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Abstract

Results of a pilot public opinion survey regarding privacy and secondary uses of medical data are presented. Data was gathered using a self administered household survey. The setting for the survey was regional New South Wales and Darwin, Australia. 482 surveys were distributed in randomly chosen residential blocks. The main outcome measures included respondent views regarding concern for personal privacy and support for secondary uses of medical data for utilitarian purposes. 165 surveys were returned giving a 34.2% response rate. Aspects of the Restricted Access Limited Control theory of privacy were explored via the survey. Results indicate the value of further research to give insight into operationalising RALC to support secondary uses of medical data for health research.

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Emerging Consumers View of Secondary Uses of Medical Data

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Abstract

Results of a pilot public opinion survey regarding privacy and secondary uses of medical data are presented. Data was gathered using a self administered household survey. The setting for the survey was regional New South Wales and Darwin, Australia. 482 surveys were distributed in randomly chosen residential blocks. The main outcome measures included respondent views regarding concern for personal privacy and support for secondary uses of medical data for utilitarian purposes. 165 surveys were returned giving a 34.2% response rate. Aspects of the Restricted Access Limited Control theory of privacy were explored via the survey. Results indicate the value of further research to give insight into operationalising RALC to support secondary uses of medical data for health research.

1. Introduction

Computing technology can be well utilized in analyzing large volumes of medical data that are collected during the care of medical patients and recorded in electronic medical records. Such uses of medical data are 'secondary' as they are uses outside of direct healthcare delivery[1].

Tension exists between consumer's expectations of individual privacy and recognition of the utilitarian gains available through secondary uses of medical data for health research.

As Grulich and Kaldor observe [2] 'privacy is largely a cultural construct, with meaning that differs markedly across countries and communities'. In communities where privacy is considered a human right, there exists legislation, policy and guidelines surrounding secondary uses of medical data. Such legislation, policy and guidelines are formulated with an assumption that patients prefer to prioritize their individual rights to privacy above public health research. This assumption and subsequent legislation constrains the scope and opportunities for retrospective, observational health research[3-8]. Few studies have captured public opinion on the secondary use

of medical data for research purposes. The response from consumers who have been surveyed has largely supported the secondary use of personal medical data for research. This outcome thus challenges the assumptions upon which legislation, policy and guidelines are based and may support the wider use of computing technology for retrospective, observational research.

The paper begins with a review of earlier attempts to garner public opinion regarding secondary uses of medical data and associated consent matters. Following the review of prior surveys, a description and summary statistics from a pilot public opinion survey conducted in New South Wales and the Northern Territory of Australia during 2009 are presented.

The questions in the 2009 Australian Pilot survey are exploring Moor and Tavani's RALC privacy theory[9] with an aim of validating the theory and subsequently operationalising the theory through the development of a conceptual Medical Information Privacy Model (MIPM) to support research oriented secondary uses of data.

The paper moves to conclusions and an outline of future research including a larger scale Australian public opinion survey and comparative survey currently underway in Ontario, Canada.

2. Earlier Surveys of Consumers View of Secondary Uses of Medical Data

Prior surveys are presented here in chronological order. These surveys were identified via key term searches of academic databases in medical, informatics and ethics domains. The surveys below tend to focus on only one aspect of consumers views such as consent or de-identifying data.

Prior to 2003 in Southern Ontario Canada 123 patients were involved in a survey regarding patient consent. 17 patients were interviewed and 106 completed a survey regarding patient consent preferences for research uses of information in electronic health records. A semi-structured interview was used and structured fixed response survey.

The patients included were registered with doctors who had agreed to take part in the study. [10]

In February 2003 a public opinion survey regarding how well Canadian legislation protected personal health information was conducted across 10 provinces in Canada with 1224 survey participants. Secondary use of data was visited in the survey however the focus was more specifically on genetic privacy [11].

In 2003 a South Wales (UK) survey investigated public attitudes towards use of primary care records for research without consent. Focus group participants included 49 members of the general public and four non-medical members of local community health councils [12]. The primary care setting provided ready access to patients who participated in the survey and there was general support for secondary use of medical data.

