privacy Act 1998 protects privacy of individuals and not organisations. Do you agree that to assist government in promoting organisational participation in the PCEHR system (while protecting the privacy of individual health providers) that the HI Act should change its current definition of "healthcare provider" to distinguish between "healthcare provider organisations" and "individual healthcare providers"?

Answered: 239 Skipped: 104

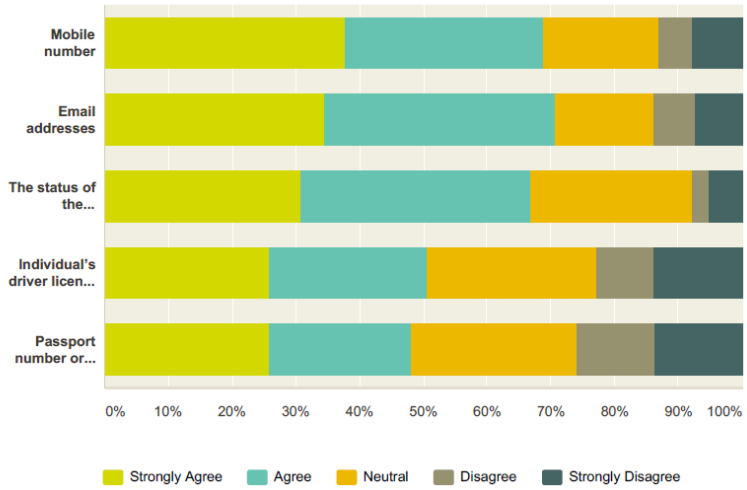


	Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree	Total	Weighted Average
<------ agreement --- disagreement ------>	31.38% 75	38.08% 91	23.85% 57	2.93% 7	3.77% 9	239	2.10

There was strong support from respondents for greater clarity in the definition of "healthcare provider" with almost 70% agreeing or strongly agreeing to this premise. Perhaps more importantly, the level of disagreement was low at under 7% of respondents.

Q12 Do you agree with the proposal that the PCEHR Act and HI Act should change the definition of "identifying information" to include i) more contact details for communications and ii) identifiers for opt-out verifications, as follows?

Answered: 233 Skipped: 110



	Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree	Total	Weighted Average
Mobile number	37.66% 87	31.17% 72	18.18% 42	5.19% 12	7.79% 18	231	2.14
Email addresses	34.48% 80	36.21% 84	15.52% 36	6.47% 15	7.33% 17	232	2.16
The status of the Individual's Healthcare Identifier (IHI)	30.70% 70	35.96% 82	25.44% 58	2.63% 6	5.26% 12	228	2.16
Individual's driver licence number	25.86% 60	24.57% 57	26.72% 62	9.05% 21	13.79% 32	232	2.60
Passport number or Immicard	25.76% 59	22.27% 51	26.20% 60	12.23% 28	13.54% 31	229	2.66

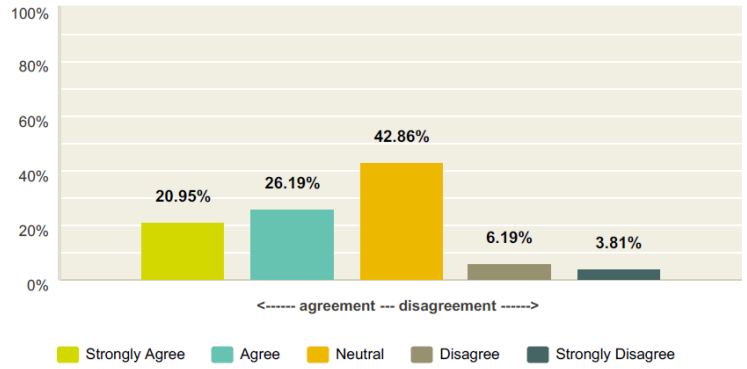
The inclusion of additional contact details for communications, i.e. mobile number and email address, was strongly supported by respondents with around 70% support for those items. Support for the status of the IHI was slightly lower at 65% with a high level of neutral views of over 25%.

While there was almost 50% agreement on the use of driver's licence or passport number as identifiers, respondents expressed significant concern on the privacy aspects in relation to their use in a health record as instanced by the level of strong disagreement of over 13%.

Section 2: Governance

Q14 Do you agree, as recommended by the PCEHR Review, that the PCEHR Act should be revised to disband the current Jurisdictional Advisory Committee (JAC) and the Independent Advisory Council (IAC) with their roles to be performed by a new ACeH Jurisdictional Advisory Committee (which will assume the responsibilities of PCEHR System Operator currently undertaken by the Department of Health)?

Answered: 210 Skipped: 133



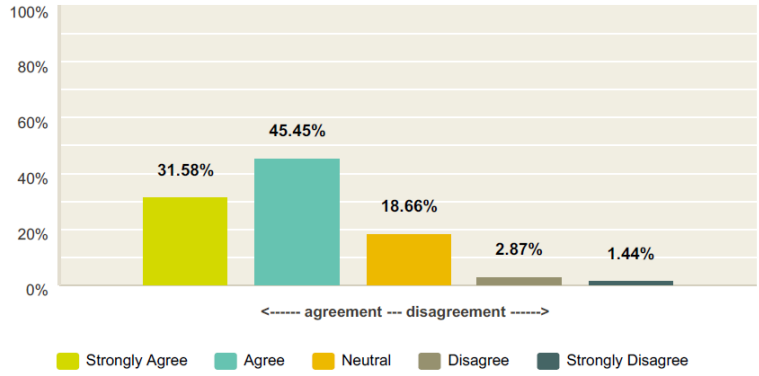
	Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree	Total	Weighted Average
<------ agreement --- disagreement ------>	20.95% 44	26.19% 55	42.86% 90	6.19% 13	3.81% 8	210	2.46

Responses to this question showed a strong level of neutrality plus a high degree on non-response with 133 respondents skipping the question. The reasons for this are unclear but may reflect a lack of clarity of the benefits of such a change.

There remained a high level of agreement of just under 50% but, more importantly, the low level of disagreement at 10% of respondents should be noted.

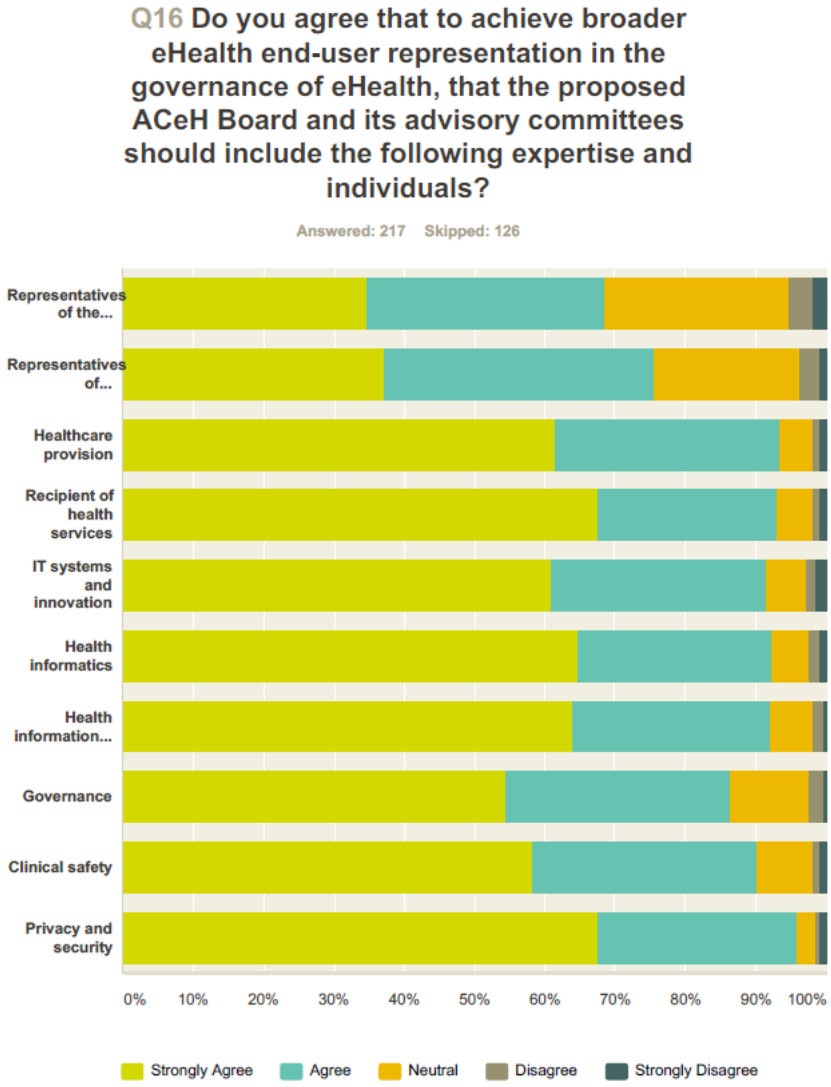
Q15 Do you agree with the recommendations of the PCEHR Review for an implementation task-force to be established (administratively) to oversee and advise on the design, establishment and transition to the new national eHealth governance arrangements, including transitioning functions from NEHTA?

Answered: 209 Skipped: 134



	Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree	Total	Weighted Average
<------ agreement --- disagreement ------>	31.58% 66	45.45% 95	18.66% 39	2.87% 6	1.44% 3	209	1.97

There was strong support from respondents for establishment of an implementation taskforce with almost 80% agreeing or strongly agreeing to this premise. Perhaps more importantly, the level of disagreement is regarded as low at under 5% of respondents.



	Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree	Total	Weighted Average
Representatives of the Commonwealth	34.74% 74	33.80% 72	26.29% 56	3.29% 7	1.88% 4	213	2.04
Representatives of jurisdictions	37.09% 79	38.50% 82	20.66% 44	2.82% 6	0.94% 2	213	1.92
Healthcare provision	61.61% 130	31.75% 67	4.74% 10	0.95% 2	0.95% 2	211	1.48
Recipient of health services	67.59% 146	25.46% 55	5.09% 11	0.93% 2	0.93% 2	216	1.42
IT systems and innovation	60.95% 128	30.48% 64	5.71% 12	1.43% 3	1.43% 3	210	1.52

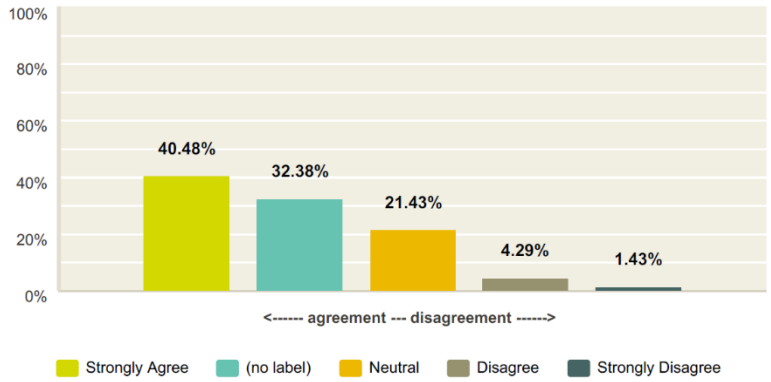
The notion of broader e-health representation in the governance of e-health was broadly supported with varying degrees of support for different representation. Strongest support was found for Privacy and Security representatives , healthcare providers and health care consumers. These groups were closely followed by Health Informatics, Health Information and IT Systems groups.

Interestingly, while still over 2/3rds supported their involvement (via "strongly agree" or "agree" responses), representatives of the Commonwealth and Jurisdictions gained lesser support than the aforementioned groups.

HISA and HIMAA both strongly recommend to the government that health informatics and health information management expertise be present at all levels of governance within ACeH. The skill sets, knowledge base and experience of health informatics and health information management professionals is critical to the success of e-health initiatives.

Q19 Do you agree that changes are made to enable the Information Commissioner to conduct assessments and carry out investigations of AHPRA in respect of its handling of healthcare identifiers (note, currently the AHPRA is outside of the Commissioner's jurisdiction because it is neither an agency nor an organisation)?

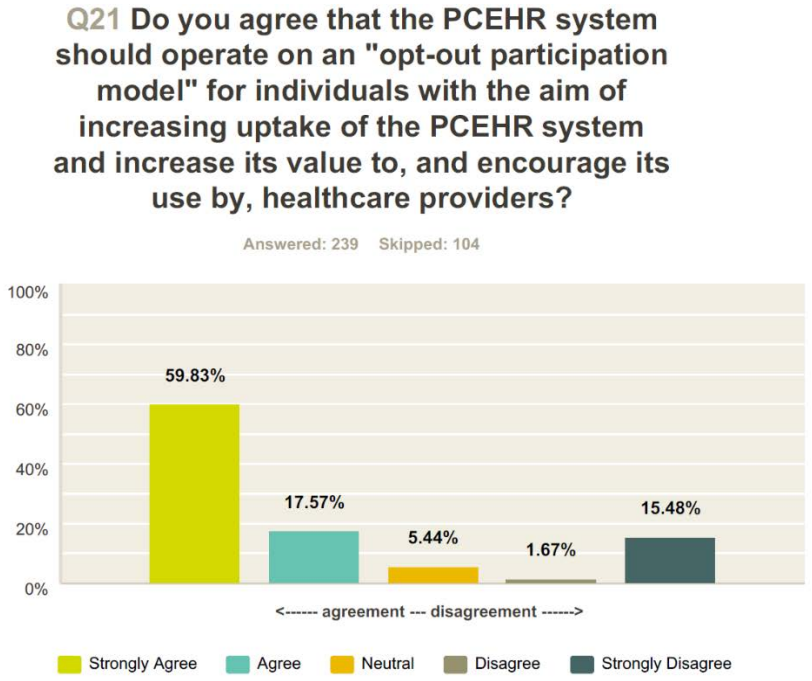
Answered: 210 Skipped: 133



	Strongly Agree	(no label)	Neutral	Disagree	Strongly Disagree	Total	Weighted Average
<------ agreement --- disagreement ------>	40.48% 85	32.38% 68	21.43% 45	4.29% 9	1.43% 3	210	1.94

There was general support for this question with over 72% agreement compared to just over 5% disagreement. Very few comments were made in response to this question.

Section 3: Individual's Participation



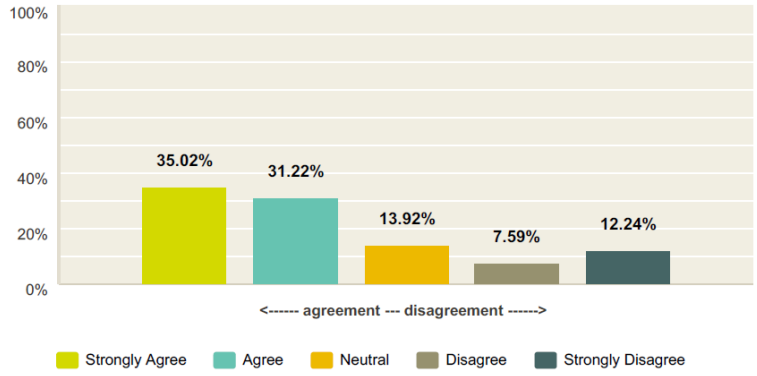
	Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree	Total	Weighted Average
<------ agreement --- disagreement ------>	59.83% 143	17.57% 42	5.44% 13	1.67% 4	15.48% 37	239	1.95

The response to movement to an "opt-out participation model" was strong support with over 77% of respondents in agreement. Interestingly, there was a low level of neutrality to this question. A significant minority, of over 15% of respondents, strongly disagreed with the opt-out model with comments like "I never want a PCEHR as I had my own privacy breached" and "not until proven and safe".

Conversely, many comments stated that the PCEHR would never work while not opt-out with comments like "opt-in has led to too low an uptake", "don't know why it wasn't so in the first place", "I don't think anyone should be allowed to opt-out" and "just make it compulsory".

Q22 Do you agree that the PCEHR Act and HI Act should be amended to enable opt-out "trials" to operate in selected regions in 2016 (Note the stated purpose of the trials is to: identify appropriate methods of targeting and delivering critical information to key audiences; assess the effectiveness of targeted communications, and education and training for healthcare providers; and test implementation approaches)?

Answered: 237 Skipped: 106



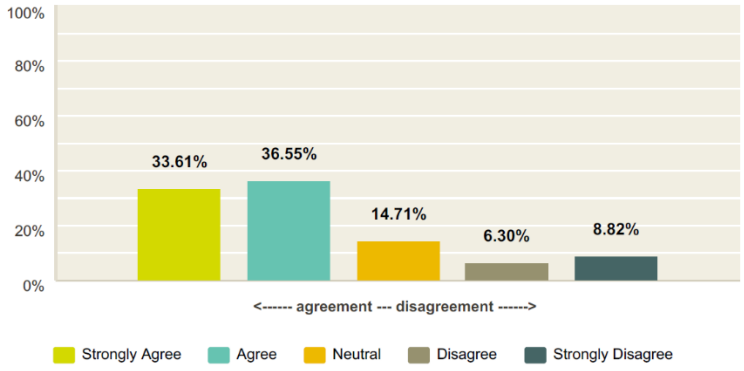
	Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree	Total	Weighted Average
<------ agreement --- disagreement ------>	35.02% 83	31.22% 74	13.92% 33	7.59% 18	12.24% 29	237	2.31

The response to the prospect of legislative amendments to allow for trials of the opt-out model was agreement by almost 2/3rds (66%) of respondents with almost 14% having a neutral view.

A significant and impatient minority, of almost 20%, trials disagreed with the need for trials at all with comments like "this has been done before", "don't pilot, more delay and loss of momentum (opt-out is a no-brainer)" and "trials too time wasting, just get in with it" and "just switch it on and get it over with".

Q23 Do you agree that individuals choosing to opt-out of the PCEHR system would need to verify their identity with the System Operator who will write to that person at the latest address held by Medicare confirming that they have opted out?

Answered: 238 Skipped: 105

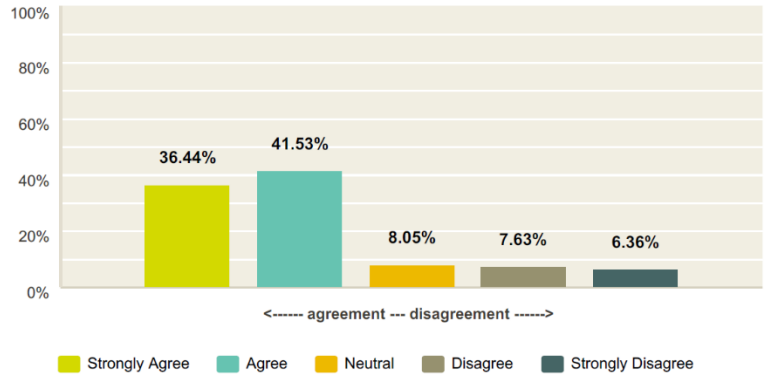


	Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree	Total	Weighted Average
<------ agreement --- disagreement ------>	33.61% 80	36.55% 87	14.71% 35	6.30% 15	8.82% 21	238	2.20

The response to individuals needing to confirm their identity to the System Operator was that over 70% of respondents were in agreement. Their comments confirmed that respondents were keen for the process to be simple in ensuring that "opt-out need to be very easy", "must be easy to opt-out" and, put another way, "this (process) makes it too hard to opt-out".

