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## A Model of Patients' Attitudes in E-health

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## A Model of Patients' Attitudes in E-health

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### ABSTRACT

*Changing patterns of healthcare delivery, which emphasize the use of multi-disciplinary teams, mean that there is an increasing need for healthcare professionals to exchange information about patients and their treatment, which is being facilitated by the use of electronic communications systems and e-health systems. Despite the increasing recognition of the importance of patients' views about these changes, especially about their concerns about the implications for their personal privacy, there is a lack of theoretical modelling of their perspective. This paper evaluates the application of the model of trust and risk-taking within organisations which was developed by Mayer et al. (1995) to explain the empirical findings of a national survey of New Zealanders' attitudes to e-health systems.*

### Keywords

e-health, Trust, Consumers' attitudes

### INTRODUCTION

Healthcare organisations around the developed world are facing increasing demands for services due to the growth in the aging population and the increasing prevalence of chronic diseases such as diabetes and cardiovascular problems (WHO 2005). The changing nature of service, from episodic care to ongoing disease management, is resulting in changes to organisational structures with an increase in the emphasis on integrated care by multidisciplinary teams (Minister of Health 2001). At the same time there has been a recognition of the importance of information to the treatment of patients and the management of the health service and a number of countries have undertaken strategic initiatives to increase and improve the flow of patient-related information (HealthConnect Program Office 2002; Ministry of Health 2005).

Despite the enormous resources which have been deployed in the development of some of the technical systems, until recently relatively little attempt has been made to investigate the views of a significant body of stakeholders; the patients. Patient buy-in for these systems is vital, otherwise, they are likely to withhold information which may be crucial for their correct treatment or they may refrain from seeking treatment altogether (NZHIS 1995; Sankar et al. 2003). Increasingly, the importance of patients' views is being recognised and a number of studies and surveys have begun to gather information about their perspective (Hunter et al.

2009; NHS Information Authority 2002; Shickle et al. 2002; Whiddett et al. 2006). However, the research to date has tended to be very empirical and has explored how patients' attitudes are influenced by various parameters that surround the use of their information, this paper will develop a more theoretical framework which can serve as a basis for interpreting current findings and directing future research.

This paper begins by outlining Mayer et al.'s (1995) model which describes the relationship between trust and risk-taking behaviour in organisations. The following section examines how the model can be applied in the specific context of patients' sharing their personal information in a healthcare setting. The third section of the paper then evaluates the model using the findings from a national survey of the New Zealander public. The final part of the paper draws some conclusions from this investigation and makes some recommendations for health service policy and future research.

## **MODELLING OF TRUST IN ORGANISATIONS**

In their insightful paper, which draws on research from various areas of management and leadership, Mayer et al. (1995) proposed a widely respected model of trust between individuals in organisations. The model, shown in Figure 1 below, outlines the relationship between trust, risk and risk-taking behaviour in organisations. Central to the model is the idea that the willingness of an individual (the trustor) to undertake some risk-taking behaviour which relies upon the performance of another individual (the trustee) will depend on their level of trust in the trustee. The trustor's willingness to act will depend both on their perception of the trustworthiness of the trustee and on the perceived risk of the activity. For example, a manager's willingness to delegate a task to a subordinate will depend on their level of trust that the subordinate will complete the task and on the severity of the consequences if the task is not done satisfactorily.

In the model, the perceived risk depends on the balance between the potential risks from a bad outcome and the potential rewards if there is a successful outcome.

The level of trust is dependent on a number of factors. Firstly, it is postulated that individuals each have a particular predisposition towards trusting others (called the trustor's propensity within the model), which will depend on a number of factors in their history and personality. Secondly, the particular level of trust that a trustor will place in someone will depend on their perception of the trustworthiness of the trustee, which is influenced by their perceptions of three factors: the ability, the benevolence and the integrity of the trustee.

The final part of the model represents the feedback loop, where the outcomes of some activity are evaluated and are used to update the trustor's perception of the trustworthiness of the trustee.