Between March and April 2005, 1230 Canadians participated in fixed response, random digit dialed telephone surveys. This survey investigated alternatives to project specific consent for access to personal medical information for health research [13]. Results indicated support was strong for secondary uses pertaining to research. Respondents also expressed a desire for privacy protection.

The 2005 British Omnibus Survey was the vehicle used to capture public opinion in England, Wales and Scotland [5]. These were very specific questions regarding use of identifiable data by the National Cancer Registry combined with broader research areas beyond healthcare. 2872 participants were involved in this routine national omnibus survey. Nine questions regarding cancer registration and personal privacy were included in the face to face interviews. Respondents supported secondary data use for cancer research purposes.

In July 2006, 68 participants were included in focus groups and clinician interviews investigating public opinion regarding the holding of personal information in a disease specific register. English and Irish Multiple Sclerosis (MS) patients and their families participated [14].

The Australian Government commissioned surveys in 2001, 2004 and 2007 to investigate consumer's attitudes towards a wide range of privacy matters [15-17]. There was little focus on protection of personal medical records without distinguishing between primary healthcare delivery and secondary uses. There were some questions related to use of de-identified patient data, however it was not clear what use would be made of such data.

Additionally, the National Health and Medical Research Council of Australia (NHMRC) conducted random telephone surveys with 301 Australians [18]. 64% of respondents were in favour of medical information being used for research purposes. As a result of this public opinion survey the NHMRC submitted recommendations to the Federal Privacy Commissioner's Review of the Privacy Act.

In June and July 2007 Canada Health Infoway, Health Canada and the Office of the Privacy Commissioner sponsored an electronic health information and privacy telephone survey [19]. 2469 Canadians participated in this survey. Survey respondents were 16 years of age or older. The questions captured public opinion at a much finer level of detail than the other surveys mentioned above. For example, respondents were asked their opinion on specific secondary use of data such as (1) to anticipate and address public health issues, (2) to plan, monitor and evaluate health care system and (3) to prevent improper use of the health care system. An additional question canvassed specific responses to health research purposes with and without patient consent.

Many of the surveys above were canvassing public opinion on a wide range of societal issues. This contrasts to the pilot survey results presented here which firmly focus on secondary uses of medical data. Broad similarities between Australian and Canadian society, government, legal and health systems motivate this comparative study.

The next section of this paper describes the 2009 Australian pilot public opinion survey conducted by the University of Wollongong School of Information Systems and Technology and Graduate School of Medicine.

3. Pilot Survey Method

A pilot survey was developed with attitudinal statements focusing on constructs related to the RALC theory as appropriate for secondary use of medical data. Focus groups reviewed the survey design. These groups included teenagers, aged pensioners, early school leavers, post graduates and those with English as a second language.

Between August and November 2009, 482 hardcopy self administered surveys were distributed to sample populations in residential blocks in regional NSW and Darwin the capital city of the Australia's Northern Territory. High, medium and low socio-economic areas were surveyed in urban and regional populations.

Respondents were asked to complete 30 Likert scale attitudinal questions and two open ended questions. Five optional demographic questions regarding the survey respondent were also included.

At the time of writing this paper 165 surveys have been returned giving a response rate of 34.2%. Questions focused on: rights-based views of personal privacy; loss of privacy; secondary uses of medical data for various purposes; altruistic notions of donation and consumer control of data access.

Statistical analysis was conducted using the Statistical Package for the Social Sciences (SPSS) 15. Descriptive statistics are presented in the results section. Nominal demographic data and ordinal Likert data were analysed following the recommendations of Arlene Fink, Professor of Medicine and Public Health at University of California, Los Angeles campus[20].

A seven point Likert scale was used ranging through 'strongly disagree', 'disagree', 'tend to disagree', 'neutral', 'tend to agree', 'agree' and 'strongly agree'. An eighth option of 'Don't know' was also included.

Statements were presented and respondents asked to use the Likert scale to indicate their response to the attitudinal statement. Ethics approval to conduct the consumer public opinion survey was granted by the University of Wollongong Ethics Committee.