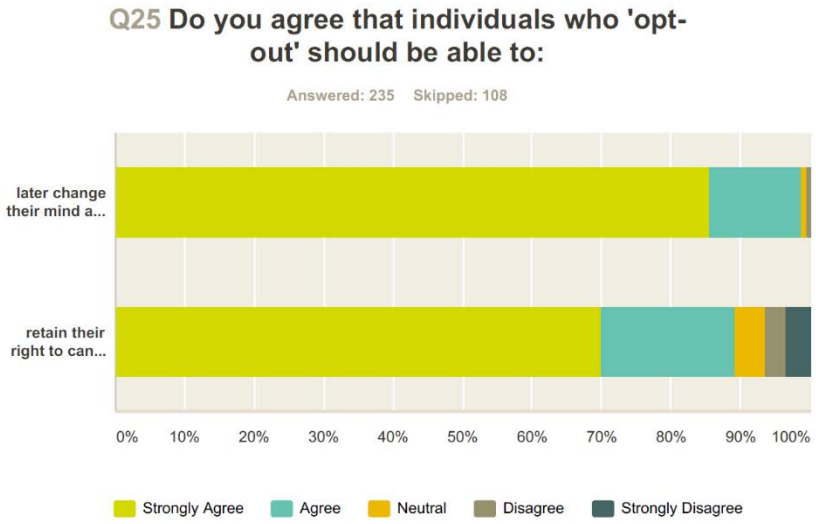
Q24 Do you agree that minors and people with limited or no capacity to make their own decisions could be opted out by a representative (who would need to have their identity verified and able to demonstrate to the System Operator that they have the authority to act on behalf of that individual)?

Answered: 236 Skipped: 107



	Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree	Total	Weighted Average
<------ agreement --- disagreement ------>	36.44% 86	41.53% 98	8.05% 19	7.63% 18	6.36% 15	236	2.06

The response to the ability be opted-out by a representative of minors or people with limited capacity was even more positive with almost 78% in agreement. Respondents suggested that holding Guardianship, Medical Power of Attorney or a Statutory Declaration may be possible mechanisms for use by a representative.



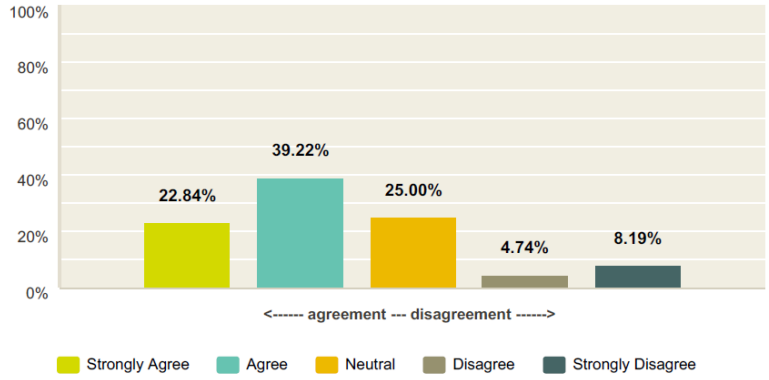
	Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree	Total	Weighted Average
later change their mind and register for a PCEHR?	85.53% 201	13.19% 31	0.85% 2	0.43% 1	0.00% 0	235	1.16
retain their right to cancel their PCEHR at any time?	69.96% 163	19.31% 45	4.29% 10	3.00% 7	3.43% 8	233	1.51

There was very strong support of over 98% for the ability to change one's mind and register for the PCEHR. A smaller, but still very positive, response of 89% to the retaining the right to cancel one's PCEHR at any time.

The minority who disagreed to the latter proposition suggested that "I think that no-one should be able to opt-out", "the unavailability of a certain record can pose a risk" or "health information should always be mandatory".

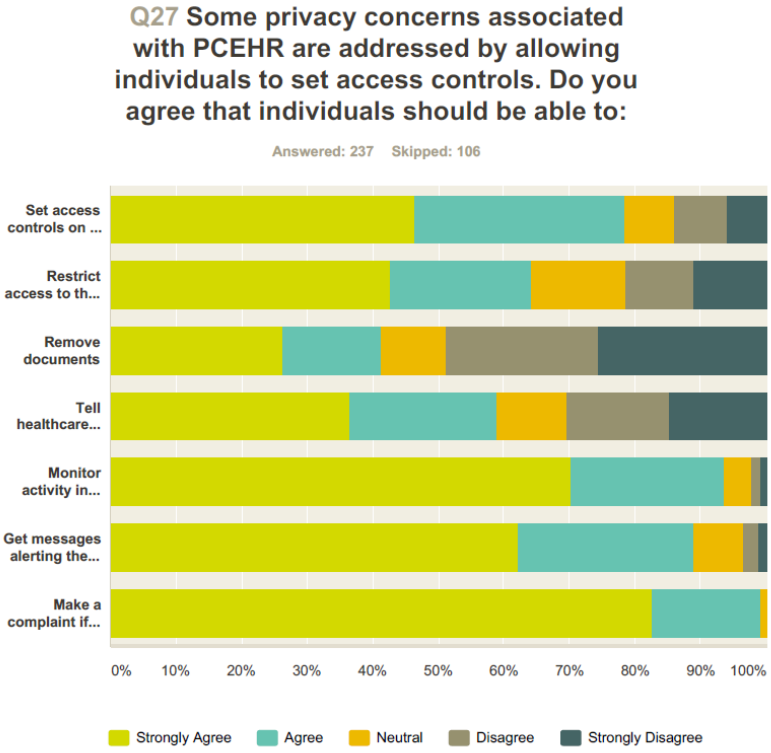
Q26 The plans for individuals in trial regions are to i) have the opt-out period set for two months; ii) after six weeks records will be available to individuals (not healthcare providers) to allow access controls to be set; iii) healthcare providers can access from July 2016 and will be able to upload records; and, iv) all data e.g. Medicare data (MBS), (PBS) Childhood Immunisation (ACIR) Donation Register (AODR) details will be uploaded and available (unless the individual opts-out or applies the access controls built into the PCEHR). Do you agree with this approach?

Answered: 232 Skipped: 111



	Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree	Total	Weighted Average
<------ agreement --- disagreement ------>	22.84% 53	39.22% 91	25.00% 58	4.74% 11	8.19% 19	232	2.36

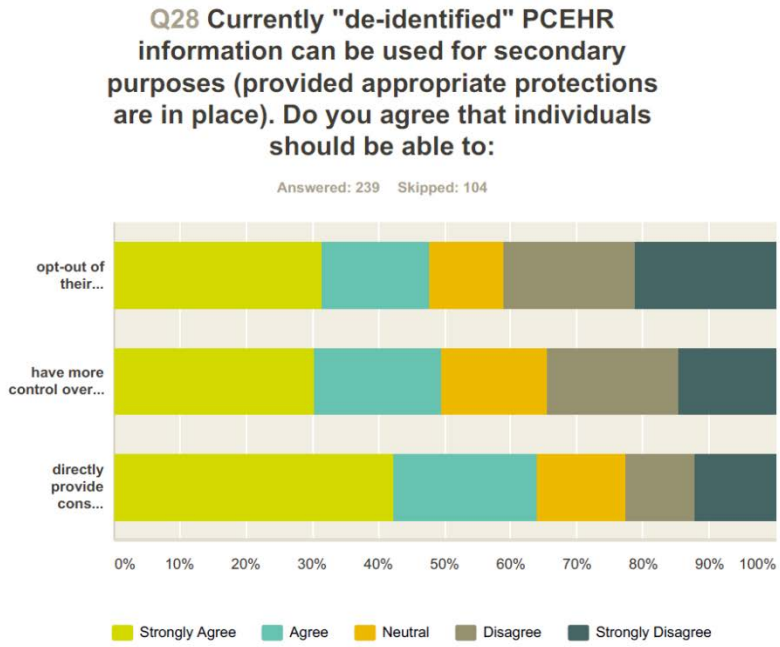
A majority of 62% of respondents supported the proposed approach to the trials with another 25% being neutral. The latter figure is unsurprising given the complexity of the question.



	Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree	Total	Weighted Average
Set access controls on who can access what information	**46.38%** 109	**31.91%** 75	**7.66%** 18	**8.09%** 19	**5.96%** 14	235	1.95
Restrict access to their Medicare data	**42.62%** 101	**21.52%** 51	**14.35%** 34	**10.55%** 25	**10.97%** 26	237	2.26
Remove documents	**26.16%** 62	**15.19%** 36	**9.70%** 23	**23.21%** 55	**25.74%** 61	237	3.07
Tell healthcare providers on a case-by-case basis to not upload certain documents	**36.44%** 86	**22.46%** 53	**10.59%** 25	**15.68%** 37	**14.83%** 35	236	2.50
Monitor activity in their PCEHR using the audit log	**70.04%** 166	**23.63%** 56	**4.22%** 10	**1.27%** 3	**0.84%** 2	237	1.39
Get messages alerting them when someone has viewed or used their PCEHR	**62.03%** 147	**27.00%** 64	**7.59%** 18	**2.11%** 5	**1.27%** 3	237	1.54
Make a complaint if they consider that there has been a breach of their privacy	**82.63%** 195	**16.53%** 39	**0.85%** 2	**0.00%** 0	**0.00%** 0	236	1.18

In response to privacy concerns via access controls, a range of responses were received. Ability to make a complaint was agreed by 99% of respondents, monitoring via an audit trail by over 93% and the use of alerts and messages by almost 90%. The ability to set access controls was supported by 78% of respondents being in agreement while advising providers to not upload documents had a high level of disagreement (30%) though still over 50% in agreement .

The mechanism that had least level of support was the removal of documents with almost 50% of respondents disagreeing to that process.



	Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree	Total	Weighted Average
opt-out of their de-identified information being used for research purposes	31.38% 75	16.32% 39	11.30% 27	19.67% 47	21.34% 51	239	2.83
have more control over how their de-identified information is used	30.25% 72	19.33% 46	15.97% 38	19.75% 47	14.71% 35	238	2.69
directly provide consent to a researcher (who has ethics approval) to use their PCEHR information	42.26% 101	21.76% 52	13.39% 32	10.46% 25	12.13% 29	239	2.28

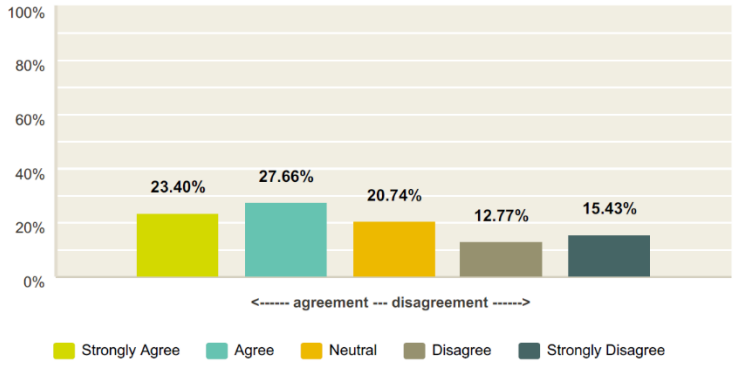
In terms of secondary purposes, there was majority agreement of 64% that individuals need to provide direct consent to a researcher (with ethics approval). There are lesser degrees of agreement (under 50%) for "more control over de-identified information" and the ability to "opt-out of de-identified information for research purposes" of 49% and 47% respectively.

The opt-out mechanism for de-identified information also had a high level of disagreement of over 40%. Several comments were that the question is an over-simplification of a complex issue.

Section 4: Obligation of Parties

Q30 Do you agree that healthcare provider organisations, contracted service providers, repository operators and portal operators should be allowed to continue to participate on an opt-in basis with government encouragement to use the system through revised incentives, and education and training services?

Answered: 188 Skipped: 155



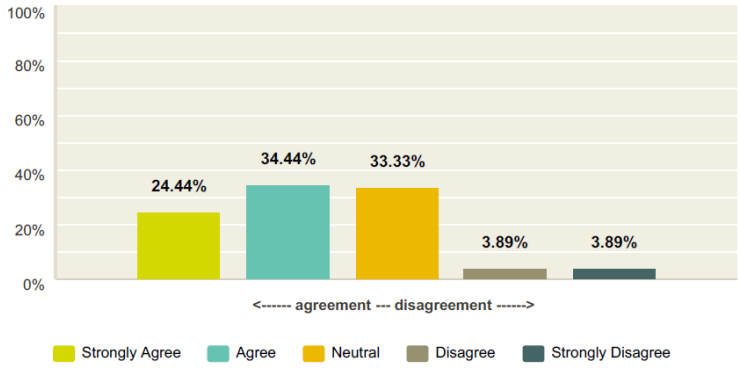
	Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree	Total	Weighted Average
<------ agreement --- disagreement ------>	23.40% 44	27.66% 52	20.74% 39	12.77% 24	15.43% 29	188	2.69

A bare majority of respondents (51%) agreed or strongly agreed to healthcare provider organisations and associated operators continuing to participate on an opt-in basis with over 20% being neutral to the proposition.

Respondents that disagreed with the proposition were overwhelming of the view that provider organisations should "opt-out as well", "should be same as individual so opt-out only" and "participation should be mandatory".

Q31 Do you agree that the current arrangement of using "participation agreements" with healthcare and other provider organisations should be stopped and the requirements in such participation agreements should be transferred into the legislation (note, this includes Intellectual Property, Liability and Data Breach Notification)?

Answered: 180 Skipped: 163

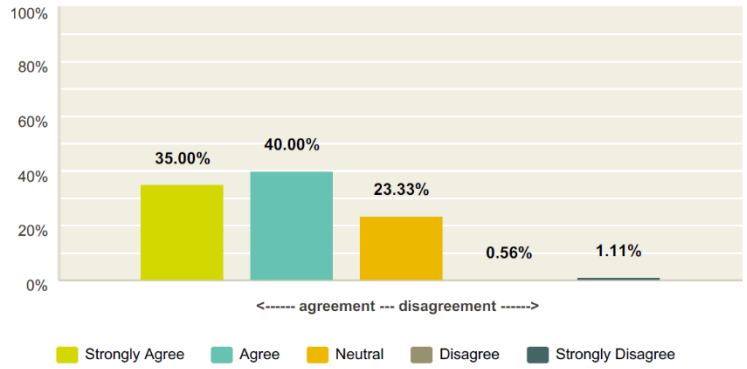


	Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree	Total	Weighted Average
<------ agreement --- disagreement ------>	24.44% 44	34.44% 62	33.33% 60	3.89% 7	3.89% 7	180	2.28

A majority of respondents (58%) agreed or strongly agreed to moving participation agreements into the legislation with a very high neutral response rate of 33% (1/3). Of interest for this question was the low rate of disagreement to the proposition at under 8%. Comments on this question were few but varied from "incorporate into legislation is better" and "prefer both legislation and agreement" to "oh my God".

Q32 Do you agree that legislation regarding compliance with the PCEHR Rules that currently only covers specific organisations (such as section 78 of the PCEHR Act which currently only applies to registered repository operators and registered portal operators) should change to apply to all participants in the PCEHR system?

Answered: 180 Skipped: 163

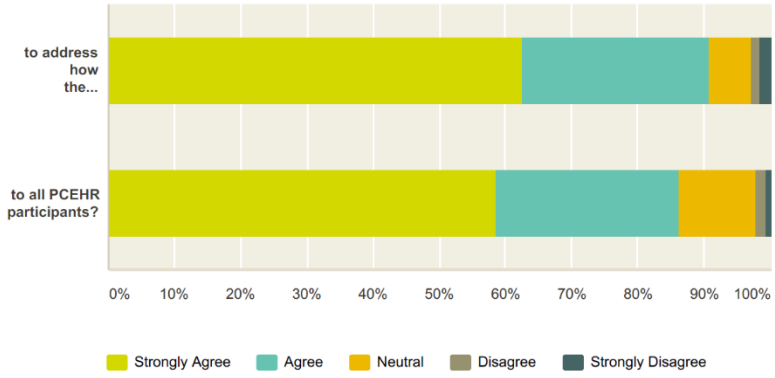


	Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree	Total	Weighted Average
<------ agreement --- disagreement ------>	35.00% 63	40.00% 72	23.33% 42	0.56% 1	1.11% 2	180	1.93

There was a high level of agreement to this proposition with 75% of respondents in agreement and an extremely low disagreement rate of under 2%. However, it should be noted that almost half the potential respondents skipped this question as, possibly, the implications of the change were unclear.

Q33 Do you agree that the PCEHR Rules currently requiring registered healthcare provider organisations to have in place appropriate security measures should now be expanded:

Answered: 187 Skipped: 156



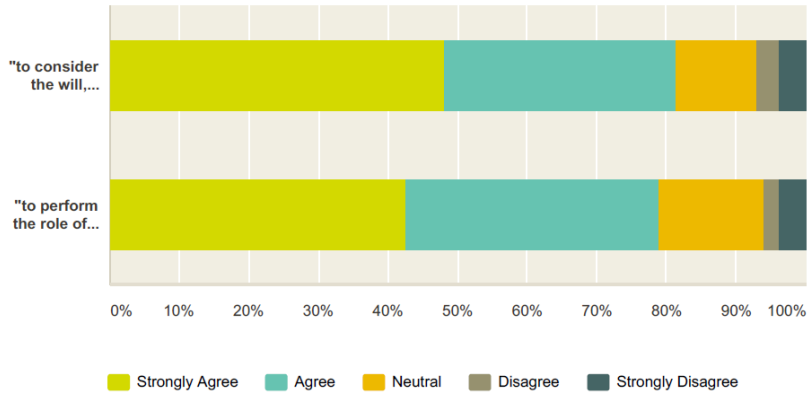
	Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree	Total	Weighted Average
to address how the organisation will ensure data quality?	62.50% 115	28.26% 52	6.52% 12	1.09% 2	1.63% 3	184	1.51
to all PCEHR participants?	58.56% 106	27.62% 50	11.60% 21	1.66% 3	0.55% 1	181	1.58

There was very strong agreement from respondents (over 90%) that the PCEHR rules be expanded to address how a healthcare provider will ensure data quality. A slightly smaller but still highly significant number (85%) were in agreement that security measures be expanded to all PCEHR participants.

The difference between the parts was a higher neutral rating (11%) for the second proposition. However, by their comments, several respondents were unsure as to whether consumers were included within the category of "all PCEHR participants".