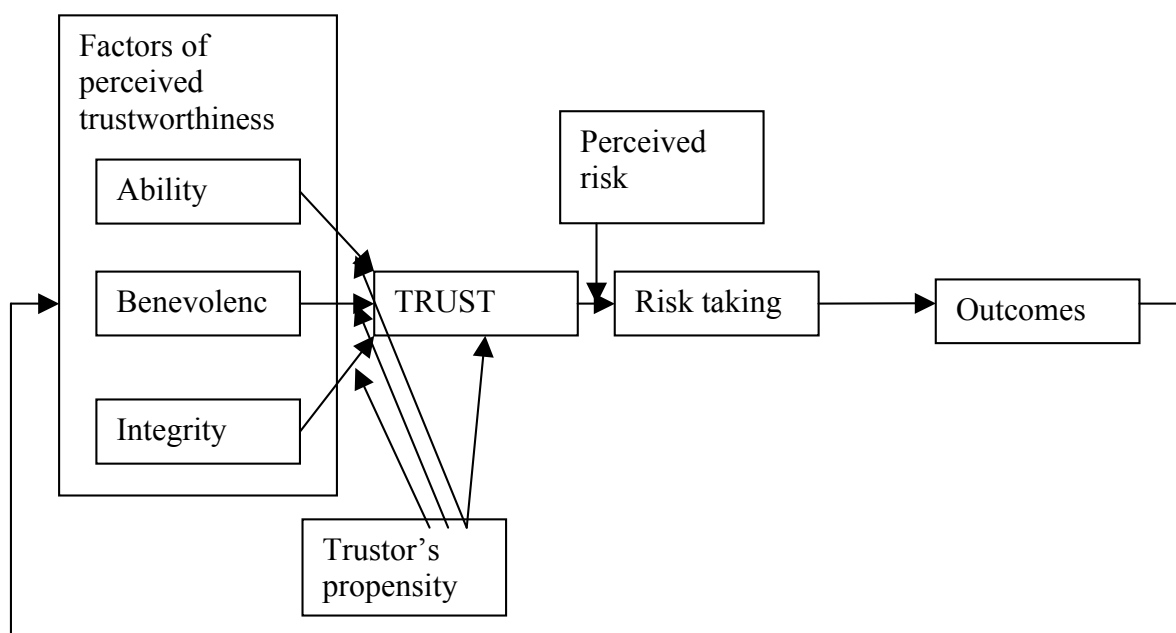


Figure 1: Generic Model of Trust in Organisations based on Mayer et al. (1995)

## MODELLING INFORMATION SHARING IN HEALTHCARE

The above model gives a generic picture of how risk, benefits and trust influence an individual's behaviour. In this section these factors are explored in more detail in the context of a specific risk-taking activity; that of a patient agreeing to share their personal health information with healthcare professionals or organisations. This is risk-taking behaviour since the disclosure of the information makes the patient more vulnerable to a loss of personal privacy. An individual's response to a particular situation will be influenced by their personal characteristics and by a number of factors in each particular situation in which access to their information is desired.

The personal characteristics which will influence a response will be the patient's propensity to trust and also their requirements for personal privacy. These individual characteristics will not be explored further in this paper, which will focus on the influence of the characteristics of the situation and the risk-taking activity. This section of the paper identifies four propositions which will then be tested against the empirical findings of a survey of public attitudes towards sharing their information.

### Trust

Personal health information can be used by a wide variety of people or organisations, such as various healthcare providers, government departments, insurance companies and pharmaceutical companies. Patients' perceptions of the trustworthiness of these organisations will vary with their perception of the integrity and benevolence of the organisation and its ability to ensure the privacy of their information.

*Proposition 1: The likelihood of disclosing information will increase with the increase in the level of perceived trustworthiness of the recipient to safeguard the information.*

### Risks

The main risks involved in this behaviour are associated with the loss of personal privacy which might occur if the information is misused either directly by the person or organisation receiving the information, or indirectly if the information is subsequently passed on or accessed by a third party. The potential impact of these risks is dependant on two factors: firstly, the level of detail of the information and secondly, the level of identifiability of the patient involved.