4. Pilot Survey Results

Females comprised the largest percentage of respondents at 70.4% followed by 29% male and 0.6% with sex not specified. Respondents were asked to self identify if they had worked or trained as a member of the medical profession, allied health worker or other medical care related occupation. 15.2% of the respondents identified themselves as belonging to this medical group. Respondents covered a range of education levels as presented in Table 1.

Highest Level Education	Frequency	%
	4	2.4
Left school before Yr10	10	6.1
Year 10 / 4 th Form	33	20.0
Year12/6 th Form/Leaving	19	11.5
Trade Qualification	11	6.7
Professional	35	21.2
Bachelor Degree	40	24.2
Postgraduate	13	7.9
Total	165	100

Table1: Respondent level of education

indicates the suitability of the survey instrument in engaging with a broad range of members of the general public.

4.1. Rights Based Privacy

The first Likert scale statement was 'I believe that I have a 'right' to personal privacy', responses are summarized in Figure 1.

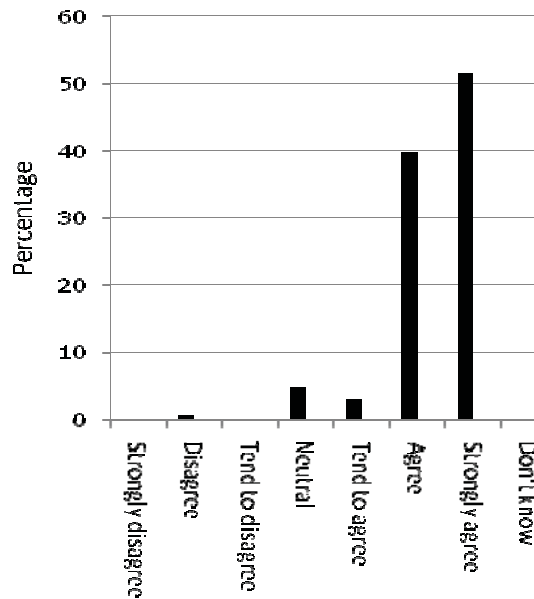


Figure1: I believe that I have a 'right' to personal privacy.

One of the few earlier surveys [19] to consider the consumers views on access to their medical information indicated more concern regarding IT staff access rather than medical receptionist access to personal information. Two statements in the Australian survey sought similar attitudinal data.

The responses have been combined in Figure 2. The two statements are 'I worry about medical receptionists reading my medical information' and 'I worry about computer staff being able to read my medical information when they are looking after medical systems'.

As Figure 2 illustrates pilot survey respondents are also expressing more concern regarding IT staff accessing patients medical information. This results is consistent with earlier Canadian research [19].

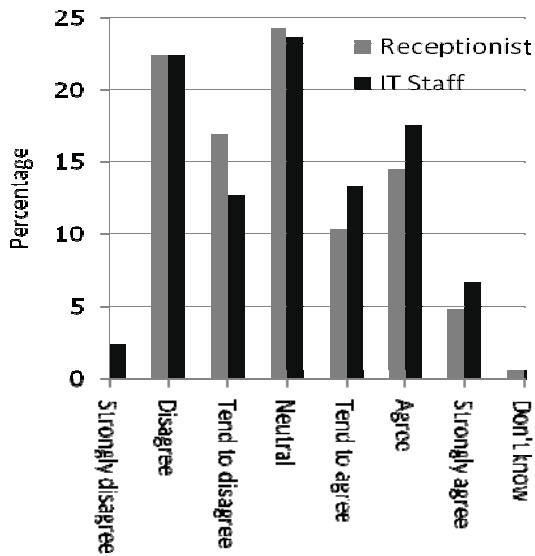


Figure 2: Concern about medical receptionist and IT staff accessing personal medical information.

The surveys three concern for privacy constructs resulted in a Cronbach's alpha of .82.