Q34 The PCEHR Act currently provides for authorised representatives and nominated representatives to assist individuals to manage their PCEHR. Do you agree that their responsibilities should be clarified by changing the current obligation which states that representatives are "to act in the best interests of the individual" to the following:

Answered: 184 Skipped: 159

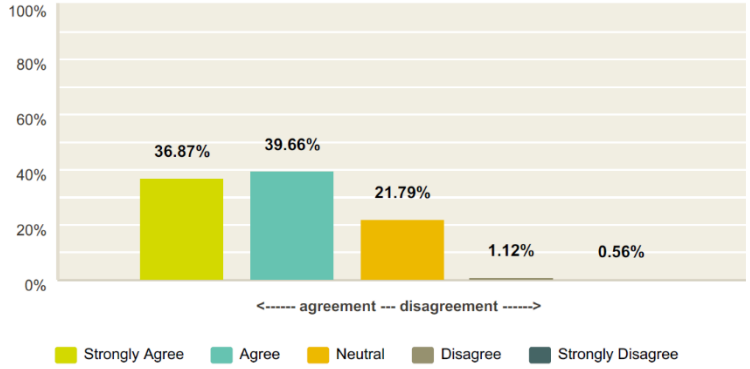


	Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree	Total	Weighted Average
"to consider the will, preferences and rights of the individual when making a decision"?	48.09% 88	33.33% 61	11.48% 21	3.28% 6	3.83% 7	183	1.81
"to perform the role of representative diligently and in good faith"?	42.54% 77	36.46% 66	14.92% 27	2.21% 4	3.87% 7	181	1.88

There was clear agreement from respondents to the proposition that responsibilities should be clarified by amending the current obligation with around 80% agreement to both propositions (81% and 79% respectively). There is a low level of disagreement to these propositions of around 7% of respondents.

Q35 Do you agree that the HI Act should be changed to align with the PCEHR Act by specifying how obligations will apply to organisations that are not separate legal entities (e.g. "trusts", "partnerships" and "unincorporated associations")?

Answered: 179 Skipped: 164

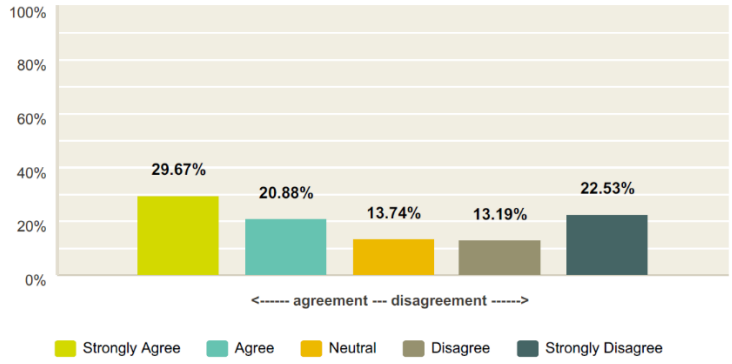


	Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree	Total	Weighted Average
<------ agreement --- disagreement ------>	36.87% 66	39.66% 71	21.79% 39	1.12% 2	0.56% 1	179	1.89

There is a high level of agreement (over 75%) that the process for organisations that are not legal entities should be aligned between the relevant Acts. Importantly, there is an insignificant level of disagreement of 1 or 2 responses only (under 2%) and very few comments.

Q36 The PCEHR Review recommended that payment for Medicare items should depend on the uploading of specific documents to the PCEHR system (i.e. relating to health assessments, comprehensive assessments, mental healthcare plans, medication management reviews and chronic disease planning items). Do you agree?

Answered: 182 Skipped: 161



	Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree	Total	Weighted Average
<------ agreement --- disagreement ------>	29.67% 54	20.88% 38	13.74% 25	13.19% 24	22.53% 41	182	2.78

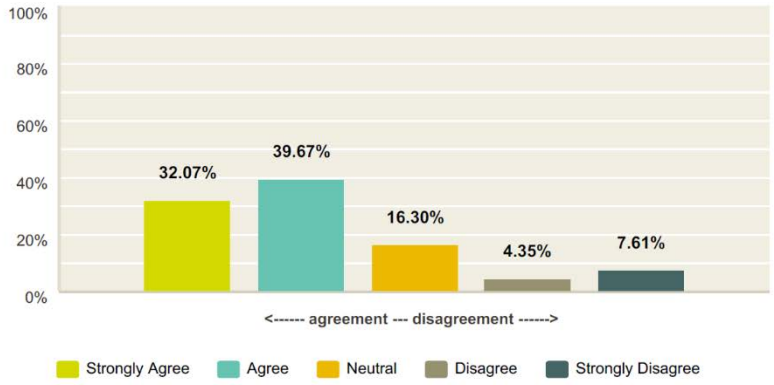
A bare majority of respondents (50%) agreed or strongly agreed to aligning the payment of Medicare items to the uploading of documents to the PCEHR while a significant minority (over 35%) disagreed or strongly disagreed to this proposition.

Some of the useful comments included that "there should be recognition that the maintenance of this system will require time and expertise - this could be reflected in Medicare payments", "sounds like a good idea but not sure how it will work" and "that's a tough one - ideally, that should be the case. However, if the patient doesn't want that to happen we shouldn't deny the doctor MBS payment for it".

Some respondents suggested a cautious approach with comments like "this seems too strong at this stage, but some extra financial incentive would be fine".

Q37 Do you agree that the PCEHR System Operator should be allowed to use (when authorised by the individual) electronic notifications or phone and to only use written notifications when no other forms of communication are practical or appropriate?

Answered: 184 Skipped: 159

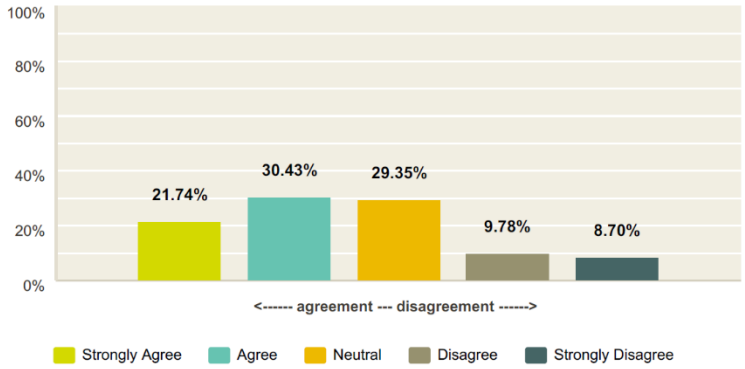


	Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree	Total	Weighted Average
<------ agreement --- disagreement ------>	32.07% 59	39.67% 73	16.30% 30	4.35% 8	7.61% 14	184	2.16

There was fairly strong support for this proposition with over 61% of respondents agreeing or strongly agreeing to electronic or telephonic communications. However, there was support for retention of post as a last resort as represented by a comment on communication with the aged population e.g. "consideration must be given to the frail aged population in relation to direct contact by the system operator. This is when the "snail mail" approach should be in place. We cannot assume all frail aged people have access to electronic media and many are suspicious of "system operator" phone calls".

Q38 Do you agree with the proposal to amend the requirements to only retain PCEHR records for 30 years after date of death; or if date of death not known, 130 years from the individual's date of birth?

Answered: 184 Skipped: 159



	Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree	Total	Weighted Average
<------ agreement --- disagreement ------>	21.74% 40	30.43% 56	29.35% 54	9.78% 18	8.70% 16	184	2.53

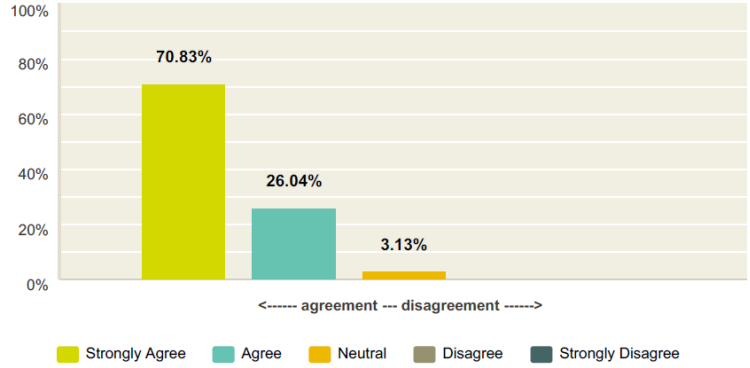
A bare majority of respondents (52%) agreed or strongly agreed to amending the requirements to retain PCEHR records for 30 years after date of death (or 130 years from date of birth). A significant minority of respondents (just under 20%) disagreed with this proposition.

Significant comments were that the PCEHR should align with current Health Records legislation which specifies record retention for 7 years (after the age of 18) or perhaps extending to 15 years. For example, "seems excessive when the standard is 10 years medical record retention for adults and "I would think 30 years is a long time. Maybe 15 would be sufficient". At the other extreme, one comment was that "retaining this data for research purposes is critical. PCEHR Records should be retained indefinitely".

Question: would jurisdictional legislation, e.g. Health Records Acts, require amendment to avoid conflicting with the PCEHR legislation?

Q39 Do you agree that a test environment should be developed and implemented by the PCEHR System Operator to allow vendors and other stakeholders the opportunity to test how systems operate and interact before they are implemented (note, the test environment would not use any real information and would be isolated from the live system)?

Answered: 192 Skipped: 151



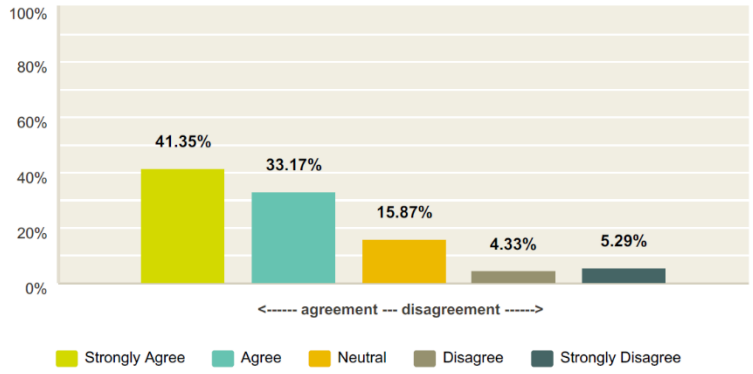
	Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree	Total	Weighted Average
<------ agreement --- disagreement ------>	70.83% 136	26.04% 50	3.13% 6	0.00% 0	0.00% 0	192	1.32

There was very strong agreement (over 95%) and NO disagreement from respondents that a test environment be developed and implemented for use by vendors and other stakeholders. Comments were consistently of the theme that "surely this was already in place", "absolutely!", "this was one of the biggest problems I had when implementing the system - no test/train environment and "what, you mean there isn't one currently?".

Section 5: Privacy

Q41 Do you agree that the PCEHR legislation should be amended to require the System Operator to add an optional access control that alerts individuals by SMS or email each time their PCEHR is opened?

Answered: 208 Skipped: 135

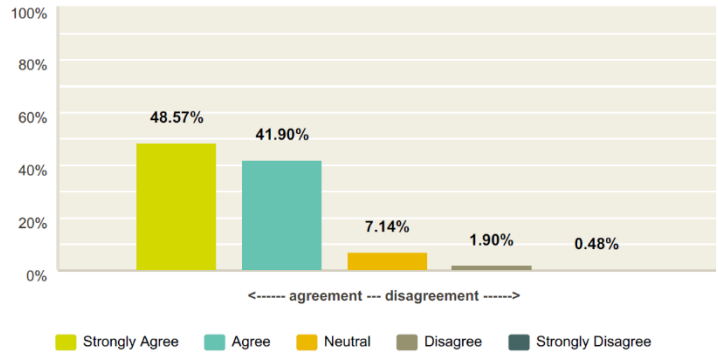


	Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree	Total	Weighted Average
<------ agreement --- disagreement ------>	41.35% 86	33.17% 69	15.87% 33	4.33% 9	5.29% 11	208	1.99

There is a high level of agreement (over 74%) to allow the System Operator to send an alert by SMS or email each time an individual's PCEHR is opened. Total disagreements amounted to under 10% with the expressed concerns about the potential for alert fatigue perhaps being confused about the operation of the "optional access control".

Q42 Do you agree that the System Operator should have the power to suspend access to a PCEHR by representatives and other participants when they suspect issue with security or identity of individuals (or their representatives') or other technical or operational issues?

Answered: 210 Skipped: 133

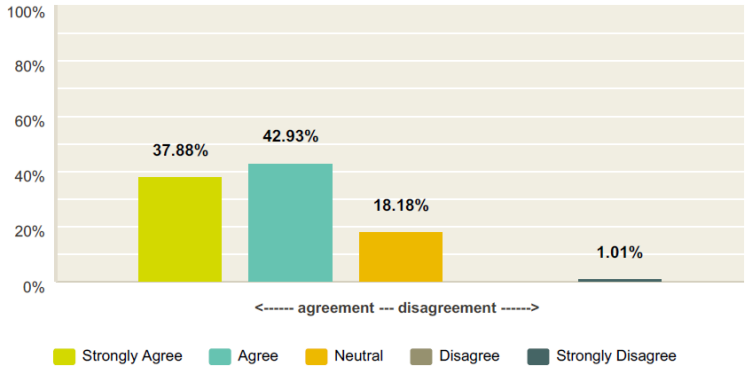


	Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree	Total	Weighted Average
<------ agreement --- disagreement ------>	48.57% 102	41.90% 88	7.14% 15	1.90% 4	0.48% 1	210	1.64

There was very strong agreement (over 90%) and very low disagreement (under 2.5%) from respondents that the System Operator have the power to suspend access to the PCEHR when an issue is detected e.g. security, identity issue.

Q43 Do You agree that authorisations in the HI Act and PCEHR Act should be simplified by specifying which particular entities may collect, use or disclose information and for what purposes, by moving from a "prescriptive approach", which specifies how an entity carries out an activity, to a "principles-based approach", which would list the information that is protected, the entities who are authorised to collect, use and disclose, and the purposes for that collection, use and disclosure,?

Answered: 198 Skipped: 145

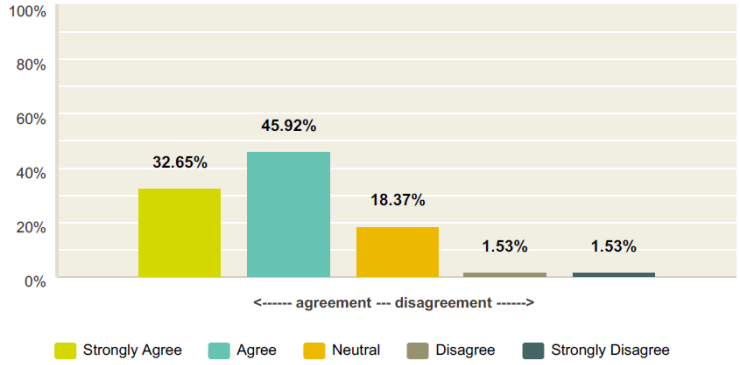


	Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree	Total	Weighted Average
<------ agreement --- disagreement ------>	37.88% 75	42.93% 85	18.18% 36	0.00% 0	1.01% 2	198	1.83

There was general agreement to this proposition (over 80% agree or strongly agree) with a very low disagreement rate (2 responses only). Concern from the comments was that the question was an over-simplification of a complex issue and general comments like "principles always better than prescriptions".

Q44 Do you agree that clarification should be made through legislation to remove any doubt that healthcare providers may include relevant third party personal information in a record that's uploaded to the PCEHR, and that the System Operator is authorised to collect the information in the record for inclusion in the individual's PCEHR?

Answered: 196 Skipped: 147

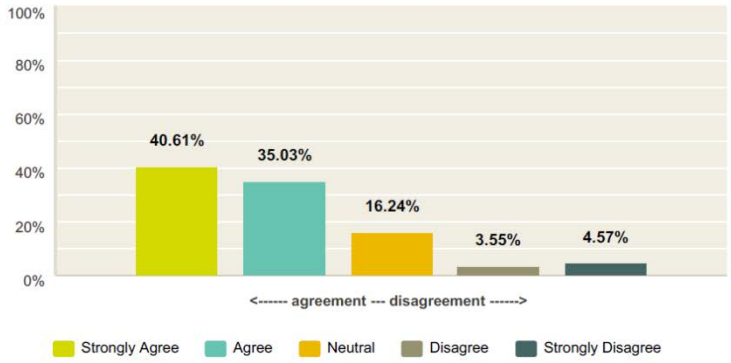


	Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree	Total	Weighted Average
<------ agreement --- disagreement ------>	32.65% 64	45.92% 90	18.37% 36	1.53% 3	1.53% 3	196	1.93

There was strong agreement (78%) that the proposition that clarification should be made through legislation to remove any doubt that healthcare providers may include relevant third party personal information in a record that's uploaded to the PCEHR (and that the System Operator is equivalently authorised). The level of disagreement was low at just over 3%.

Q45 Do You agree that changes are required to the HI Act to remove the need for consent so organisations are automatically listed in the Healthcare Provider Directory (note that the government's aim is to remove barriers to effective communications that adversely affect other eHealth services dependant on the HPD, such as secure messaging)?

Answered: 197 Skipped: 146



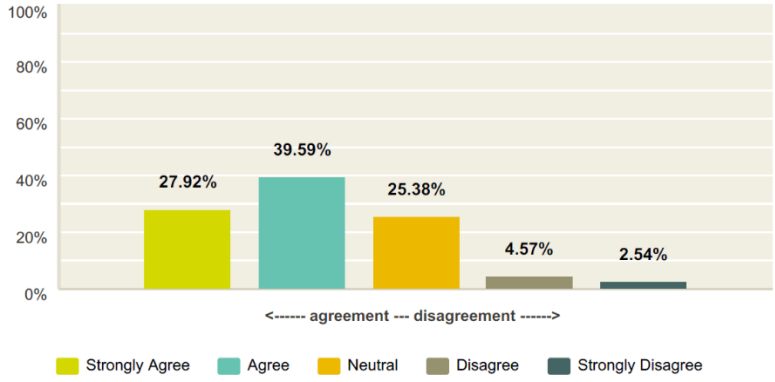
	Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree	Total	Weighted Average
<------ agreement --- disagreement ------>	40.61% 80	35.03% 69	16.24% 32	3.55% 7	4.57% 9	197	1.96

There is a high level of agreement (over 75%) to remove the need for consent for organisations to be listed in the Healthcare Provider Directory. Overall disagreement was just over 8% with those that disagreed implying that providers should be able to opt-out of the provider directory.

A supportive summary comment was that "an organisation has no right to privacy and withholding listing from the HPD inhibits secure messaging".

Q46 Do you agree that change should be made to the HI Act to allow regulations to be made prescribing additional uses of healthcare identifiers in closely restricted areas, for example the National Disability Insurance Scheme (NDIS) records?

Answered: 197 Skipped: 146

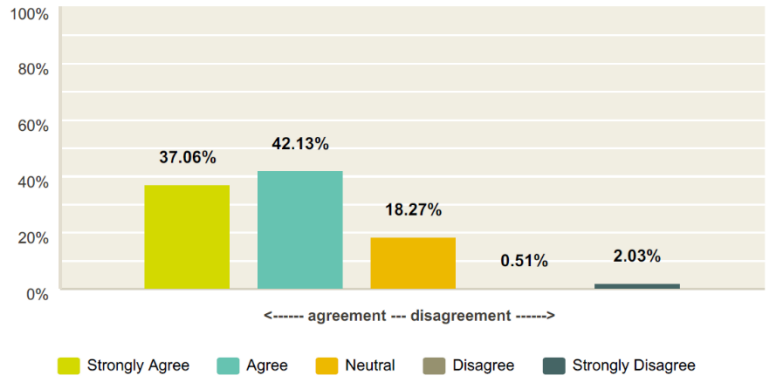


	Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree	Total	Weighted Average
<------ agreement --- disagreement ------>	27.92% 55	39.59% 78	25.38% 50	4.57% 9	2.54% 5	197	2.14

Again there was majority support for this proposition with over 2/3rds (67%) in agreement and just over 7% in disagreement with the proposition that regulations could allow for additional use of identifiers e.g. for the NDIS. Opposing views included that "this should not be an Australia Card" while a supporter stated that "the creation of another identifier scheme for NDIS would be a waste of effort and resource, add to burden on providers and not make the most of existing e-health infrastructure".