*Level of detail* refers to the amount of the information to be released, which in practice might vary from a brief summary of the patient's current health concerns to their complete health history, depending on the particular circumstances.

*Proposition 2: The Perceived Risk of disclosing information will increase with the increase of the level of detail of the information to be disclosed.*

Level of identifiability refers the ease with which it is possible to identify the person to which the information refers. The risk to personal privacy will be much greater if the information includes the patient's full name and address compared to information which only includes a numeric personal identifier or information that has been made anonymous by having all the personal details removed.

*Proposition 3: The Perceived Risk of disclosing information will increase with the increase of the level of identifiability of the person who's information is to be disclosed.*

### Benefits

Personal health information has a wide range of potential uses which bring a range of direct and indirect benefits to a patient or to other parties. Firstly, the information may be necessary to provide the patient with the correct care, which clearly is a direct benefit for them. Indirect benefits might be derived from using the information for secondary activities such as clinical audit, public health applications such as managing epidemics or medical research which have the overall goal of improving the service provided to patients. Other uses might include the financial management of the healthcare system or more targeted advertising by pharmaceutical companies which would seem to provide less direct benefit to the patient.

*Proposition 4: The Perceived Risk of disclosing information will be mitigated by the increase of the level of direct benefit which is expected to result from the disclosure which will depend on the proposed use of the information.*

The resulting model of patient consent is summarised in Figure 2, below, which identifies the situational factors which will influence a patient's assessment of a particular situation and determine whether they will consent to share their information.

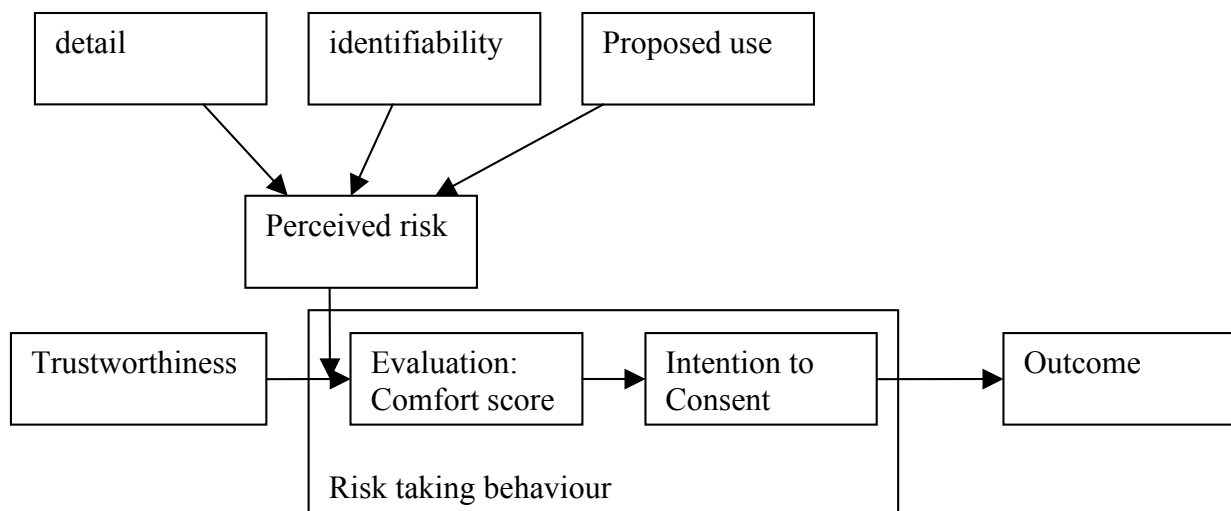


Figure 2: Proposed model of Information Sharing in Healthcare

### EVALUATION OF THE MODEL

This section will evaluate the above propositions, primarily with reference to the findings from a nationwide survey of New Zealanders' attitudes to the disclosure of their health information which was conducted using Computer Aided Telephone Interviewing (CATI). The findings presented here are based on the analysis of the first 1828 respondents, in the final study there were 4219 individuals who answered any vignettes and in total there were 31118 vignettes responses. A more detailed description of the survey and some of the findings can be found elsewhere (Hunter et al. 2009), this section will focus on relating the findings to the Propositions derived from the above model.