Post graduate level educated respondents strongly disagree with the statement 'I am concerned that my medical information may be stolen'. Twenty percent of respondents who left school prior to completing 10 years of schooling strongly agree with the statement. Table 2 presents a cross tabulation of Highest Level of Education and attitudinal response.

Highest Education	Q6. I am concerned that my medical information may be stolen.							
	Strongly disagree	Disagree	Tend to disagree	Neutral	Tend to agree	Agree	Strongly agree	Don't know
Left before Year10		25.0%	10.0%	20.0%	20.0%	50.0%	20.0%	
Year 10/4thForm	6.1%	12.1%	18.2%	24.2%	12.1%	21.2%	3.0%	3.0%
Year12/6thForm/Leaving	5.3%	5.3%	5.3%	21.1%	31.6%	21.1%	10.5%	
Trade Qualification		18.2%	9.1%	27.3%	18.2%	18.2%	9.1%	
Professional Qualification		22.9%	20.0%	20.0%	14.3%	17.1%	2.9%	2.9%
Bachelor Degree	2.5%	27.5%	15.0%	35.0%	7.5%	12.5%		
Postgraduate	15.4%	15.4%	23.1%	38.5%		7.7%		
Total	3.6%	18.8%	15.2%	26.1%	13.9%	17.0%	4.2%	1.2%

Table 2: Cross tabulation of respondent education level and attitudinal response.

4.2 Altruism

Consumers views regarding altruism and 'for the common good' utilitarian attitudes were clearly displayed through surveys as illustrated in Figures 3 and 4. Figure 3 illustrates responses to the attitudinal statement 'If information about my health can be used to help others who are suffering ill-health then I believe my information should be used to help those people'.

The agreement to secondary data use is a 'motherhood' type statement that requires further clarification regarding 'who' decides 'what' data is available for 'which' purpose. Further statements are posed in the survey to investigate these concepts.

Consumers voiced overwhelming support for blood donations and financial donations to support medical research, as illustrated in Figure 4. Two statements were used to capture consumer views: 'I support the idea of people making money donations to support medical research' and 'I support the idea of people making voluntary blood donations'.

These results illustrate that survey respondents have a positive attitude towards 'donation' of a range of valuable resources including blood, money and personal medical data.

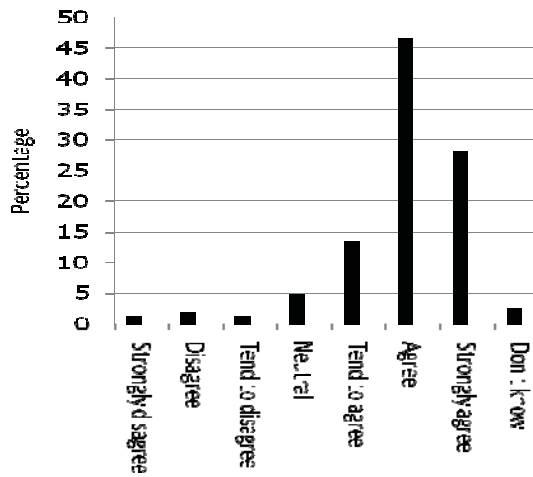


Figure 3: If information about my health can be used to help others who are suffering ill-health then I believe my information should be used to help those people

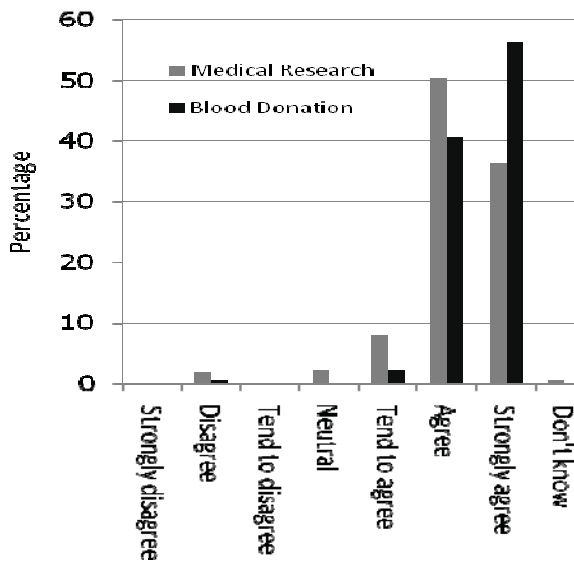


Figure 4: Altruism statements

4.3. 'Donating' data

The Million Women study from Oxford University [21] has demonstrated the valuable resource that is available when patients contribute data to large data warehouses. This pilot survey included measures to capture Australian consumer support for 'data donation' to a similar national warehouse. In response to the statement 'I support the idea of people being given a personal choice about 'donating' their medical