Q47 Do you agree that the Information Commissioner should be "expressly authorised" to handle healthcare identifiers and associated information as part of carrying out her or his functions under the Privacy Act and the HI Act (note, currently the Commissioner's role is unclear in regard to healthcare identifiers)?

Answered: 197 Skipped: 146

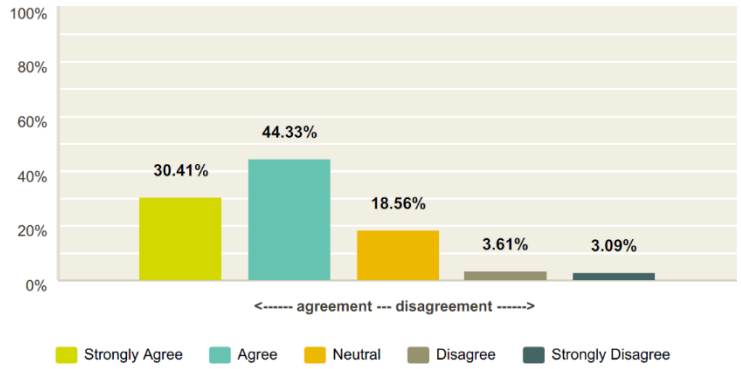


	Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree	Total	Weighted Average
<------ agreement --- disagreement ------>	37.06% 73	42.13% 83	18.27% 36	0.51% 1	2.03% 4	197	1.88

There was strong support for this proposition with over 77% in agreement with only 2.5% (5 respondents) in disagreement with the proposition that the Information Commissioner be "expressly authorised" to handle healthcare identifiers and associated information. Few comments were made on this question.

Q48 Do you agree that the HI Service Operator should be authorised to disclose to a healthcare provider organisation the healthcare identifiers status for an individual healthcare provider (e.g. inform the organisation that a particular identifiers has been suspended and it belongs to a GP)?

Answered: 194 Skipped: 149

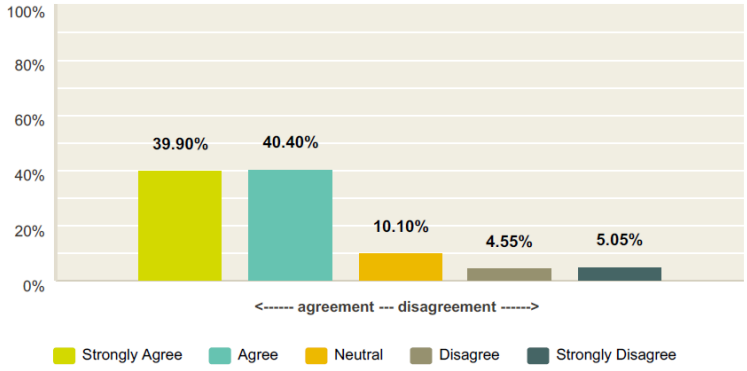


	Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree	Total	Weighted Average
<------ agreement --- disagreement ------>	30.41% 59	44.33% 86	18.56% 36	3.61% 7	3.09% 6	194	2.05

There was strong support for this proposition with over 74% in agreement with 6.7% (13 respondents) in disagreement with the proposal to disclose the status for an individual healthcare provider e.g. where it has been suspended. Few comments were made on this question.

Q49 Do you agree that the HI Service operator should be allowed to undertake actions that would enable resolution of an individual's identity when a direct match is not working (e.g. a mismatch due to minor spelling or punctuation difference in an individual's name since currently the Act requires a perfect match before disclosure)?

Answered: 198 Skipped: 145



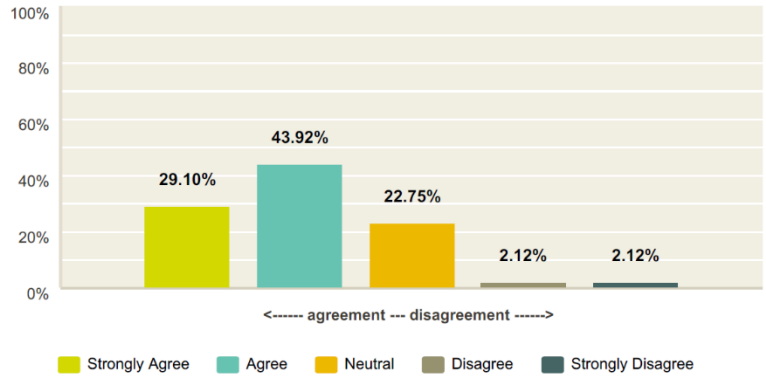
	Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree	Total	Weighted Average
<------ agreement --- disagreement ------>	39.90% 79	40.40% 80	10.10% 20	4.55% 9	5.05% 10	198	1.94

There was strong support for this proposition with over 80% in agreement with under 10% in disagreement with the proposition that "the HI Service operator should be allowed to undertake actions that would enable resolution of an individual's identity when a direct match is not working".

A number of comments were made in response to this proposition including suggestions that "HIMAA need to be asked to develop actions in this space as they are SMEs in name mismatches and correct identification of individuals" and that "the HI Service Operator is held to account for its actions and that recovery pathways that are efficient and respectful are in place to address the inevitable mistakes".

Q50 Do you agree that changes be made in what personal information can be collected, used and disclosed by the PCEHR System Operator for the purposes of detection, prevention and enforcement activities associated with fraudulent activity or security activities of the PCEHR system?

Answered: 189 Skipped: 154

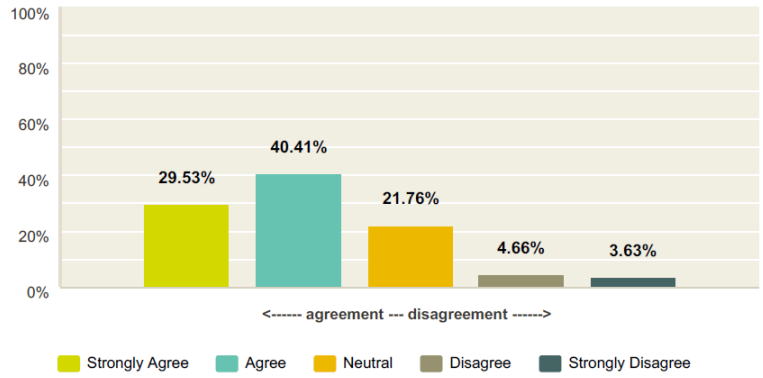


	Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree	Total	Weighted Average
<------ agreement --- disagreement ------>	29.10% 55	43.92% 83	22.75% 43	2.12% 4	2.12% 4	189	2.04

There was strong support with over 74% agreement, with 4.2% (8 respondents) in disagreement, for the proposal to make changes for the detection, prevention and enforcement of fraudulent activities.

Q51 Do you agree that changes should be made to allow the HI Service Operator to disclose personal information back to the AHPRA, which is the agency responsible for assigning Healthcare Identifiers (Note, currently disclosure is only allowed from AHPRA to HI Service Operator. The government's stated aim is to facilitate greater data quality and accuracy and also permit information to be corrected at source)?

Answered: 193 Skipped: 150

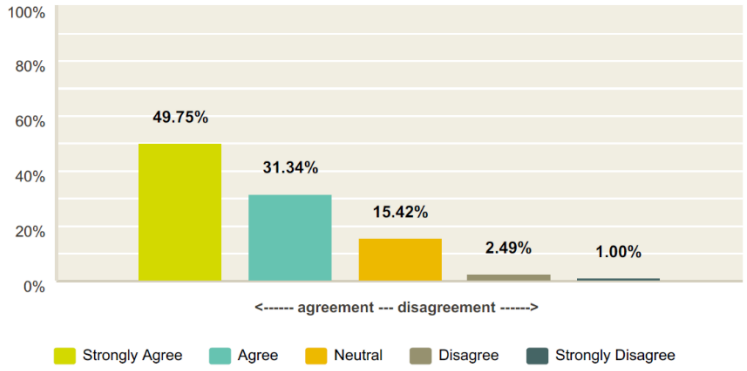


	Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree	Total	Weighted Average
<------ agreement --- disagreement ------>	29.53% 57	40.41% 78	21.76% 42	4.66% 9	3.63% 7	193	2.12

There was strong support with just under 70% agreement, and 8% in disagreement, for the proposal to the HI Service Operator to disclose personal information back to the AHPRA, which is the agency responsible for assigning Healthcare Identifiers. Supportive comments included that "two-way feedback and allowance for validation is required" but that "it needs to be closely monitored and transparent".

Q52 Do you agree that, in future, more serious misuses of PCEHR information should be subject to "criminal penalties" (including the possibility of imprisonment), as well as retaining the current civil penalties (monetary fines, injunctions, etc.) for less serious breaches?

Answered: 201 Skipped: 142



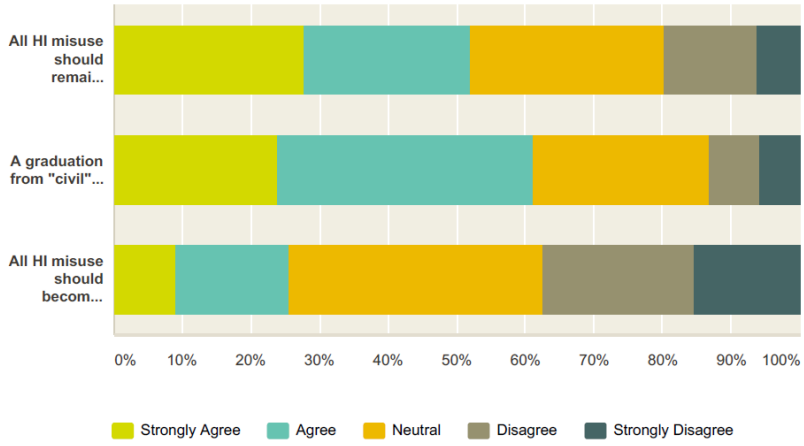
	Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree	Total	Weighted Average
<------ agreement --- disagreement ------>	49.75% 100	31.34% 63	15.42% 31	2.49% 5	1.00% 2	201	1.74

There was very strong support, at over 81%, for the proposition that more serious misuses of PCEHR information should be subject to "criminal penalties" (including the possibility of imprisonment). Interestingly, disagreement to the proposal was low at under 4%.

Supportive comments included that "strong penalties are required, including imprisonment, as a message to the community that this is the expectation" and that "there must be (a) sufficient penalty to make misuse a very unpalatable option".

Q53 The government states that Healthcare identifiers are simply a number which does not contain any health information. Therefore do you agree in regard to the penalties for offences imposed by the HI Act, they should be as follows:

Answered: 191 Skipped: 152



	Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree	Total	Weighted Average
All HI misuse should remain criminal penalties?	27.75% 53	24.08% 46	28.27% 54	13.61% 26	6.28% 12	191	2.47
A graduation from "civil" to "criminal" for less to more serious HI misuse?	23.94% 45	37.23% 70	25.53% 48	7.45% 14	5.85% 11	188	2.34
All HI misuse should become civil penalties?	8.99% 17	16.40% 31	37.04% 70	22.22% 42	15.34% 29	189	3.19

There were varying degrees of support (or lack hereof) for these propositions. Support for the proposition that all HI misuse should remain as criminal penalties had bare majority support at 51% while graduation from civil to criminal was supported by a higher level with 61% of respondents in agreement.

The proposition that all HI misuse should become civil penalties had a much lower level of agreement at 25% while its rate of disagreement was over 37%.

A typical comment was from a respondent that was "concerned that less serious penalties could become simply become a cost of doing business to the private market. The potential misuse of Healthcare identifiers is about their identifiability (sic), not that they have health data".

Conclusion

HIMAA and HISA have obtained feed back to the propositions in the “Electronic Health Records and Healthcare Identifiers: Legislation Discussion Paper”.

Respondents have provided detailed responses to propositions each of which were subject to strong agreement, agreement, neutral opinion, disagreement or strong disagreement. The results of the survey have been shown above while detailed comments for each question are detailed in the Appendix.

> **HISA and HIMAA both strongly recommend to the government that health informatics and health information management expertise be present at all levels of governance within ACeH. The skill sets, knowledge base and experience of health informatics and health information management professionals is critical to the success of e-health initiatives.**

Significant changes proposed, many from the Royle Review, were generally supported by respondents to the HISA and HIMAA Survey.

For example, there was general agreement to the proposed name change of the PCEHR to "My Health Record" with almost 70% in favour of the change while less than 9% of respondents disagreed with the proposed name change.

There was also strong agreement from respondents for the alignment of definitions between the HI Act and the PCEHR ACT and agreement to the encouragement of secure messaging and other forms of communication by ensuring that healthcare providers can be more easily identified e.g. by their email address.

One of the areas of strong agreement (over 95%) and NO disagreement from respondents was the proposition that a test environment be developed and implemented for use by vendors and other stakeholders. Comments were consistently of the theme that "surely this was already in place", "absolutely!", "this was one of the biggest problems I had when implementing the system - no test/train environment and "what, you mean there isn't one currently?".

Overall, apart from minor areas of strong disagreement on secondary use of information for research and related consent issues and the use of identifiers like drivers licence or passport number, respondents were generally in agreement with to the majority of propositions.

However, careful perusal of the comments to each question is warranted as many useful comments and ideas were made by the respondents to this survey.

Further analysis of the raw data would enable stratification of the sample and more useful information extraction eg how do the opinions of clinicians and vendors vary? HIMAA and HISA would welcome the opportunity to do this further analysis should the Department find this useful.

Appendix One

LIST OF ALL COMMENTS RECEIVED

Q1) With which title do you most closely identify from the following list? Academic/educator/researcher Allied health / dental CEO/GM CIO/CFO Consumer Consultant Engineering or science professional Health information manager Health informatician Health IT professional Manager/Head of Dept Nurse Pharmacist Physician or General practitioner Policy Officer Student
A consultant previously involved with PCEHR work
and consumer and academic/researcher and health IT
Archivist
Clinical Business Analyst/RN Clinical Application Support ICT
Clinical Coder
Clinical Coder and IT student
Clinical Development QA Manager (Clinical Trials)
Current Medicare Local staff - former e-health staff/adviser
Director E-Health
E-Health Program Officer
E-Health support staff
evaluator
Health educator
Health IT Project Manager
Health Project Office
Health promotion officer
health public servant
Health Service Manager
Healthcare administrator
ICT Project officer
Informatics Pharmacist
Nurse Informatician
Practice Manager - GP Clinic
Practice Support - North Coast NSW Medicare Local
Primary Care Liaison Officer
Primary Care Liaison Officer - E-Health Officer
Primary Health Network -E-Health Advisor
Project manager
Project Officer & Primary Care Liaison
Regulator
Volunteer
Web Administrator

Q2) What type of organisation do you work for?

Association

Austin Hospital Olivia Newton John Cancer and Wellness Centre
Board member of not for profit HIM organisation and Community Board member of health service.
clinical college
commercial
consultancy
Consultancy
consultant
Consulting
contractor - self employed
Currently on parental leave
Government Archive
Government funded e-health development organisation
Government funded private organisation
health informatics consultancy
health insurer
health workforce peak body
independent consultant
Independent trainer
IT solution vendor
Management consultancy practice
Media
Medical College
Medicare Local
Medicare Local
Medicare Local
Medicare Local
Medicare local
Medicare Local
Medicare Local
Medicare Local
Medicare Local
NFP NGO
NFP preventative and emergency services health entity
NGO
not for profit health consumer advocacy organisation
Not relevant
Own consulting firm
Peak Body
Pharmaceutical Company
private company
Private gp
private health insurance organisation
Private Health Insurer
Private practice
professional services consulting

Public hospital
publishing medical information
Retired
Retired pharmacist & health informatician
Rural Workforce Agency
Software vendor
Tech Company

Q3) Have you registered for a PCEHR?
No, haven't considered it yet.
No, didn't know I could
As a pharmacy software vendor we put in an application to be part of the Wave 1 project I think it was some years ago and heard nothing.
Will not register as i don't believe patient privacy exists this makes it too easy for anyone to access simply by hitting the override button.
Tried too but it failed and required me to call. That's more effort than I wish to give
Not Australian resident
Not applicable for role/organisation
Yes but cancelled my pcehr,
unsure
not sure
Tried to but original website was rubbish
Yes, and on behalf of my cared-for relatives who are vision impaired

Q4-5) – No comments allowed

Q6) Do you agree that the name PCEHR should change to 'My Health Record'?
Ideally the scope of the current PCEHR would be expanded to include as wider range of 'government funded or government supported services as possible, to broker the ability for as wider range of health and human services data to be centrally managed and provided for multiple use including personal care plans, but also government planning and reporting, and de-identified data for ethically approved research.
All services need to be customer/recipient centric
PCEHR is an absurd acronym to expect people to associate with a medical record.
The term PCEHR is meaningless and even when expanded is quite long winded
Shame to loose the 'Personally Controlled' aspect but the current name will not stick with the general public
Just like every other national programs central health record
They are both bad names. "My health record" implies that this is the person's entire health record, which it definitely is not.
"My Health Record" would mean more to the end user
Too similar to the system created in the NT
I don't disagree with a name change but don't agree with the proposed new name
The new name is simpler than PCEHR, which most people didn't know what it was. I think there is an "e" missing in "My Health Record", as something by this name could also be paper based, which of course would defeat the purpose of the entire structure.
A more formal name, such as the Australian personal health record would be more appropriate. My Health Record is too colloquial a label for such an integral part of coordinated care.