In the CATI survey, respondents were presented with a series of vignettes which described different ways in which their health information might be shared. Each vignette contained various permutations of the attributes contained in a generic vignette as follows:

*<person requesting information> would like to access your medical notes which contain <content of medical information> as <reason for request>. The information about you would contain <type of identification details>.*

For the survey, 58 potential vignettes which were likely to occur were identified and each respondent was asked about five vignettes selected at random. Two typical vignettes are:

*'A doctor or practice nurse working in a GP setting would like access to your notes which contain all your medical history as part of the health care that you are receiving. The information about you would contain your name and address.'*

and

*'A government health agency such as the Ministry of Health would like access to your notes which contain information relevant to your current health problem in order to improve the health of New Zealanders. The information about you would be totally anonymous and would have no information to link the record to you.'*

After each vignette, the respondents were then asked to identify how they felt about the particular vignette on a scale in the form "On a scale of 1 to 10, where 1 is very uncomfortable and 10 is very comfortable, how comfortable would you be for this person to see your medical notes?"

This 'comfort score' is effectively asking respondents to integrate their perceived risk and the trustworthiness of the recipient for the particular situation. However, since it is possible for respondents to feel uncomfortable about the situation but still agree for it to occur, a second fixed choice question was included, asking if the respondent would give consent for the information sharing in the vignette to happen, with the options of Yes/No. In combination, these two questions provide information about how the perceptions of risk and trust translate into intended action of information disclosure in each risk-taking situation.

## **Trust**

*Proposition 1: The likelihood of disclosing information will increase with the increase in the level of perceived trustworthiness of the recipient to safeguard the information.*

Figure 3 shows that there is a wide range in the proportion of respondents who would agree to share their information with different recipients. In each case other parameters are kept constant and represent vignettes where the purpose is to provide care and the information is identified by name and address. It can be seen that recipients fall roughly into four groups in order of decreasing acceptability, which are:

1. Doctor, nurses and paramedics.
2. Allied health professionals and community health workers.
3. Managers, pharmacists and laboratory workers.
4. Government agencies.

Unfortunately, our survey did not attempt to measure trustworthiness, but this ordering would seem to reflect an intuitive assessment of the trustworthiness of profession, which is also supported by two recent New Zealand surveys of people's views of the trustworthiness of professions or organisations.

Firstly, a survey conducted for the Privacy Commissioner (2008) found that 92% of respondents rated health service providers (such as doctors and hospitals) as totally trustworthy, but only 65% of respondents rated government departments as totally trustworthy.

Secondly, a survey to determine New Zealand's trust in professionals conducted for the Readers Digest (2008) found that Ambulance officers, Nurses and Doctors were among the top five most trusted professions. It also found that psychologists and social workers, who could be considered as Allied Health Professionals, were ranked 23 and 26 respectively out of a list of 40 professions.

The only anomaly in these findings is that of pharmacists, who scored relatively poorly in the CATI survey, but were ranked much more highly in the other surveys, coming in at number 6 in the Readers Digest poll.

The results of the survey would therefore give strong support for the proposition that the perceived trustworthiness of the recipient is a key determinant of a person's willingness to share their health information.