information for research', such a choice is clearly expected from consumers.

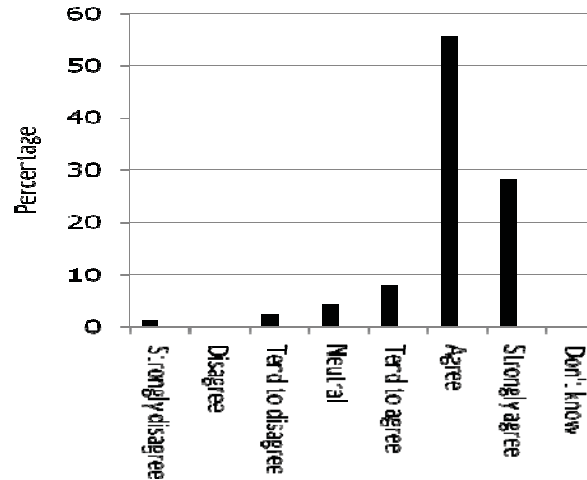


Figure 5: I support the idea of people being given a personal choice about 'donating' their medical

The survey moves on to explore in more detail the way in which respondents would like to be able to 'donate' data. Currently protocols and guidelines exist to guide organizations such as the UK National Health Service and Australian Department of Health and Ageing in the secondary use of patient data. This survey is exploring beyond these guidelines to situations where it may not be the national health authority that is seeking data 'donations'. Can consumers/patients instruct the national health organizations to release their data to third parties? RALC theory suggests consumers/patients should have the ability to permit such use of their 'donated' data by third parties.

This type of situation leads to open research questions surrounding ownership of personal medical information. Is the data generated and stored during the treatment of patients owned by (1) the medical practitioner, (2) the healthcare organization capturing and storing the data or (3) the consumer/patient?

4.4 Access Control's for 'Donated' data

Moor and Tavani's Restricted Access / Limited Control privacy theory calls for more control over access to an individual's information as a key aspect of delivering privacy [9, 22, 23]. Figure 6 illustrates the frequency of responses to three Likert statements concerning control over medical information and control over donation of personal medical data. Table 3 reports

the statements used in the survey that are included in Figure 6.

S17	If I give consent for my health information to be used for research I want to be able to say who can use my information like 'medical researchers', 'drug companies', 'university researchers' or 'insurance companies'.
S23	If people agree to donate their data for medical research there must be a way for them to stop the donation agreement.
S24	If people agree to donate their data for medical research from time to time they must be asked if they want to continue to donate.

Table 3: Survey statements regarding access control

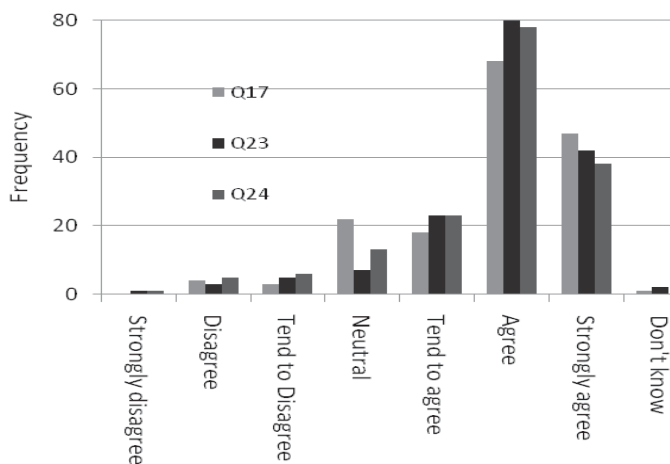


Figure 6: Three survey questions relating to consumers access control over their medical data.