My Health Record is meaningful to the general public
PCEHR means nothing to the average person
It is already know as PCEHR, rebranding will not improve the product
More consumer friendly and intuitive
Significant name equity and recognition in PCEHR (good and bad) but changing risks additional confusion.
Name changes and branding seem to be a common trend when it is not progressing well. Systems, policies, documentation needs to reflect the name change. This is sometime not as easy.
I think they are both kind of bland. How about 'Australian Health Record'?
I think it would be more wise to associate it with electronic - especially for older populations who may not understand. I am an OT by background and the aging population, ie "eHealth Record" - Have you got an e-health Record? sounds much more clear than - Have you got a My Health Record?
Too presumptuous - it is no more "my" record that the seatbelt in my care which is also mandated
PCEHR is meaningless to the average consumer and a bit of a mouthful...
Acronyms too confusing and nondescript for many people.
Hardly matters
Would prefer "My eHealth Record"
More personable and marketable
To the general public, it shows ownership rather than being just another acronym
Should read my national health record as state authorities such as NSW are creating a clinical portal for public hospital records.
I believe it is protected copyright of another organisation so maybe conflicted but really good explanation. Maybe just eHealth record may be easier
The new name is more user friendly
Resonates better with the common man
The change should only accompany significant change to the package eg a change to opt-out.
I think My Health Record is okay - but very hard for clinicians to say would you like me to upload a shared health summary to your 'My Health Record' - I think iHealth record or eHealth record would be better.
It is better than PCEHR but could be more catchy
PCEHR too long for consumers to remember.
PECKER is not a good acronym
people can connect with my health record better
The fact that the record was to be PERSONALLY controlled was vital to its acceptance. The Royle Report severely undermines that in terms of over strengthening health professional control and weak to non existent involvement of health consumers in the governance structure
Needs to change, not sure this is right either.
I agree that the name should change. I am not entirely sure that 'My Health Record' is suitable.
My e-health record would be more suitable
Don't care what it is called, needs to be useful and useable
It is important that changes like this are also implemented in the vendor systems. Having a situation where there are multiple different names for the same thing only leads to confusion.
Patient Controlled Electronic Health Records spooks the doctors ;)
It should be called "My Health Record System", otherwise it is difficult to name it as anything other than a single record.
"My Health Record" is too generic and hence will add confusion. Also, the PCEHR is now a known acronym and hence should not be changed.
PCEHR is a meaningless acronym - using a more direct and clearer name would be beneficial to encourage ownership.

A more simplistic and explanatory name.
It should have some indication that it is a National Health Record.
It doesn't really matter

Q7) Do you agree that the definition of "healthcare" in both the HI Act and the PCEHR Act be expanded to include the following: Health-related disability? Palliative care? Aged care services? Treatment of injury?

I would like this to be as wide a scope as practical, not limited to Health, but all Human Services including mental health, employment services, housing/rental assistance and ageing services, disability, education and training related data records.
Holistic healthcare covers all facets of care an treatment.
Injury is too broad - treatment by a registered healthcare practitioner?
Quality of life more important
All social and community serves across the continuum of care.
Yes because all types of care require sharing of information
I think healthcare is all encompassing. Otherwise too wordy
I thought it already was!
no idea what this means in context of the Act or what the impact would be
with the introducing of the my aged care record to go live in 2015, i find it unbelievable that this was not done via PCEHR considering its a commonwealth requirement after removing HACC
(it'd be helpful to summarise what the current definition is in the question)
include the ambos. that's who needs it
All of the above are critical components of healthcare
provide any evidence it will save money or result in significant improvements in health outcomes
Actually, think we should just focus on "Care"
Would be better presented as "health services" so that agencies other than "Health" could also be a provider.

Q8) Do you agree that the different definitions of "consumers" in the PCEHR Act and "healthcare recipients" in the HI Act should be aligned by using the following in both Acts: "Individual", "Healthcare Recipient", "Subject of Care"

In these contexts nomenclature from the Acts leaks into systems and services. Hence naming should be plain English understandable to both providers of care and patients. Don't consumers mostly resonate with the term "patient"?
healthcare recipient makes it clear who is being referred to
All individual's are healthcare recipients at some stage. It's an individual's health record not just a medical record of incidences.
Healthcare recipient' and 'subject of care' both imply passive roles - which jars with the idea of active control of the PCEHR/MyHR by the individual.
The Acts should be aligned
Just pick a name and stick to it. However, individual is too broad, as it could be an individual healthcare provider, rather than individual consumer. I also don't like "subject of care", because it implies that this person is completely passive when in fact it's the consumer who is in charge of their health. I prefer "consumer" or "healthcare consumer".
Do not mind as long as definitions of each are available
no idea what this means in context of the Act or what the impact would be
I feel that people receiving care generally want to be known that they are a "patient" of a health service,

the political correctness of definitions can make it confusing for patients when they don't know what they're being referred to as.
there needs to be uniformity in definitions and use of terms
How about being blunt and call it for what it is "patient"
consumer pretty well known in health
Healthcare recipient is the most intuitive of all
Consider other health related Acts to ensure a consistent approach to the language (consumer or individual)
either of these definitions would fit, perhaps individual as the record could be used when a person is not actually a healthcare recipient at that time, ie they are not receiving care
A term that reflects the active and empowered and respected involvement of the individual for whom the system exists is vital. Those people are no longer 'patients' or passive recipients in all circumstances
consumers are shoppers and have choice. health care users may not have choice - so don't call them consumers.
Either, individual is confusing with hppii

Q9) Do you agree that definition of "health information" in both the PCEHR Act and the HI Act should expanded to include the following: "Mental or psychological health"? "Disability of an individual"? "Genetic information"?

However, this should not imply compulsory provision of data (esp genetic) in to the PCEHR.
Genetic information was not included in the discussion paper but it should have been as this knowledge is now becoming more critical for effective healthcare.
All or any information generated in the delivery of medical, social and/or community services that warrant the application of concepts of accountability, consent, privacy and/or security applied to them.
Important these are considered however think Health covers it. Though maybe doesn't cover disability.
I don't understand why we need to be specific
Not sure of the impact of this change - but if it is about what goes in an e-health record then 'health' should mean 'all health' - no exclusions. How can medical professions manage someone's health on only part information? Comorbidities are important.
these are all important aspects of every individual
Need to be very careful about what is included and the health care ramifications on a patient who will see this information. Genetic and HIV results should at all times require counselling of patient to truly understand what the information means, otherwise can cause more harm to patient's wellbeing
bit of ethical concern
The viewing of this information should be restricted as it is highly sensitive, yet it should be made available to at least one primary care provider to view if required, in light of recent incidents such as the Germanwings air crash.
Genetic information should be left to the discretion of the individual however if an individual has government funded services relating to Metal/Psychological and/or disability then this should be included
There should be strong privacy process to enable Genetic information to be included.
Genetic information is going to be important for the next generation of healthcare consumers as disease management will rely on modification of risk factors and gene targeted therapies.
I think genetic information should be considered separately. Unlike symptoms of illness and state of health, genetic information is an identifier of an individual.
Only if it's a health related disability
How will the ethical issues and security of information relating to genetic information be maintained. This information should not be as readily accessible as other health information
Mental & Psychological well-being is less likely have a stigma attached
If genetic information is included there needs to be clear legislation to limit any negative impacts to

health insurance and care coverage based on genetic profiles
It depends on what the genetic information is used for - it should only be made available if related to being able to care properly for the individual.
I understand genetic information is often subject to a higher standard under privacy laws

Q10) Do you agree that regulations under the Acts should exclude activities from being defined as "healthcare" which are performed for reasons other than care or treatment (e.g. for the purpose of life insurance, health insurance etc.).

I am unsure on this, as to the proposed use or purpose relating to Life insurance 'assessment', however the records would be useful to be collated where there is $1 or more of Government funding assistance provided for the activity - which I would expect would be a wide scope for activates to be included?
Based on examples provided above, these are assessments. Any healthcare related issue should have been/will be documented by a healthcare provider and that is the information that should be in the health record
It is Privacy Invasive for insurance companies to use your personal HI
Caution must be taken to ensure there are no unintended consequences potentially detrimental to the healthcare recipient by excluding these.
Personally, I wouldn't care about this, but I can see the potential for consumer backlash if this kind of information is included by default. Can this information be "opted in"?
still is useful data
All in! One source of truth.
it should only be about care or treatment. Life insurance and other such investigations are for a specific administrative purpose not for continuing care or treatment
Avoiding Americanisation is very important
health insurance should be kept out of scope
Every test and it's result builds up the story board for the patient's healthcare regardless of why it was done.
If health insurance information is available in the My Health Record, then there should be provisions that the life insurance company has only access to that particular life insurance information and no other information that may be available about the person/subject of care.
if it is a basic medical that data may be useful, when other health care providers see the record.
life insurers and health insurers have the largest sets of health records in the land. They need to be treated the same as any others who are to be entrusted with health information
It is important that insurance remains separate from personal health other than identified risk factors such as smoking, alcohol consumption and personal activity.
This information could also be critical when taken into conjunction with other information
There are no activities performed for health insurance purposes as health insurance is community rated. Treatments for health insurance should not be excluded
Whether something is health related or not should depend on the activity not the purpose of the activity.
Would want to see some specific scenarios to understand this more.
Many of the investigations often undertaken for insurance purposes are relevant clinical details and if these were available included in the PECHR that could potentially reduce duplication of tests and investigations, even if the cost is not covered by Medicare
This may be impacted by activities that are undertaken for the purpose of life insurance that identify activities that require healthcare. Clarity regarding preventative healthcare - for example dental check ups, needs to refined.
If this includes a screening chest x-ray for pre-employment or immigration purposes for example should be included. These all contribute to the patient's overall health picture.

Q11) The Privacy Act 1998 protects privacy of individuals and not organisations. Do you agree that to assist government in promoting organisational participation in the PCEHR system (while protecting the privacy of individual health providers) that the HI Act should change its current definition of "healthcare provider" to distinguish between “healthcare provider organisations” and “individual healthcare providers”?
I want to know if my GP is participating - once they sign they should consent to information about their participation being available.
Good to have tight definitions as possible
I'm not sure exactly what's in the ACT, but that's the structure we have: HPI-O and HPI-I.
What happens to situations where public health services are run by private providers?? eg/Mayne health running a Emergency department for public patients?.
there does need to be organisational participation and if this change promotes and encourages it, ffering the same protection to the individual, then it needs to be changed
definitions around both would be required
Clarity is paramount for privacy purposes
given that both are registered as 2 entities for PCEHR security purposes they should be quite separate
Unsure of the implications. What is blindingly obvious is that the Privacy Commissioner is so under resourced for the task by the government that regardless of the words in the law, it is impossible for the Commissioner to be sufficiently effective
This question is difficult to follow
It's clear to me that when referring to organisations we are talking about those for which the healthcare provider works for and therefore not any other organisation.

Q12) Do you agree with the proposal that the PCEHR Act and HI Act should change the definition of “identifying information” to include i) more contact details for communications and ii) identifiers for opt-out verifications, as follows? Mobile number Email addresses The status of the Individual’s Healthcare Identifier (IHI) Individual’s driver licence number Passport number or Immicard
mobile numbers and e-mail addresses can change frequently for some individuals
The mobile messaging is too easily seen by others (e.g. family members). Emails can be anonymous and kept more private. Individuals need to control this. Too much personal information is dangerous (no driving licence or passport numbers please!) - if an individual have been opted out inappropriately they will be informed and can reverse this.
Didn't quite understand this question so have not answered it.
We currently have a problem with email addresses. The PCEHR system assumes that email addresses are unique identifiers: Every user needs their own unique email address for the PCEHR. That is not real life - many older people don't use email, so they should be given the option to use the email address of a relative or close friend. Yes, I think it could be used as an identifier, but remove the requirement to make this a unique identifier. With all the identifiers above - the should be optional, not something the user must know/be able to quote.
If someone opts out, they should not be targeted as someone doing something wrong. it needs to be a free choice without repercussion.
That is a passport is definitely identifiable information, hence should be guarded and not divulged
Don’t understand why we need this. If a person has a HI, all this information should already be available
Why do they want to do that? What impact would that have? Don't have enough understanding to answer this question.

although passport and driver's licence are photo id, I think they are not necessary for health related purposes
Need to limit identifying information to specific what the purpose of the record keeping and not "big brother" as many patients may and probably don't have a drivers licence or passport number.
maybe not all required
Transparency of information is vital for follow up purposes
Most of these are optional 'achievements' totally unrelated to the provision of healthcare and should not be centrally recorded. Some individuals do not drive, have internet access, travel overseas or use a mobile telephone - especially the elderly or marginalised members of society.
a lot of older people do not have a mobile or email so you can't rely on either
Very poorly phrased question. If such information is attached to a health record, it should be included. If it isn't, then it shouldn't. This question misses that nuance. The nuance has been made significantly more poignant with the advances in IT, especially analytics and the corresponding determination by the Commissioner that confirms that even metadata can be personal information (regardless of those who had tried to deny it).
It is essential that individuals have positive identification and the best way of determining this at present is by a passport if available.
I don't understand how status of an IHI can serve as an identifier.
Individuals may be comfortable with various levels of opt-out. It would be good to encourage as many people to stay in as possible by providing levels that are acceptable to as many people as possible rather than all or none.
Consideration should be given to the ability to capture and hold the additional information. Mobile and email may be shared and not unique to an individual. The additional information should allow more algorithms for correct matching and therefore increase the likelihood on a match. The risk of an incorrect IHI being provided and resulting in a clinical document in the wrong patient record should not be underestimated and hence the risk should not be increased just to achieve a higher match rate.
individual's drivers licence no. or passport no. not both.
What "identifying information" would be required if the individual does not have a driver licence or passport/Immicard?

Q13) No comment allowed

Q14) Do you agree, as recommended by the PCEHR Review, that the PCEHR Act should be revised to disband the current Jurisdictional Advisory Committee (JAC) and the Independent Advisory Council (IAC) with their roles to be performed by a new ACeH Jurisdictional Advisory Committee (which will assume the responsibilities of PCEHR System Operator currently undertaken by the Department of Health)?

Especially with Consumer ad community participation on the IAC.
At least some health input should be assumed - hopefully department of HEALTH should do this!!!
WHICHEVER COMMITTEE IS SELECTED SHOULD AIM AT FACILITATING THE CONSOLIDATION OF REQUIREMENTS SO THESE ARE ACCESSIBLE, EASY TO REFER TO, UNDERSTAND AND APPLY
And there must be HIM involvement on this committee as this is not just an IS issue. HIMs have been the drivers of Health Information since 1948 in Australia.
Musical chairs from my perspective
I am not sure why we need to disband when teh 'non' success' of PCEHr was not related to the JAC. It wsa the opt-in, in my opinion. Losing IP by disbanding
What difference would it make either way?
ACeH should also set policy NOT DoH!
need a lot more information on the benefits or disadvantages of both options before being able to comment

didnt know what they do or what value they added
We need to keep an open and transparent governance process with broad representation form the community
Without being totally aware of the roles of the various groups, one significant concern is that decision-making and efficiency will simply disappear within the large framework of DoH
as long as there is legal expertise on the one new committee
Names don't matter. Composition, powers, make up of membership do. And Royle basically recommended a structure that did NOT reflect the very significant change from Opt Out to Opt in which MUST have correspondingly strengthened governance and accountability arrangements to offset that change. Opt in was a vital part of the 'keep them honest' governance and accountability framework that gave some credence to the previously weak arrangements as currently constituted. Change to Opt Out and corresponding checks and balances must be put in if health consumer trust is to be earned. Royle's recommendations don't to that
The IAC and JAC are not proposed to be replaced by a ACeH JAC. THe ACeH JAc is intended to replace the PCEHR JAC. The paper states that the AcEH Board which will replace the NEHTA Board and the PCEHR governance arrangements in Health. The ACeH Board is to have a consumer sub committee which I assume will replace the IAC.
But the devil will be in the detail, needs to include gps and racgp
I would have concerns that the system operator responsibilities would be passed to a 'multi' representational body and how responsibility would be managed in that environment.

Q15) Do you agree with the recommendations of the PCEHR Review for an implementation task-force to be established (administratively) to oversee and advise on the design, establishment and transition to the new national e-health governance arrangements, including transitioning functions from NEHTA?

need to include clinicians
There should be real end users with a knowledge of e-health on this task-force
Not if it makes more bureaucracy.
Perhaps, a fresh pair of eyes
HISA and HIMAA should be at the table
waste of time, just rebrand nehta, give them the necessary powers and get on with it,
Maybe NEHTA could be the implementation task force.
But it must include a genuine health consumer and health consumer input
Nehta needs to be shut down now, and no one from there be on any new group
It is always positive to see a Recommendation actually being implemented. They have usually been carefully thought through but all too often are not implemented.
Membership and recruitment responsibility for the taskforce need to be considered

Q16) Do you agree that to achieve broader e-health end-user representation in the governance of e-health, that the proposed ACeH Board and its advisory committees should include the following expertise and individuals? Representatives of the Commonwealth Representatives of jurisdictions Healthcare provision Recipient of health services IT systems and innovation Health informatics Health information management Governance Clinical safety Privacy and security

The views of the end user and their privacy will make or break this system - they must be involved.
This was a massive and dangerous 'gap' in the Royle report. It was clear that at all governance levels that Royle and co were recommending increased doctor input but what was sorely missing was experts in managing healthcare information and healthcare technology implementation. Doctors are not trained in health informatics and this unique and broad skill set and knowledge base is required to avoid many

of the problems in design, implementation and engagement that have thus far befell the PCEHR.
There should also be a representative of the health and medical research community on the advisory committee.
Aged Care representation
Representative with expertise in real life tertiary care delivery should also be invited
GPs are not included on this list and I believe they should be under Primary health care providers.
Child Safety
Where is the general public or health consumer?
What is health care provision?
Privacy, security and confidentiality are my biggest concern
Medicare locals who have proven track record in earlier implementation
Clinicians!
Unable to answer question as it does not distinguish between the Board and Committees. The requirements for Advisory Committees (which should be representational) are different from those needed for a Board which should be mainly skills-based.
all these stakeholders need to be included and their expertise used
Someone from the legal as some of the decisions made at the administrative tribunal make implementation of those decision hard if not impossible.
The broader the representation the better. However, there must be some process to ensure that decision-making is not impeded. Terms of reference would need to ensure that aims are clear to help overcome impasses.
See earlier comments
Need to make sure that the taskforce establishing this recognise the opportunity to have committed people that can tick more than one box. Make sure they are not political appointments, and that the people selected are recognised by the community as people who will deliver a practical workable future e-health for Australia. Please make sure they don't fill these roles with academic doomsayers that can't be satisfied with anything that anyone else delivers, but is incapable of delivering anything themselves. The current programme has already suffered the burden of clinicians that have a vision but can't lead people to deliver it.
Vendors need to be represented as changes frequently affect those systems also.
Consumer Advocates especially lawyers -
Carer representatives are also important
Some of these are obviously more important than others, and it may be best if roles are clearly defined as advisory or decision-making to allow sensible decisions to be taken in the presence of potentially conflicting advice.
This question should distinguish between the board and its subcommittees. For example, I don't think it's appropriate for the board to be discussing issues detailed issues. Instead, their role is to set the strategic direction and monitor performance.
Ethics and data quality

Q17) Do you agree that regulations of the HI Act should be changed to provide the flexibility of allowing an entity other than the Chief Executive Medicare to be the HI Service Operator; as long as they are an entity established by Commonwealth law?

Don't understand the impact of doing that.
not a private or publicly list company
it depends on who the entity is, their experience, governance, etc. Medicare already holds much of the information, so is the most appropriate entity to be the HI Service Operator, but if another entity could provide the same level of privacy and governance but also experience in other linked areas then they may be more appropriate
Last thing i want is an overseas or private company in control of patients health records.

I don't see anything wrong with the current arrangement
need to maintain neutrality. govt is enough
The HI Service Operator function could be sub contracted but it would need strict control and governance and will need to keep its level accountability to the department.
WHO does it doesn't matter. A Government body can do a good job or a bad job. A private sector body can do a good job or a bad job. What matters is the contractual arrangements, the standards and expectations set and the governance and accountability arrangements in place to ensure expectations are met. Who owns the delivery vehicle is irrelevant by comparison
Allowing choice will improve functionality and provide individualisation.
This should never be outsourced to a private establishment.