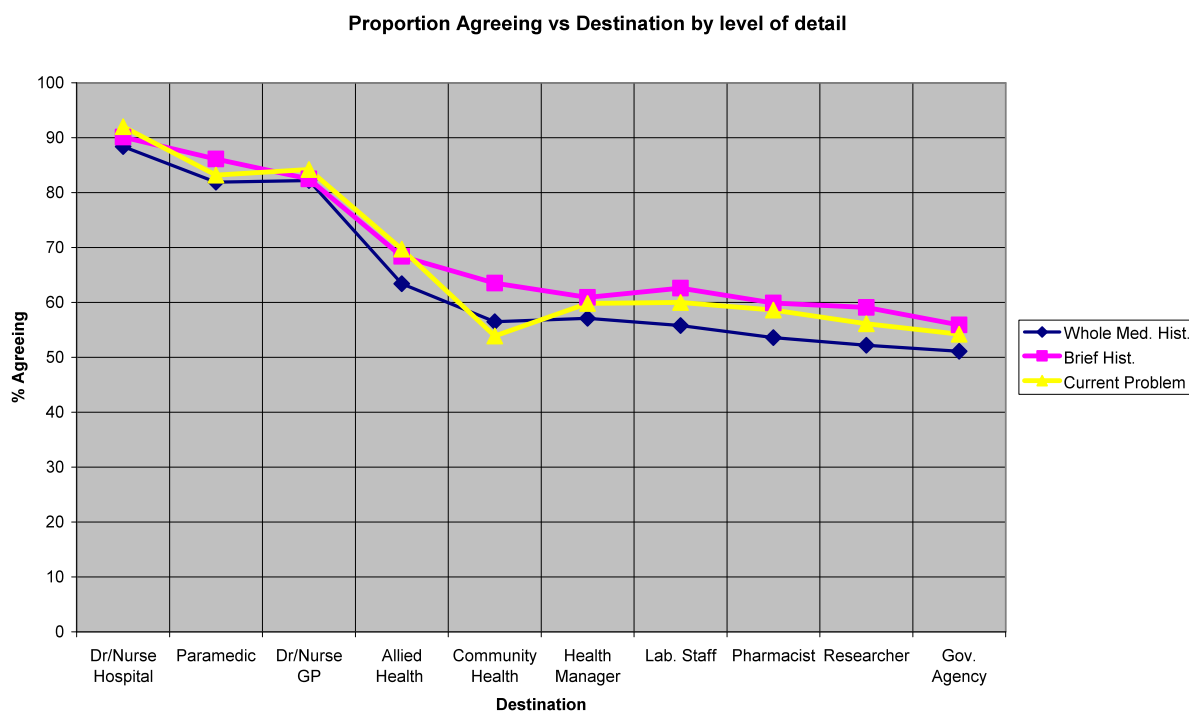


Figure 3: Proportion of respondents who agree to the sharing their information with different 'roles' for different amounts of personal health information, identifiable by 'name and address'.

### Risk

*Proposition 2: The Perceived Risk of disclosing information will increase with the increase of the level of detail of the information to be disclosed.*

The survey explored respondents' reactions using three levels of detail of personal information: "information about your current health problem", "a brief summary of your medical history", "all your past medical history".

The proportion of respondent who would agree to share their information with different recipients for these different levels of detail of information are presented in Figure 3. In each case the purpose for disclosing the information is to provide care (i.e. the level of benefit is relatively constant) and the level of identifiability is constant and includes name and address. The level of trustworthiness of the recipients is not the same, but for each recipient it should be constant across the different scenarios. Therefore, the only variable influencing perceived risk for each recipient should be the level of detail.

The general trend of the results supports Proposition 2 as in most cases respondents are least likely to agree to release their whole medical history. The relationship between the brief medical history and information about the current problem is not clear but in many circumstances the results are virtually identical. However, it can be seen that overall, the level of detail has a relatively small impact on respondents' decisions.

*Proposition 3: The Perceived Risk of disclosing information will increase with the increase of the level of identifiability of the person who's information is to be disclosed.*

Figure 4, below, presents the findings for the level of agreement for different levels of identifiability of the data when accessed by different recipients for different purposes. Three levels of identifiability were used in the vignettes, "identified by name and address", "identified by medical record number" and "totally anonymous". However, it was found that statistically there was no difference in response to the latter two cases so the results have been combined.

It was also assumed that if information was to be used for the purpose of care it would have to be identified by name and address, so the impact of identifiability can only be seen for non-care purposes. The term 'Health Professional' was used in vignettes to include all doctors and nurses when they are working in a non-care capacity.