Statement 17 drew survey responses beyond the Likert scale. Many respondents included further personal opinions regarding this statement in open-ended responses. Respondents emphasized their desire to donate data to support their chosen organizations. Negative comments were expressed about secondary data use by insurance companies. In addition, respondents stated they would not give consent for employers to use health information. Five consumer access control related statements from the pilot survey resulted in a Cronbach's alpha of .71. Discussion of the public attitude towards access control and Moor and Tanavi's theory are considered in the discussion section of this paper.

4.5 Profit Making Purposes

Profit making from donated data was explored via two Likert statements. Consumers who identified themselves as medical workers indicated comparatively strong

attitudes towards these matters as illustrated in Figure 7. Medical workers expressed stronger attitudes towards payment for personal medical information. The survey does not gather evidence regarding 'why' this sub-population have stronger feelings than the non-medical respondents concerning payment for data and profit-making goals of secondary data use. This is an open research area.

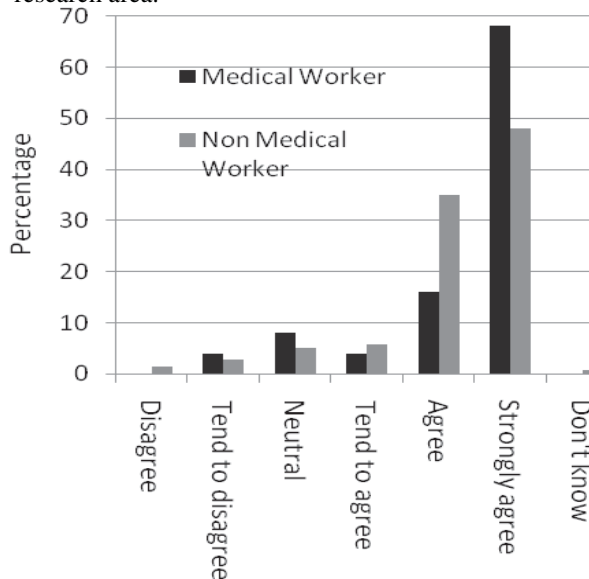


Figure 7: Using my donated medical information for profit making purposes is not OK

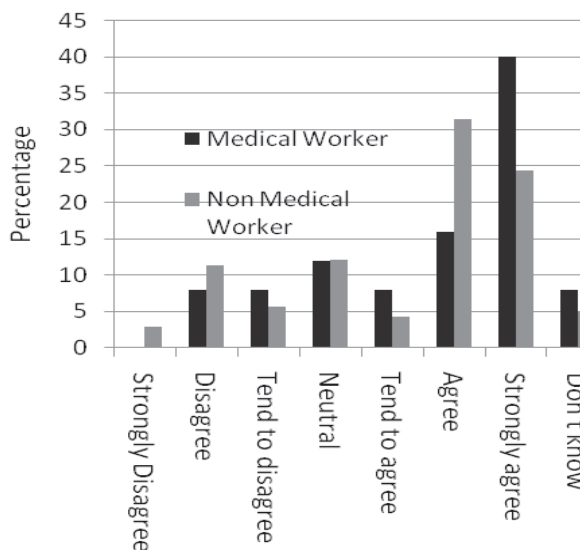


Figure 8: I would expect to be paid if I provided my medical information to someone who was using the information for profit making purposes. In this case my data should *not* be considered a donation

5. Discussion

The tension between consumer's expectations of individual privacy and recognition of the utilitarian gains available through secondary uses of medical data are apparent in these survey responses. Figure 1 illustrates consumers who responded to this survey believe they have a 'right' to privacy. Figure 3 illustrates altruistic attitudes regarding use of consumer's medical data for utilitarian common good. It could be argued that the 34% of people who responded to this survey are demonstrating their utilitarian beliefs by actually filling in the survey and returning it to the University researchers conducting this study. It is clear that the consumers who responded to the survey desire personal privacy. The consumers are also supportive of data re-use which at first appears contradictory.