Q18) Do you agree that two years after the above proposed changes to the HI Act and PCEHR Act are made, an independent review should be conducted to ascertain whether these changes have achieved the desired results (note, such a report would need to be provided to health ministers and tabled in Parliament)?

As long as they don't just sit on it for years!
More reviews, more destabilisation...we need a consistent set of KPI that are simply tracked and evaluated and corrective action taken over a five year period. An 'independent review' simply leads to more uncertainty and political interference. Just get on with it.
Wasting time - just get on with it!
should be 3 years and federally bipartisan support
depending on the cost and what it is set up to review
Possibly even sooner than 2 years
So long as it includes a health consumer
There needs to be a review, five years may be more appropriateness, not sure two years is sufficient time when there is still such a lot to do before the PCEHR begins to reach its potential and there is confidence in the functionality both from consumers and healthcare providers.
12 - 18 months would be better, if it is not working effectively n the first year why waste a 2nd?
It is always important to review implementation as there can be unintended consequences of change, both positive and negative.
The independent review should be focused on a few key results that are capable of objective measurement.
Maybe 3 years
as long as there was no identifying information available for review or presentation.

Q19) Do you agree that changes are made to enable the Information Commissioner to conduct assessments and carry out investigations of AHPRA in respect of its handling of healthcare identifiers (note, currently the AHPRA is outside of the Commissioner's jurisdiction because it is neither an agency nor an organisation)?

Is AHPRA alleged to have done something wrong here? I appreciate you're trying to avoid bias, but context is still useful if you want a proper response.
I don't believe the Information Commissioner is the appropriate person to conduct investigations. Concerns regarding providers conduct should be reported to AHPRA
Current arrangements for assurance processes are very, very weak. The Commissioner has limited powers and no real funding to do the job anyway.

Q20) comments allowed

Q21) Do you agree that the PCEHR system should operate on an "opt-out participation model" for individuals with the aim of increasing uptake of the PCEHR system and increase its value to, and encourage its use by, healthcare providers?
The PCEHR as seen in the coordinated care trials is useful for patients with chronic disease esp ones going between health care providers and hospitals. These patients should be encouraged to have an electronic record.
If the privacy and security of the e-health system can be guaranteed as much as possible then I agree on the opt out model. Pts should be involved in their care and if a pt elects to opt out this could provide an opportunity to discuss and hopefully allay their concerns
State Health Department Systems are/may not be compatible with the PCEHR operating systems and this will greatly limit the effectiveness.
opt-out was the only way forward with no other real incentives to join up
Will need a lot of attention to special cases (adolescents, incompetent, uninterested, demented)
Data for someone who opts out will still be created and not deleted but merely hidden, thus not really opt out. The poor uptake is a symptom of a flawed system. Causing everyone to be in by default does not fix the flaws.
Will the user still have to "register" to enter their demographic details? If they never login can a SHS still be submitted by providers?
Work must be done to increase health literacy around PCEHR to consumers as well
As long as those who are opt out are not unfairly targeted, identified, made to feel they are in breach. It must be a free choice.
This was recommended by HIMs at a PD event I attended a few years ago and was identified as a flaw in the uptake of the PCEHR with the opt in model.
Or just make it compulsory
I never want a PCEHR as I have had my own privacy breached and nothing was done about it. I do not want this risk to my health information again by having an 'opt-out model'. Rather I think an 'opt in model' is more appropriate.
Countless person hours and dollars have been wasted by not having this in the first place
I don't think anyone should be able to opt-out. While it is information about you, it is kept so that medical professionals treating you can better do their jobs. I don't feel it is warranted to have this great sensitivity - why should a patient have the choice to opt-out? The data is about them but don't belong to them. It's hyper-privacy and over the top!
The PCEHR will never work without an opt-out model... It may cause some angst amongst the general public initially, and generate discussion, but that is a good thing. Consumers need to participate more in their health care - and any discussion is better than nothing.
this will help the most vulnerable in our societies eg: disabled, aged and children. Opt-out will remove the biggest consumer barrier - registration
Not until proven and safe
Given that the PCEHR is a nationwide model driven by the federal government, an opt-out participation model minimise disparity issues like those seen in the USA. The EHRs used in the USA are modelled around businesses / funders (eg health insurers) and it can be very frustrating for individuals navigating through the health care system. I have both the PCEHR and an EHR in the USA. I think the PCEHR has something going for it if it could gain a better momentum of usage.
it has not been very easy to opt-in
much needed, don't know why it wasn't so in the first place
Not to increase uptake just for the sake of it but to provide value to consumers and providers who care for them using e-health to connect and improve communication
The 'opt in model' has clearly not worked to date.
Health information should always be mandatory to ensure optimal care especially if the patient could

have been injured or too sick to provide the info, or if the patient's disease could pose a risk to others.
Should only be opt in
Not if Opt in is based on Royle. It simply takes out one of the assurance measures that was part of the 'deal' with health consumers without putting in place any other corresponding assurances.
Looking at the Danish experience it's frustrating to watch the slow progress
as long as no better privacy protection is in place, anything but a well informed opt-in would be a gross violation of patient rights
Yes lets stop wasting people's time having to know about and register for an e-health record.
If it is opt out, where is the implied consent to upload clinical documents? Will providers need to consent before each upload? If it still doesn't work still won't get used, the problem isn't not enough people signed up, the problem is a broken system
Uptake is not a useful measurement of PCEHR effectiveness. As with other health interventions there needs to be evaluations based on improvement in health outcomes. There is no evidence that the PCEHR improved health outcomes. Such evidence is required to allow proper targeting of the PCEHR.
Opt-in has led to too low an uptake to make the system work. Opt out allows for choice but will ensure the implementation will be effective.
If the system is to work, it requires individuals to WANT it. Currently that is NOT the case, despite clear medical/technical/cost reasons why they should. Those goals should NEVER trump personal choice.
Too much fear mongering occurs for people to properly understand what they are opting in to - there should be minimal reasons for people to want to opt-out. Ownership and responsibility should be with both the individual to ensure that PCEHR reflects reality, and care providers to ensure they enter details accurately.
Provision of a single, unique person identifier/record should either be mandatory or an opt-in system. Wherever an "option" (either in or out) is available, the useability of the "single identifier/record" to support integrated client care will be compromised.

Q22) Do you agree that the PCEHR Act and HI Act should be amended to enable opt-out "trials" to operate in selected regions in 2016 (Note the stated purpose of the trials is to: identify appropriate methods of targeting and delivering critical information to key audiences; assess the effectiveness of targeted communications, and education and training for healthcare providers; and test implementation approaches)?

This has been done before and it is a shame that the original users of the shared electronic health records weren't consulted.
Just proceed with consumer and community engagement
If the trial is necessary to establish the privacy and security of the e-health record then I support the trials
As soon as possible
Again this must include free choice without retribution.
Don't pilot...more delay and loss of momentum. Opt out is a 'no-brainer'
Do we have nationally agreed definition and what comprises 'critical information'? I believe having a nationally agreed definition and standard for 'critical information', relevant to common conditions is mandatory for effectiveness and bring efficiency into the system. Without it, we would be again shooting in the dark.
agree any new thing should be trialled first
But these trial cannot drag on.
the trial areas need to include a Consumer PCEHR (myHealthRecord) app for smart phones
It should just be opt out for everybody, no need for trials
Trials too time wasting, just get on with it.
just switch it on and get it over and done with, focus on system usage

Trails in selected areas should target whole of population not just a few primary care practices or selected public hospitals.
Testing the approach prior to wide scale implementation seems reasonable
I thought the trials could be done without changes to the PCEHR Act & HI Act ie I thought there were current provisions for trials to progress.
personally I believe that the system should be opt out which would negate the need for a trial. Who is going to decide which regions and populations are going to form the trial ??
Only if the governance and accountability arrangements are significantly strengthened at the same time and not put off till later (and then forgotten).
The trials must be scientifically structured and published in a peer reviewed journal to ensure rigorous oversight and quality of the assessment
Trials is one way of delaying the progress, Apple or Microsoft does not do any trial and life continues
No more trials
See 21
We should be beyond trials now and get on with it.
It's not clear to me that trials are necessary - why not just make the change?

Q23) Do you agree that individuals choosing to opt-out of the PCEHR system would need to verify their identity with the System Operator who will write to that person at the latest address held by Medicare confirming that they have opted out?

There should be an identifying loop in the opt-out process, however, physical mail seems like a poor choice eps for those under 40.
This is essential. It provides an opportunity to explain the implications of opting out to the pt and also ensures there has been no human error in opting a pt out of the system
In regional areas the latest Medicare address is often wrong especially for inhabitants in remote communities.
Why do they need to verify their identity to opt out. Do they have to verify their identity of they remain "opted in"? If they do have to verify their identity could they not supply their address then? And does it have to be via snail mail? Surely email is ok?
Conformation should be just be done electronically at time opt out has occurred. It should be similar to subscriber opt out so that it is easy to understand.
opt-out should be able to do it electronically - no need for letters and things that don't get read
This would be unfairly targeting those who choose to opt out and appear as an attempt to coerce them into not taking this option.
Individuals should be 'educated' and provided more information to make an informed decision. A system operator writing to an individual for confirmation - how does that help?
If we have to allow opt-out at all, make it hard to achieve. They need to give good evidence of why.
Too lengthy process. Need a national ID number for citizens and PRs. No one knows their IHI and it is too hard too remember.
Opt-Out needs to be very easy - just use-email check or something much simpler
Being an e-health system I don't think snail mail is an efficient means. It should all be completed online.
This sounds like a deliberate mechanism to make it harder to opt out.
writing to the person at their email address (if they provide and agree to be contact through that means) would be more cost efficient, environmentally friendly etc
Yes individuals need to verify their identity to opt out. Not sure we should send everyone a letter if the individual has nominated a mobile phone then use SMS or their email if provided. Postage is a waste of money. Could also develop a tool like the Assisted Registration Tool that has a level of trust in the system to help patients Opt Out at different points of contact with the health system
Everyone should be accountable for their decisions
How current is the Medicare postal address data?

I strongly advocate for the opt-out model, but opting out should not be made difficult or imply prejudicial treatment in any way.
The strength of the security and privacy measures in the first instance should be sufficient to ensure appropriate identity when opting out. If there is a presumption the security integrity is insufficient to opt-out it is likely to be insufficient for all other operations. Also, sending information to a 'last known address' could be considered a breach of privacy assuming the intended recipient is not longer at that address. A better method than 'an operator writing to that person' needs to be found as this is prone to all sorts of (human) errors.
Email should be considered
Must be easy to opt out of
This makes it too hard to opt out.
Yes I think that could be helpful but could be seen as pursuing people who wish to remain out of the system.
Email or phone contact should be considered.
Should be able to opt out online or in writing at Medicare/Centrelink office and verify their identity the same way that they opt in to other gov programs eg Medicare online, ATO, Centerlink, PCEHR,

Q24) Do you agree that minors and people with limited or no capacity to make their own decisions could be opted out by a representative (who would need to have their identity verified and able to demonstrate to the System Operator that they have the authority to act on behalf of that individual)?

This is similar to the way other healthcare related decisions are made. it would greatly assist the system operator if there was a clear definition of a 'minor' - re: health >18yrs doesn't seem to be the guideline - around 14 yrs pts can be involved in their healthcare decisions
Only in special circumstances - this should not be the default and what about two parents who disagree?
Minors should not be opt put until they can make a decision to do so themselves. people with limited capacity should not be opt out as it would be obvious their care would benefit tremendously from sharing information especially if a carer is not available.
Agree more strongly re limited or no capacity. Less so re 'minors'
It must be a choice for parents to opt their children out.
That person acting on behalf of the individual must have legal rights to be able to approve an opt out. This would have to be a sighted Power of Attorney or Guardianship identification. They should also have a good reason stated to opt out possibly signed by their primary health care giver (GP)
This question is very badly worded and very leading. Minors and people with limited capacity should remain as opt-in.
Only because they should not need to be opted-out at all
This needs some more thought.
Medical Power of Attorney document needs to be able to be used for this purpose
minors and people with limited or no capacity are exactly the people who need a PCEHR
if they use Medicare services, they better believe we want them to be enrolled
Elderly patients who do not understand this system will need special persuasion, since they are the main ones who can benefit from this, particularly so for Alzheimer's patients who seem many healthcare providers and have no memory of their health status. Enduring power of attorney representatives should be involved if it promotes better care for the individual.
This assumes that the representative has the necessary powers to represent the individual.
Kids rely on parents for all key decisions that they wouldn't be able to make and so this seems fair.
Health information should always be mandatory to ensure optimal care especially if the patient could have been injured or too sick to provide the info, or if the patient's disease could pose a risk to others.
A Statutory Declaration should be sufficient.

minors shouldn't be opted in without parents/guardian express consent
Consider the abuse and secrecy issues. This may act as a protective factor for abusive authorities
This would not necessarily represent the best interests of the affected party on basis they were able to decide for themselves.
Not enough information.
It is important that this option exists for those who cannot speak for themselves.
These vulnerable patient cohorts may benefit greatly
When the child reaches a responsible age, they should be allowed to reverse the decision taken earlier by their representative. In cases where there is more than one potential representative, there needs to be a process for resolving any disagreements to the benefit of the child.

Q25) Do you agree that individuals who 'opt-out' should be able to: later change their mind and register for a PCEHR? retain their right to cancel their PCEHR at any time?
Essential
No punishment for opt-out should apply or individuals will simply lock out all the access controls and make the record unusable
rather than cancel, prevent access
retain right to cancel - but information in it stays in it ie, stops more info being added into after cut off date is applied.
I do not see why they would been to cancel their PCEHR, it would not be created.
If you have opted out how can you cancel your PCEHR?
Everybody should always have this right.
It depends upon the PRIMARY objective of PCEHR. This is a national system, if built with the view to improve patient safety, continuity of care then, retain the right to cancel their PCEHR is redundant.
I think no-one should be able to opt-out.
However, there should be some process to address individuals who may do this a number of times.
a. This is about the patient after all b. The unavailability of a certain record can pose a risk to that individual or to the society at large
Health information should always be mandatory to ensure optimal care especially if the patient could have been injured or too sick to provide the info, or if the patient's disease could pose a risk to others.
They can retain their right - but why are they opting out in the first place?
Please note that I'm answering these "opt out" questions even though I do not think that it should be an "opt out" system. It should either be a mandatory system or an opt-in system. Wherever an "option" (either in or out) is available, the useability of the "single identifier" to support integrated client care will be compromised.

Q26) The plans for individuals in trial regions are to i) have the opt-out period set for two months; ii) after six weeks records will be available to individuals (not healthcare providers) to allow access controls to be set; iii) healthcare providers can access from July 2016 and will be able to upload records; and, iv) all data e.g. Medicare data (MBS), (PBS) Childhood Immunisation (ACIR) Donation Register (AODR) details will be uploaded and available (unless the individual opts-out or applies the access controls built into the PCEHR). Do you agree with this approach?
I think it will be confusing to the individuals
Phased introduction is ok
Can the individual have access to all of the uploaded information without making it available to others? At least this way the individual has access to the information and can share it with a healthcare provider as they choose

I hope the access controls are easy or this will not work
Include DVA in upload access
As long as the access process is vastly improved from before. Ie my gov issues fixed, codes not required etc
If you want healthcare providers to see the benefit of sharing the data and 'sell' the concept to consumers then health providers need to access within 6 weeks as well.
I don't understand the following: - why delay the start of a trial to July 2016. Does it really take that long to get ready? - why the 6 week delay - why limit the time of the opt-out to two month
Errors in uploading correct data need to be robust and availability of the user to remove ANY data must be in place.
What support will be provided to individuals setting their access controls? How will this be managed? What happens with people with limited computer knowledge?
What is the rationale for the period of two months? Is this long enough?
Two months is a short period of time and my only concern would be the quality and type of education provided in the trial regions. It would have to be at saturation point to really sell the advantages of the PCEHR.
If a trial of opt-out has already been decided why bother asking question 22?
Should be an 'opt in model' therefore you don't get it unless you apply. You can advertise just the same so there is no missing the opportunity so to speak.
I'd prefer to see the opt-out period set for three months.
please see previous comment
What about the clinical information for management of specific condition?
2 month op-out period MUST be clearly marketed and each individual on the PCEHR MUST be notified with opportunity to opt-out
MBS and PBS data is less useful for clinical care - at best it can act as a surrogate for Event Summaries and Dispense Records which don't currently exist but in the long run probably should. Rather than containing useful information, they mostly act as a prompt for the clinician to seek further information.
if the trial period is for two months and the record will be available after 6 weeks, this indicates only 2 weeks of access to the record by individuals and providers - not much of a trial Also, history shows that not many individuals actually go online to look at their own record
too long, just switch it on
Some individuals may not feel competent in their computer knowledge to be able to manage their own access controls
suggest opt out period durations vary from trial site to trial site, to find the best outcome.
Logistically practical
You are assuming computer access and literacy. Many people have neither and you demonstrate no consideration of this issue. The time periods suggested are ludicrously inadequate even for the computer literate.
why the 6 week waiting period - is that how long it will take to create the record ??
What is the default if access controls are not set by individuals? I presume that all information will be accessible to any providers who access it. People will need to understand the granularity of default access controls. For example, can all of Queensland health see my record, or can I block it by hospital? Can I block individual pharmacies from seeing my data?
If the trials must be done, then this is a way to do it. BUT what also matters is whether the rest of the previous Personal Control structure remains in place, ie ability to control which events are added to a record and ability to control which health provider can see which events or entries. The argument that without a 'complete' record, it is not worth doing is specious: there never has been and never will be such perfection in place for all sorts of reasons including trust or lack thereof. What matters is to get the best record possible in the circumstances, which includes the level of trust the system EARNS from

participating individuals and hence the level of sharing with which they are comfortable.
Published evidence suggests a thorough public information campaign in the area, prior to the set up of the opt-out record is critical to public acceptance
How would I as a registered PCEHR patient then know - what had been uploaded, if it fully represented all records from any number of providers? How would it be verifiable to me it was 100% complete and as accurate as it could be(with all provider information now included)?
Seems overly complicated
This has a slightly coercive feel to it that some consumers will find very challenging. If perhaps it could stop at point ii that could work?
I'm against the trial, hence N/A
It seems unnecessarily complicated
It represents a sane incremental roll out.
Individuals should not be able to select what information is included.
Time frame should be the same for all and it go live and accessible on the same day.
don't agree with trials, either do it or don't