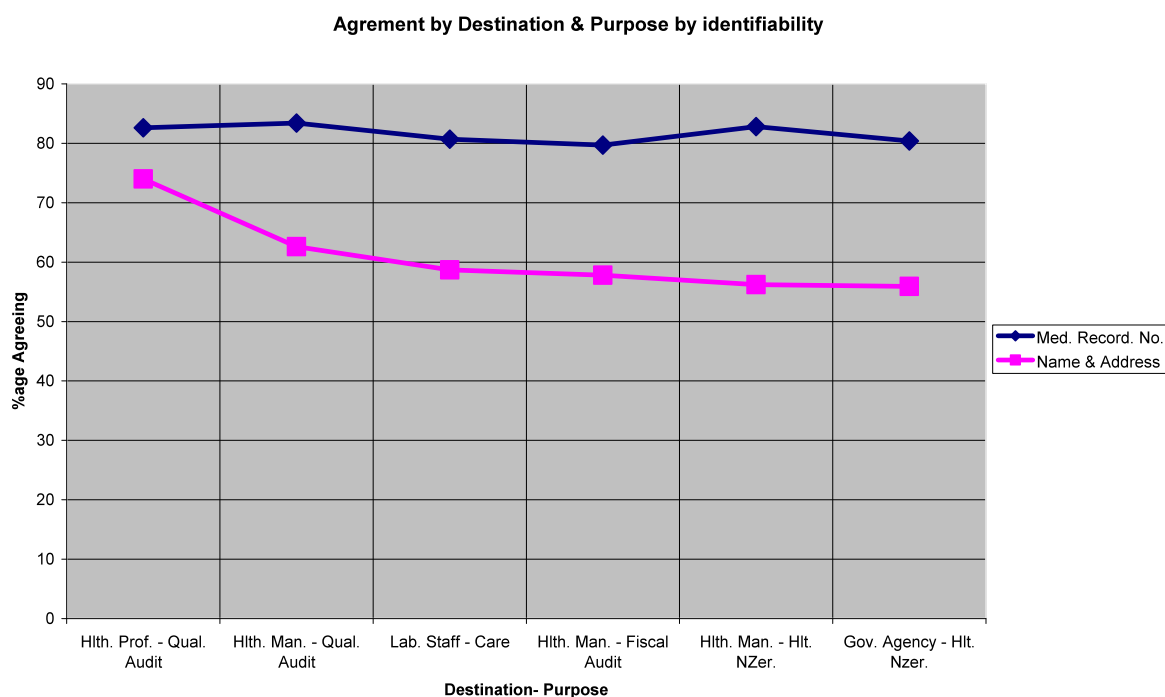


Figure 4: Proportion of respondents who agree to the sharing their information with different 'roles' for different purposes by different levels of identifiability.

In each case there is a marked increase in the proportion of respondents who would agree to release information which does not contains their name and address, which suggests an decreased perceived risk. In most of these cases, the recipient of the information has a relatively low trustworthiness rating, but by reducing the risk by removing the name and address greatly increased the willingness of respondents to share their information. In fact it increases the willingness to share information to a level which is similar to that of sharing the information with a doctor to receive care.

The fact that people are much more willing to release their information once their name and address has been removed seems to imply that much of the perceived risk is associated with the accidental casual disclosure of information which might occur from someone seeing their information rather than from any systematic process which could still link the information back to them using their medical record number.

Overall, these finding strongly support Proposition 3, that the level of identifiability of the information has a impact on perceived risk.

### Benefits

*Proposition 4: The Perceived Risk of disclosing information will be mitigated by the increase of the level of direct benefit which is expected to result from the disclosure which will depend on the proposed use of the information.*

The influence of the proposed use of the information can also be seen in Figure 5, which presents the acceptability of using identifiable data for various purposes by various recipients. Several different uses of information were identified in vignettes: provision of care, assessment for benefits, quality audit, financial audit and improving the health of New Zealanders.