When these survey responses are considered in terms of Moor and Tavani's [9, 22, 23] Restricted Access / Limited Control theory of privacy it is possible to conceptualize both the achievement of privacy while simultaneously making data available for research.

The hybrid RALC privacy theory suggested by Moor and Tavani can be applied within the medical domain when considering secondary uses of medical data. Healthcare providers limit access to patient's medical records thus affording those in their care 'privacy'. Limitation theories of privacy are consistent with this common approach taken by healthcare providers.

RALC takes a more sophisticated approach by suggesting that if a person (in this case patient/consumer) can control who has access to their medical information they have increased privacy. If a consumer wants to release their medical information to a third party for use as determined by the consumer RALC suggests they retain their privacy. The consumer's privacy is retained because they are the people deciding who can /cannot view their medical information. In the domain of secondary use of medical data this is the concept of 'donating data' as explored via this survey. The consumer provides 'explicit consent' at the time of 'donating data' thus ensuring the ongoing utilization of their data according to their wishes.

A small part of the 2007 Canadian survey of public opinion concerned secondary uses of medical data [13]. 84% of surveyed Canadian consumers agreed that electronic health records could be used for health research

if personal identifiers were first removed. Similar levels of support are found in the 2009 Australian Pilot survey.

The 2001, 2004 and 2007 Australian Surveys [15-17] reported that 66%, 64% and 76% of respondents respectively wanted to choose if their medical information would be included in a National Health Information Network. The 2009 pilot survey presents results, Figure 5, re-iterate this consumer view. This growing expectation of choice amongst consumers also indicates a suitable opportunity to apply RALC to these medical records.

Many of the earlier surveys focused on consumer consent issues regarding secondary use of personal medical records [6, 12, 14, 24]. The debate had been over simplified into 'consent must be gained' or 'consent is not required'. The 2009 Australian pilot survey is suggesting 'data donors' can provide explicit consent and instructions regarding 'who' can use the data and for 'what' purpose. The survey respondents have supported such notions of access control at establishment of 'data donation' and at later dates as described in Table 3 and Figure 6. This increased access control is well supported by Moor and Tavani's RALC privacy theory.

As described in section 4 above, this survey moves beyond secondary data use by national health organizations. In February 2010 the Australian Schizophrenia Research Institute launched a 'databank' project that involves data donors contributing medical information to a schizophrenia research database [25]. This is an example of a third party organization calling for data donations. It is interesting to note that from July 2011 this 'databank' will be available for use by commercial organizations. Responses to the pilot survey described here indicate a preference for donated data to be used by non-commercial organizations.

The emerging voice of medical workers as consumers is interestingly illustrated via this pilot survey. The medical workers have expressed strong attitudes towards de-identifying medical data and profit oriented secondary uses, as seen in Figures 7 and 8. This warrants further research as medical workers often participate in ethics committee's and other governance bodies which make important decisions regarding secondary uses of medical data.

5. Further Research

This pilot survey is a first step in a much larger research project that seeks to validate Moor and Tavani's RALC and operationalise for secondary uses of medical data to support healthcare research. This pilot survey was

also run in Canada during October and November 2009. Comparative studies will be conducted with both pilot surveys. In early 2010 the surveys will be deployed across much larger

sample populations in both Australia and Canada with an expectation of having generalisable datasets at the completion of the two surveys to facilitate comparative studies. The data ownership issues raised in section 4 of this paper are open research areas that require further research.

6. Conclusions

This pilot survey provides evidence of the Australian general public interest in engaging in matters related to

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secondary uses of medical data. The results of this survey: are similar to earlier survey findings; assist with evaluation of RALC and suggest the value of larger deployment to more broadly capture emerging consumer's views.

7. Acknowledgements The assistance provided by the anonymous residents of Camden, Kiama, Shell Cove, Tenambit and Darwin who voluntarily participated in the public opinion survey is gratefully acknowledged.

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