Q27) Some privacy concerns associated with PCEHR are addressed by allowing individuals to set access controls. Do you agree that individuals should be able to: Set access controls on who can access what information Restrict access to their Medicare data Remove documents Tell healthcare providers on a case-by-case basis to not upload certain documents Monitor activity in their PCEHR using the audit log Get messages alerting them when someone has viewed or used their PCEHR Make a complaint if they consider that there has been a breach of their privacy
hacking risks are a valid concern particularly as such events feature so frequently in world and local news
Removal of documents should be done in consultation with the healthcare provider that uploaded the document
Audit must stay together with messaging on usage. Selective blocking of documents should be as effective as not uploading providing good security is maintained. This must be easy to do and highly usable by the general public!
Also I should have total yes/no control of access by other gov departments, such as law enforcement, ASIO and the like. This access cannot be approved by other bodies like politicians, or government employees without a referendum.
If it is an opt-out system, I think Medicare and PBS data should be complete for those who have opted in i.e. if a health provider accesses a record, they can assume the PBS/MBS data is complete. If an individual does not want complete MBS/PBS data to be accessible by their authorised health providers, they have the option to opt out.
SMS alert when PCEHR has been accessed should be mandatory if moving to an opt-out model
There needs to be basic standard maintained ie, minimum data that everyone can see ie, allergies, ADRs, medicines prescribed and dispensed, last 6 weeks of diagnostic tests and high level co-mordities list for it to be pof benefit to the patient care.
Allowing "personal" control of an EMR may well result in the EMR being a sanitised version of reality and not only render the EMR useless but very dangerous particularly in emergency situations.
It is all or nothing otherwise the information available to a provider is useless.
The individual must be in control. This is a privacy, identity and freedom issue. Without this, incorrect information may persist on the record that might inadvertently put the individual at risk.
Not sure about removing documents. If a document has been used by another party then maybe at least the metadata of the document should be retained.
The integrity of the PCEHR rests upon the health information available to all professional health care providers. Removal of large pieces of "sensitive" information may hamper the efforts of the local

GP/psychiatrist/psychologist/geriatrician/ or other specialists in the treatment of individuals. One persons "sensitive" information can be a health care providers window into better treatment outcomes.
If a person can alter records what is the point of having the PCEHR. Also who can see the information will also be problematic in health care delivery presumably.
this involves extensive education especially to older adults who may not be aware of what they can and cannot do
The information should be accessible to the patient but not owned or controlled by them. How can reliable and effective patient management occur if the patient can control their own management system? It is for the medical staff to do that, not the patient.
allowing individuals to "play around in the PCEHR" system raises a considerable number and variety of issues. It is not clear HOW the individual will do this?? Privacy is absolutely paramount. I noted on an interview on TV that a woman in USA had her electronic medical record flagged as "HIV" at the age of 17 years (it was incorrect) and it took her 7 years of governance to have it formally removed.
Some of the questions above (i.e. remove documents) are difficult to answer... there is more to it than simply 'removing documents'... which ones, when... what about in emergency scenarios etc etc... a simple tick-box doesn't really do the complexities of the question justice.
Not everyone will go online to look at their own record
Individuals should consult with their GP to have certain docs removed as some may be critical to ongoing quality healthcare, even though a patient may not want them visible.
It may be better to allow restriction on information loaded, rather than remove when already part of the record. However, in all cases, an audit trail must be available to allow knowledge of information/document history.
As per comments made previously
Health information should always be mandatory to ensure optimal care especially if the patient could have been injured or too sick to provide the info, or if the patient's disease could pose a risk to others.
This answer assumes defeat. You also continue to assume computer access and literacy. What provisions have been made for individuals who cannot (for whatever reason) use a computer?
This is all part of the original promise. To take it away now would confirm to many just how untrustworthy the whole process has been. It would be the gravest mistake. Individuals can delegate some or all of those controls to health professionals, but it is the individuals to delegate not the health professionals to assume.
Care must be exercised in balancing the patients' rights to limit or remove some documents, which may make the PCHER more palatable to them, with decreasing the utility of the PCEHR to clinicians. If clinicians don't trust the veracity of the PCEHR because it is too easily modified by the patient, then the potential benefit of the PCEHR may be negated and we may as well not have enrolled any more patients anyway.
Only if they sign a disclaimer explaining why and that this information can be retrieved if necessary
Use of the PCEHR must reflect current practice. Currently a patient always has the option of not disclosing information to any provider. The use of IT is no reason to change such patient choice. This needs to be recognised in a medico-legal framework.
But really what is the point then???
The success of the opt out implementation will be how well this area is addressed. Eventually consumers will be able to realise the benefits in access and safety to health care when there is enough data on the system and people have experienced the benefit. But ensuring there are plenty of controls will help with consumer uptake and confidence int eh PCEHR.
They should not be able to restrict access by necessary services, e.g. emergency dept at hospital. They should not be able to remove documents without the consent of the organisation that put it there.
I'd be cautious about selective controls over medical data - it should be blanket all access or no access so as to not give the false impression of how much data is there. Individuals should not be allowed to remove documents directly - although there should be a process in place to challenge entries if necessary.
removal of documents should not be encouraged. They should be locked down and only openable on

authorisation from the individual.
I'm unable to answer this series of questions as it presumes that an "opt out" system is in place. As mentioned earlier - I think it should either be a mandatory system (a condition of service that a PCEHR is established) OR an opt-in system.
Need some controls on the removal of documents
Need controls on how documents are removed and still leave a general indication of what the document was about
To ensure that individuals have confidence in using the PCEHR all the above are necessary.
If they are allowed to set access controls on who can access the information, then the providers that are restricted will need to be required to inform the patient that their care will be impacted if they cannot access the information.

Q28) Currently "de-identified" PCEHR information can be used for secondary purposes (provided appropriate protections are in place). Do you agree that individuals should be able to: opt-out of their de-identified information being used for research purposes have more control over how their de-identified information is used directly provide consent to a researcher (who has ethics approval) to use their PCEHR information

Pre-consent for Research is critical, and allows follow-up for specific consent for specific studies.
The purpose of the e-health record is to improve health provision to individuals and improve communication between an individual's healthcare providers. There are other ways to obtain the above information and it may make people more likely to participate if data is not used as per the above and it is clear that it will be used solely for their individual benefit
It is essential to do medical research with de-identified health information - a general opt-out sets a dangerous precedence and will raise questions of bias. Good individual control on a case by case basis (where they can be educated on the benefits to science) would be preferable. Strict controls are needed to maintain trust.
I think this opens the doorway for a large administrative overhead in the future. Also people that object to this will likely be the same demographic who choose to opt out completely.
If lots of people opt out of this, the information becomes much less useful for research.
Health information is an important source of data that can be used for research that is of benefit to the whole community- a common good. An individual's only possible grounds for objecting to the use of their health information for research purposes is if they can be identified. De-identified data should not be treated as an individual's 'property' over which they have control.
You should not have to provide your information for research unless you agree or are paid.
It's either de-identified and used or it's useless
In cases where diseases are very rare, the individuals whose data is used could be clearly identified regardless of de-identified data. These people must be protected.
Once ethics approval is sought and approved and the information is de-identified the administrative task of a researcher in contacting each individual may be prohibitive. Financial costs relating to ethics approved research will need to be increased.
this happened to me and it was "ok" as it was de-identified. Not too me though. Individuals need more control over their own information as we are the "owners of the information".
The information being collected at the moment has very limited value in making any decisions on health outcomes or health economics. Cause and effect relationships based on homogenous cohorts within the PCEHR need waaaaaayyyy more structure than they currently have. On that basis as far as I can see the PCEHR is a virtually useless research repository. It may have some value in patient management at point of care but forget using it for research. This was never thought about seriously when it was designed.
De-identified information should be freely available to any researcher for the good of humanity.
"have more control" than what? What do they currently have?
Its easy to obtain ethics approval this is why i would not sign up as there is the potential to have all

sorts of people contacting regarding my health care status. Having dealt with numerous complaints i wonder how many patients will remember that is can be permitted?
the information is de-identified and poses no risk to the healthcare recipient
As long as the information provided is de-identified and cannot be linked to a particular subject of care, then I don't see an issue with providing the information to help improve healthcare of the nation.
Secondary purposes should not be allowed. Researchers can source their own subjects.
all of these items came up when I was registering consumers, and these were the reasons that people were not signing up, ie it was all around having their information available to anyone to use, and therefor "big brother"
These are ridiculously over simplified questions. What is meant by 'de-identified'? Who checks? What happens when today's 'de-identified' becomes tomorrow's 'identified', which is happening at a very fast rate? The third question is breathtakingly sweeping - what use? For how long? Etc. The data collected by these questions are only going to be useful in populist debates to 'prove' a point, but will not actually be useful in developing policy
This is complex. Patients should be given the ability to waive consent requirements for secondary research purposes. However some research using de-identified data is for the public good and holds extremely low risk to the patient, and obtaining individual consent is impractical and could bias the results; this is better determined by an Ethics committee. The best way to manage this is to establish an expert governance body that would manage access to de-identified data. Nevertheless some sensitive areas of research may conflict with patient beliefs (eg abortion) that some patients may want to know that their data is not contributing to research of in any way.
In practice many consumers are more than happy to help shape good health policy.
Assuming that the data are truly de-identified, these suggestions seem unnecessary and may lead to biased information being used for the secondary purposes.
Depends on the secondary purpose. This sort of data is extremely valuable for medical research and by allowing people to selectively opt-out, reduces the value/accuracy of the data set.
If data is properly de-identified then there is no reason for individuals to be concerned about how it is used.
There should be criteria that restrict the type of information researchers can access which would protect the privacy of individuals (e.g. if they have a condition of low prevalence / within a small demographic region; restrict access to researchers with any link to insurers or others that could impact on the financial position of the individual. Otherwise, if an individual has received government services, the information should be made available to researchers / appropriate third parties.
the consent should be applied to the overall for access for researchers to identify possible cohorts. If a persons data is to be included in a study, ethics approval has to be in place and the individual who has consented to contributing to research should be advised that there data is going to be used for a research study
as long as de-identified information is being used, this can greatly help research

Q29) No Comments allowed

Q30) Do you agree that healthcare provider organisations, contracted service providers, repository operators and portal operators should be allowed to continue to participate on an opt-in basis with government encouragement to use the system through revised incentives, and education and training services?

The time required to adopt, learn, navigate, maintain etc this system must be recognised and compensated
Strongly disagree that providers should be able to 'opt-in' . I also strongly disagree with the previous inequity of incentives, education and training offered almost exclusively to GPs only. This reinforcement of GPs as somehow being 'special' as opposed to other clinicians just exacerbates the problem and gives GPs too much power over control of consumer health information and serves to block the widespread adoption of the PCEHR by clinicians.
should be opt out as well

The patient should be able to determine that information captured in an episode of care is contributed to their record and providers and their vendors should be supported to be enabled to do so.
This needs to be reviewed inline with secondary data requirements
The main barrier to use is the convoluted registration process for providers and the terrible software interfaces - these issues also need to be addressed
disagree with financial incentives for GPs only
That's a tough one. Opt-out would be better for providers as well, but obviously they need to use their computer (not paper notes) and compliant software for it to work.
Should be an opt out option.
Simplification would always be preferable
If the users have to choose to opt out, then organisations must be treated the same way.
It should be mandatory for organisations to be registered as part of their license to operate.
Yes if the same rights are given to "health care consumers" for an "opt in" system
Healthcare provider organisations should be 'opt-out'
You cannot have both options. You trial opt out - advise outcome, phase transition and decommission.
What incentives?
for others not registered yet with the HI service, they should be opt in, for others who are register with HI Service, it should just be enabled with the understanding of the e-health record access and respecting of rights for individuals/consumers
Certainly needs to be incentives in place for GPs to use the product effectively as it will take additional time.
Hopefully the desire to use the system will increase with the more information and subsequent value of the use of the system increases.
Just like individuals, organisations should also follow the opt-out approach.
Health care provision is not the core business of most of these people. If this were banking, you wouldn't consider the question.
I think opt out should apply to these participants as well.
What about proper payment for participating. There is probably some justice in the argument that those who bear the cost of data entry and curation may not be the greatest beneficiaries. Let's put it another way: if opt out is good enough for the wider populace, then it is good enough for the health provider organisations.
if it's so good, there should be no need for incentives
Any one using Medicare funding should be on mandatory basis participate in PCEHR, similar to Danish Doctors are mandated to participate, like a hand hygiene
Some core health services should be opt-out - some are as per 3.4.6
Opt out should be for providers as well
Opt in yes, training yes, no linkage of care plan mobs rebates to pcehr use, that's financial bullying, if the system is useful and usable it will be used, there needs to be mobs payments for pcehr use but linked to patient registration
I think it needs to shift to opt out.
should be opt-out
The cost of creating & implementing integration is something the community must pay for. Currently, only DIS-incentives to create such systems; cost-wise. Govt must pay the substantial costs if this is to create savings & reap benefits for the community.
Participation should be mandatory.
The right to share personal health information should be the prerogative of the individual whose health information it is and NOT OF SERVICE PROVIDERS/ORGANISATIONS ETC.
Recommend that if the government is paying for the service provided by the healthcare provider organisation then there should be accountability to contribute to the PCEHR and significant incentives

to have the private organisations participate - something along the USA model - meaningful use
better incentive than the one proposed.
Should be same as individual so should be Opt Out basis only

Q31) Do you agree that the current arrangement of using "participation agreements" with healthcare and other provider organisations should be stopped and the requirements in such participation agreements should be transferred into the legislation (note, this includes Intellectual Property, Liability and Data Breach Notification)?
Participation agreements will still be required as legislation may not be able to go to the same level of detail.
Oh my God
Inclined to think these should be equitable and not able to be varied on an individual basis.
As long as the funds are made available and the necessary education and infrastructure is in place to allow for this to happen.
the participation agreement is the least of the problems with registering an organisation, the multiple forms required for registration of an org is over-whelming and generally not manageable by an organisation without assistance
Who ultimately is owner of the data? Patient? the author? or the person who manages the PCEHR?
do not have enough understanding of these issues to comment either way
waste of time, incorporate into legislation is better, reduces barriers for healthcare providers to participate
Yes. Standards written, compulsory annual audit required, all made compulsory by law.
prefer both legislation and agreement

Q32) Do you agree that legislation regarding compliance with the PCEHR Rules that currently only covers specific organisations (such as section 78 of the PCEHR Act which currently only applies to registered repository operators and registered portal operators) should change to apply to all participants in the PCEHR system?
Don't know enough to comment
Don't know what it covers. But "all participants in the PCEHR system" also includes consumers, so I don't know whether or not it is relevant to consumers.
make it fair

Q33) Do you agree that the PCEHR Rules currently requiring registered healthcare provider organisations to have in place appropriate security measures should now be expanded: to address how the organisation will ensure data quality? to all PCEHR participants?
Essential for user confidence
Ensuring data quality in health records will be a huge task. Unrealistic to expect much in the way of security activity from many consumers
Suggest need guidelines for how to ensure data quality
Do you include consumers here?
Will need to be staggered to allow for smaller organisations to cope with appropriate incentives given to upgrade systems etc.
all PCEHR participants includes consumers - not relevant. If they want to shout their conditions from the rooftop, that's up to them!

At this stage and if I couldn't have both I think securing across breadth is better strategy than deepening the obligations of one participant.
PCEHR participants is this including patients?
yes and look at future options for demographic data quality synchronisations
Again, assumes defeat.
Current arrangements are the result of lobbying by health provider interest groups that gutted the previous obligations. It was a low point in terms of earning the trust of the populace - all care and no responsibility
not just data quality - but errors, access, security, etc
I would like to see a published standard that can be used as governance framework for all participants acting as touch points with the PCEHR - providers AND vendors. This should be as tangible and auditable as ISO 27001, or ISO 31000 and/or other industry recognised frameworks for integrity.
Who are these additional parties
Must be technology agnostic. Often such regulations preclude certain well-established; functional technologies; and is thus discriminatory.
A pragmatic approach should be used to ensuring data quality.
Q34) The PCEHR Act currently provides for authorised representatives and nominated representatives to assist individuals to manage their PCEHR. Do you agree that their responsibilities should be clarified by changing the current obligation which states that representatives are "to act in the best interests of the individual" to the following: "to consider the will, preferences and rights of the individual when making a decision"? "to perform the role of representative diligently and in good faith"?
essential for user confidence
who decides what is in someone's 'best interests' ?
"to act in the best interests of the individual by considering the will, preferences and rights of the individual when making a decision, and performing the role of representative diligently and in good faith"
leave it as is.
I thought these reps eg/Medicare locals were doing just that??
the 2nd option is vague and subjective and will be misused
More explanation needed. Implications unclear
Why should they when the legislation clearly doesn't require provider orgs to do so
It is good to be more specific in determining "best interest"
I would expect these clauses to include "for the improvement of the health and quality of life of the individual"
Q35) Do you agree that the HI Act should be changed to align with the PCEHR Act by specifying how obligations will apply to organisations that are not separate legal entities (e.g. “trusts”, “partnerships” and “unincorporated associations”)?
Would need to read this again
keep it simple
Q36) The PCEHR Review recommended that payment for Medicare items should depend on the uploading of specific documents to the PCEHR system (i.e. relating to health assessments, comprehensive assessments, mental healthcare plans, medication management reviews and chronic disease planning items). Do you agree?
There should be recognition that the maintenance of this system will require time and expertise - this

could be reflected in Medicare payments
Not at this stage. Need positive incentives first.
what about incentives for the private and acute sectors?
As long as the clinical software interfaces are improved eg PractiX is currently horrendous
That's a tough one. Ideally, that should be the case. However, if the patient doesn't want that to happen (esp. relevant for mental health care plan), we shouldn't deny the doctor MBS payment for it. Maybe there can be a clause in there to that effect.
This will complicate an already difficult system. What happens for those who choose to 'opt out'? Payments may be delayed and that is not equitable.
This is simply a control measure once it is linked to monetary payment and must be avoided to retain trust in the system.
This seems too strong at this stage, but some extra financial incentive would be fine.
that's making people feel obliged to get a PCEHR to enable a rebate. This makes it an obligation and not a choice.
Too early to consider another change
This is "big brother" and hypocritical - in other words if you don't "stay in" you will not receive Medicare payments. Strongly disagree. Why have Privacy Laws then?
a specific MBS item is required for when a document is uploaded to PCEHR. this could also be linked to SIP payments
So much for patients being able to not have documents uploaded to PCEHR? I can just see how Drs will operate if there is money involved, patients will be pressured to agree in fear of not getting optimum treatment. Sounds wrong but that is reality of how patients respond.
If this means the Medicare payment received by healthcare providers, then yes. However healthcare consumers should not need to upload documents onto their PCEHR in order to receive payment for Medicare items
After a grace period and making this as simple as possible to implement
yes, many care plans and assessments carry valuable data helpful in many clinical situations.
Sounds like a good idea but not sure how it will work. Would need more information to comment on this.
uploading of medication management and CDM is critical, not sure about the others
they system should be maximised to reduce paperwork.
The matter that you have received a service (as evidenced by your signature) should be the end of the matter. The assessments, plans and reviews are not the concern of Medicare and indeed a patient may not agree with the contents of the documents but appears to have no right of reply or access to correction, especially where the wrong document will inevitably be loaded against the wrong patient name. You may not even know of this circumstance to address the matter.
Does that mean that doctors of patients that opt out will not get paid (or paid less) for these items for those opt out patients? There should not be a conflict of interest that rewards doctors for encouraging clients not to opt out.
Depends on financing these requirements
otherwise can't opt out - it's coercing recipients into accepting this
This is exactly what Denmark did decades ago, even before e-health
Using penalties as some form of encouragement drives distrust, disinterest and lack of buy-in...
A person who opts out should not be penalised financially
I see this as an essential part of the introduction PCEHR. It gives GP's in particular an incentive to push this information into the PCEHR cloud.
Should not be limited to these assessments. Should be an item number that can be billed the first time a HCP uploads a SHS and then thereafter when a significant change to the patients health another item can be billed. Event summaries should also have an item number that can be billed. the current e-health PIP should also remain to assist organisation to meet the IT/security requirements of the system.
Clinical consultation required for where this might not be appropriate or align to workflow.

Q37) Do you agree that the PCEHR System Operator should be allowed to use (when authorised by the individual) electronic notifications or phone and to only use written notifications when no other forms of communication are practical or appropriate?
How would SO know about non-receipt of communication? Letters get returned to sender; emails should bounce back if not received; however there is no way to know if a phone communication has been/has not been received.
how is electronic notification not written notification? Do you mean paper based notifications?
irrelevant
Consideration must be given to the frail aged population in relation to direct contact by the system operator. This is when the "snail mail" approach should be in place. We cannot assume all frail aged people have access to electronic media and many are suspicious of "system operator" phone calls.
Where is the consumer choice? I still request paper bills
Why not - If that's the individuals preference.
For what purpose?
In as many cases as possible, electronic notifications should be the preferred method
Once again the elderly who do not computers would prefer written notifications
Marginalised people without a telephone are disadvantaged. The hearing impaired can easily misunderstand on the telephone. Written communication should be the only acceptable form of communication and in hard copy only.
presumably does this mean voice recording or other data recording to show contact?
Go digital save paper and post
Whilst written form maybe the last option it should not become the default 'last straw', Sensible, practical and intelligent digital enablement should be the goal and first choice.
Subject to security audits.
Q37 is a double-barrelled question - are you asking about being allowed to use or being allowed to use when no other option is available?
Must improve ease of use and accessibility to the PCEHR by individuals if this is to supported. Right now it's awful (e.g. no way of resetting access if mobile number has changed).
Written notification allows the individual to maintain a record of of notifications. Individuals should be given the option.

Q38) Do you agree with the proposal to amend the requirements to only retain PCEHR records for 30 years after date of death; or if date of death not known, 130 years from the individual's date of birth?
There is a requirement to retain the medical records of indigenous Australians indefinitely in some jurisdictions
seems a very long time to retain inactive records (cf current 7 years in most jurisdictions, even for live individuals)
It should be shorter in accordance with maximum state and territory based retention requirements for health information e.g. 10 years after date of death and 30 years after last entry onto the PCEHR
Amend to what?
Retaining this data for research purposes is critical. PCEHR Records should be retained indefinitely.
Seems excessive when the standard is 10 years medical record retention for adults.
I would think 30 years is a long time. Maybe 15 would be sufficient.
Could records be retained indefinitely, but maybe they just get progressively summarised as they age? Is it really such a large amount of data?
Seems a bit long
I think those timeframes are too long.
I would propose 70 years instead of 30 years to facilitate long term research into rare conditions and

those occurring in later life such as motor neurone disease
Forever
There might be room for some flexibility in this....
They should be kept indefinitely
130 years why? Should be 10 years after to death. This will be such a massive cost for what effective purpose?
for research purposes it should be much longer, but for personalised information, this is quite adequate. It allows for any legal action, follow up of genetic conditions by the next generation (but not necessarily much further which can be an issue)
However, I do think that the information should be available/included in de-identified research data.
This could be beneficial for future generations genetic health history and for research purposes for many years to come. I don't see any reason why it could not be held indefinitely.
30 years is far too long. Either the General Disposal Schedule or Health Records Act provisions should apply. When governments assume the monies of untouched bank accounts after three years of inactivity and taxation records only need to held for 7 years, why make such ridiculously stringent provisions for health care records?
I believe 30 years after death is a short time and it should be extended to at least 50 years and 150 years
why are they being retained for that long when a paper health record is only 7 years unless you area a child and then it is only 21 years
Why not make it the same for all - simply for 130 years from date of birth or all.
records archived at death. authority from relatives to access post death
When considering the usefulness of diagnosis relating to hereditary issues records should be retained until such time they are no longer relevant to a family bloodline.
Why is this different to electronic record retention? Would this depend on whether there was any information uploaded?
If individual has certain conditions or is participating in research, the record should be held for longer.
Or less
Data value for research will remain long after 30 yrs
Why so long? Why wouldn't it match statutory law for the paper record (e.g. 7 years).
unsure... If this would help research, yes, but otherwise...what reason to keep
Is this not already the case under the PCEHR Act?

Q39) Do you agree that a test environment should be developed and implemented by the PCEHR System Operator to allow vendors and other stakeholders the opportunity to test how systems operate and interact before they are implemented (note, the test environment would not use any real information and would be isolated from the live system)?

Yes, this should have happened from the beginning
Doctors need an easy environment to practice to learn new skills
The test environment was certainly missed during the time when Medicare Local e-health staff were working with practices (they haven't for the past year). It was established too. It is also quite difficult to even schedule a time to use the current testing environment.
Especially important in the Primary care (GP) environment.
A test environment already exists - this is how vendors conduct NOC and CCA testing. It would be useful to have this environment expanded and populated with a large amount of "real life" information so that users of software products can train on new products (or new features of existing products).
Surely this was already in place!
Absolutely!

this was one of the biggest problems I had when implementing the system - no test/train environment
What??? you mean there isn't one currently?
There should be time limits
There also needs to be provisions for vendors and other non-medical people to use the live system to ensure their system is working. Currently it is illegal for a vendor to access the live HI Service or PCEHR to determine if their system is working. This could be facilitated by having test users in the live systems, but it requires a change in the legislation.
Yes, but haven't we done this already for goodness sake!!!!!!!!! What the hell has been happening to date!!!!
This is so important.
Why is this a question?

Q40) No comments allowed

Q41) Do you agree that the PCEHR legislation should be amended to require the System Operator to add an optional access control that alerts individuals by SMS or email each time their PCEHR is opened?

Yes, and password changes, plus any other systems changes made - this is becoming the norm for the security conscious.
SMS could get expensive - maybe just email ?
this is normal practice with everyday technology like Facebook, banking, emails etc - so it shouldn't be optional.
Do not assume that SMS or email is available to all individuals. e.g frail aged, homeless, those in rural emote areas with no NBN service.
really up to the individual
if this is the case, then the system will need to store the patient's mobile and/or email. These change very regularly for many people, so it will require governance for keeping these current. More resources required!
This is a little too far - perhaps a summary SMS/email once a day or week (similar to how notifications come from various social media things like Google Groups)
yes, allay consumer fears and good security measure that can be adjusted by consumer
We are at the start of this process & don't really know how often a PCEHR (with all of a person's medical details) will be opened or accessed during "normal" business. Having an option to be alerted is vital, though it should also be easy to adjust the frequency of the alerts, and/or exclude alerts for some access types.
As long as there is a user option to turn this notification off or on.
Many people do not have SMS or email. Yes, there needs to be a system but not limited to SMS or email - both cost money many of us do not have, apart from the issue of access for 'Luddites'.
This could be unduly worrying for patients - would this really provide any benefit to the patient if they could not know what the record was being used for?
requires mob phone data collection, who accesses SMS?
The technology & cost for this development is a major factor that needs to be centrally funded.
Might be expensive.
It's a nice to have but I don't see it as necessary given it is accessible via the online audit.
If regular audits and proper controls are put in place, I don't see a need for this.
Notification overload would prove meaningless if a provider accessed the record several times in the course of the same episode.

Q42) Do you agree that the System Operator should have the power to suspend access to a PCEHR by representatives and other participants when they suspect issue with security or identity of individuals (or their representatives') or other technical or operational issues?
Yes but notification must be given to the owner of the account
As long as this is immediately verified with the individual.
As long as they let the "health care consumer" immediately know - like what happens with online banking
yes, to prevent abuse of access
However there would need to be a very good process around this so that it did not happen 'inadvertently'; and there would also have to be a well understood and easy process to remove suspension if e.g. it was a technical or operational issue.
In this case, it should not b 'a' PCEHR but 'all' PCEHRs.
How will this be communicated to the system operator
With suitable notification and resolution procedures.
Provided that the suspension is of limited duration and can be reversed quickly or overridden if it is likely to have an adverse effect on the health of any individual.
Only if strict checks are in place that advise the suspended operator of this, and are given the option to explain what happened to enable reinstatement of access.
and advise the impacted representatives and participants of the potential breach and action plan
This should also include organisations access the PCEHR where a breach has been identified.

Q43) Do You agree that authorisations in the HI Act and PCEHR Act should be simplified by specifying which particular entities may collect, use or disclose information and for what purposes, by moving from a "prescriptive approach", which specifies how an entity carries out an activity, to a "principles-based approach", which would list the information that is protected, the entities who are authorised to collect, use and disclose, and the purposes for that collection, use and disclosure,?
As long as I retain the right to specify my authorisation on a entity by entity basis
Will need both
Principles always better than prescriptions.
Depends how implemented
as long as the penalties are in place if there is a breach
Principle-based is too open to manipulation of their interpretation. Prescriptive provides less leeway for unscrupulous use.
Again, this is so simplistic a question as to render any answers meaningless
Practical examples and guidance would need to be given
This raises the question of how authorised entities become authorised and how this is governed and maintained. What auditing would be put in place, what reporting generated, on what cyclical basis and presented to whom for signoff?
Don't understand this question

Q44) Do you agree that clarification should be made through legislation to remove any doubt that healthcare providers may include relevant third party personal information in a record that's uploaded to the PCEHR, and that the System Operator is authorised to collect the information in the record for inclusion in the individual's PCEHR?
Such as what? This question is unclear.
Where doe s GIPA and HRIPA or FOI fall with such a change?
The patient/individual should be able to have some control over what information is uploaded, so not sure how this will apply in this case.
Mean question as it has 2 parts!
No third party information should be stored under any circumstances.
Practical examples and guidance needs to be provided
relevant third party information could include education results, criminal history, social welfare etc - not health related per se, but markers for additional health service use
the original source of the information should be clear and identified in the PCEHR
Don't understand enough about this scenario (e.g. when this would / could occur).
The inclusion of third party material should be subject to the individuals controls like all data in the PCEHR.

Q45) Do You agree that changes are required to the HI Act to remove the need for consent so organisations are automatically listed in the Healthcare Provider Directory (note that the government's aim is to remove barriers to effective communications that adversely affect other e-health services dependant on the HPD, such as secure messaging)?
Automatic listing suggests that there may be no recognition by the organisation of their responsibilities under the Act. If an organisation actively seeks inclusion this would imply they are aware of their responsibilities
Absolutely, this should have been the case all along!
If it is opt out, then they will all be included?? again not a clear question.
That also takes away choice. Individuals going to these providers should be notified first that "we are NOT a PCEHR provider"
it needs to be easier for a provider to find their HPII. the HPD needs to use the NHSD
Have no idea what you are trying to communicate in this question so am naturally suspicious.
What is good for the goose is good for the gander: an opt out system
I agree that the barriers need to be removed, but am not sure if this is the correct solution. It may be some sub-section of the HPD that needs to be made automatic. It should be possible to validate all HPI-Is and HPI-Os, to confirm relationships between these and to find endpoints for secure messaging. With the use of message exchanges the endpoints are only required by a small number of organisations.
Consent to publish information should be limited to personal information. An organisation has no right to privacy and withholding listing from the HPD inhibits secure messaging.

Q46) Do you agree that change should be made to the HI Act to allow regulations to be made prescribing additional uses of healthcare identifiers in closely restricted areas, for example the National Disability Insurance Scheme (NDIS) records?
Providing some controls are imposed to prevent function creep.
This should not be an Australia card.

Hmmm. Not sure about a regulation. Think I'd prefer the stronger form of a change to an Act.
Not sure what the question is asking
yes, definitely need to ditch the AUSKEY for NDIS and My Aged Care; they both need to use the HI service platform
this needs to be managed closely so that fraudulent 'health services' are excluded
This smacks of 'convenience'. You will not allow hospitals or doctors to use the Medicare number as an identifier and I feel sure you know the Australian reaction to an 'Australia card' so this is another issue that smacks of convenience and stealth.
Depends on the nature of the decision making process. Recent governments, the current one included, have shown scant regard for openness or due process when given powers like this
prove this works first and it adds value not just costs
The creation of another identifier scheme for NDIS would be a waste of effort and resource, add to burden on providers and not make the most of existing e-health infrastructure.

Q47) Do you agree that the Information Commissioner should be "expressly authorised" to handle healthcare identifiers and associated information as part of carrying out her or his functions under the Privacy Act and the HI Act (note, currently the Commissioner's role is unclear in regard to healthcare identifiers)?

Clarify who can do what - ensure there is some muscle to act.
Not sure what this means or the impact of it
What does "expressly authorised" mean sounds like there are conditions/limitations?
This assumes the Information Commissioner and his/her department are appropriately skilled to understand EHR's, there content and context.

Q48) Do you agree that the HI Service Operator should be authorised to disclose to a healthcare provider organisation the healthcare identifiers status for an individual healthcare provider (e.g. inform the organisation that a particular identifiers has been suspended and it belongs to a GP)?

However there must be a robust system in place that when the identifier is reinstated that this also be authorised appropriately.
Where's consumer choice?
I'm not sure I understand this question
depends on security arrangements
Again, no idea what you are trying to achieve or communicate so am naturally suspicious.

Q49) Do you agree that the HI Service operator should be allowed to undertake actions that would enable resolution of an individual's identity when a direct match is not working (e.g. a mismatch due to minor spelling or punctuation difference in an individual's name since currently the Act requires a perfect match before disclosure)?

Mismatches are inevitable and need a means to be overcome
The individual should know and supply their HI when clarification is needed - to many times I have been at medical facilities when I am asked 'Which Mr Smith are you from this list".
will need to be implemented with a great deal of care.
Definitely
Hackers and those stealing identity use these sorts of loopholes to get in. There should be several exact match identity options to prevent the need for this.
HIMs or HIMAA need to be asked to develop actions in this space as they are SMEs in name

mismatches and correct identification of individuals. Incorrect identification can have huge impacts and exposure in relation to privacy of individuals.
Breach of privacy
There are some excellent lessons to be taken from the work that SA Health did with the Oacis Programme and its data linkage processes... particularly around names
the issue relating to 'address parameters' needs to be addressed eg: unusual road type and address length
mistakes happen with data entry so need to be able to update and correct names, not stay forever with an incorrect name
This is prudent, makes sense and is undoubtedly what a reasonable person would expect
As long as the HI service operator uses international and Australian standards to determine a match. The lack of commitment from HI service in participation of revision of AS4846 Person and Provider Identification in Healthcare suggests they do not have the skillsets.
Yes but would need to define or spell out criteria such as..."minor spelling or punctuation difference".
Um…that would change the whole design and interface/interoperability of the current model - a major overhaul. This needs much more analysis on impact on processes and flows of information between systems.
So long as the HI Service Operator is held to account for its actions and that recovery pathways that are efficient and respectful are in place to address the inevitable mistakes.
why not just reject it and have the health provider resubmit
Needs caution
This would leave the system open for anyone to guess their way through the people within the database.
Q50) Do you agree that changes be made in what personal information can be collected, used and disclosed by the PCEHR System Operator for the purposes of detection, prevention and enforcement activities associated with fraudulent activity or security activities of the PCEHR system?
Just good governance for 'independent' review and audit.
No, this is too broad and vulnerable to function creep. Some oversight is needed here.
With good controls in place about the use of the data for this purpose
As long as the collection is not made mandatory
Would prefer that these activities are conducted under some independent authorisation apart from discretion the System Operator.
That's taking away from the main purpose "health care".
Shouldn't be disclosing any information.
Again, so sweeping and vague as to be a useless question
implies additional information - if it's suspected criminal activity get a warrant from the courts
Depends on the personal information
Depends on what the changes are.
Q51) Do you agree that changes should be made to allow the HI Service Operator to disclose personal information back to the AHPRA, which is the agency responsible for assigning Healthcare Identifiers (Note, currently disclosure is only allowed from AHPRA to HI Service Operator. The government's stated aim is to facilitate greater data quality and accuracy and also permit information to be corrected at source)?
Two-way feedback and allowance for validation is required
Not clear on the details of the use case and why this would REALLY be required.

Yes, but only under some specific control conditions where the individual has some input.
The health service recipient should be given the option to refuse permission for this to occur.
Is that true? AHPRA registers healthcare practitioners - I didn't think they assign healthcare identifiers. I understand that the HI Service Operator receives registration numbers that they link to HPI-Is, but I didn't think the HPI-Is come from AHPRA. Unless I'm mistaken...
Exactly what type of information re we talking ?? demographic or actual clinical information?
agree for increased data quality and accuracy to be corrected at the source
needs to be closely monitored and transparent
As long as the personal information is restricted to only that necessary for the task, and this is specified beforehand. In addition, knowledge should be known by health professionals.
Again, depends on the governance and accountability arrangements that are put in place.
Why the need to discuss personal information? Couldn't a pattern of behaviour be described instead?
Q52) o you agree that, in future, more serious misuses of PCEHR information should be subject to "criminal penalties" (including the possibility of imprisonment), as well as retaining the current civil penalties (monetary fines, injunctions, etc.) for less serious breaches?
Strong penalties are required, including imprisonment, as a message to the community that this is the expectation.
There must be sufficient penalty to make misuse a very unpalatable option
Health information is too precious and once disclosed cannot readily be forgotten (by a partner for example) and compensated for.
People need to have faith in this system.
I am not sure
A bit harsh??
This is the best safeguard for privacy and makes opt-out unnecessary.
I doubt this would ever be passed as I believe many Australians do not revere health information sufficiently for imprisonment to occur.
It'd have to be very malicious use - perhaps getting secret files about a celebrity and distributing them to the media, but whilst that's horrible, it's still not in the same league as many crimes that would send someone to jail.
Depends what the breach involves
Refer Geoffrey Edelsten. There will always be one in the pack somewhere
Q53) The government states that Healthcare identifiers are simply a number which does not contain any health information. Therefore do you agree in regard to the penalties for offences imposed by the HI Act, they should be as follows: All HI misuse should remain criminal penalties? A graduation from "civil" to "criminal" for less to more serious HI misuse? All HI misuse should become civil penalties?
What is the definition of misuse? Is intent important? If an employee is performing their duties and makes an unintentional error, criminal penalties seem harsh. Whilst needing to punish intentional and serious misuse, there must be some balance for inadvertent employee error. However carelessness/wonton disregard should be punished.
The identifier is too important for big data matching not to be protected to the fullest extent.
Question to general
The HI must not become a de-facto Australia Card, or become another scoring element for security questionnaires (eg for bank accounts or passports)
The HI Act seems to be too harsh and prevents wide and beneficial use of these numbers in the community

Concerned that less serious penalties could become simply become a cost of doing business to the private market. The potential misuse of Healthcare identifiers is about their identifiability, not that they have health data.
I am not sure
The type of penalty should depend upon the misuse and harm to the individual.
Need more detail
Unsure - would need more information to decide (examples of offences)
This Q is unclear ... misuse of the HI could be as simple as using it as a unique identifier for an individual outside of healthcare.