These results do not support the proposition that perceived benefits will increase respondents' willingness to release information. Although the highest scores are for the provision of care by trusted professions, most of the other scores are very similar, and some of the lowest scores are also for the provision of care but by less trusted professions.



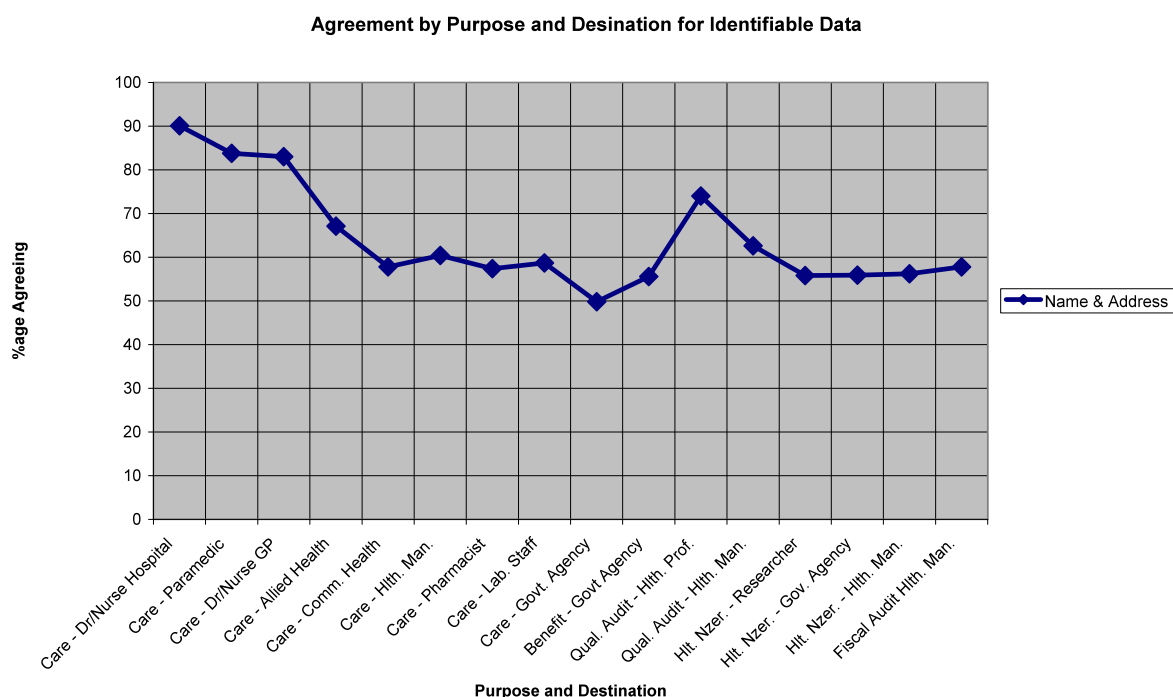


Figure 5: Proportion of respondents who agree to the sharing their identifiable information for different purposes with different 'roles'.

It can also be seen that Quality Audit (i.e. a retrospective analysis of patient records to review appropriateness of care provided), which provides little direct benefit to the patient, scores relatively highly when it is performed by a trusted health professional, even when the information is fully identifiable. Also note that in Figure 4, in cases where the risk has been reduced by making the data anonymous there is strong support for information to be used for activities which only provide indirect benefits, even when it is being used government agencies or health administrators which rank quite lowly on trustworthiness.

These finding therefore seem to suggest that, at least for the range of uses considered in these vignettes, which generally involve the public good, the expected benefits do not have much impact on peoples' attitudes to sharing their information.

## CONCLUSIONS

The framework developed by Mayer et al. (1995) which explains individual risk-taking behaviour in terms of trust and risk seems to provide a very parsimonious model to understand people's attitudes to sharing their health information and it provides a good basis for developing a better understanding of the views of this important stakeholder group.

The destination of the information has the greatest influence on people's decision to share their information. The results of the survey demonstrate a major shift from about a 50% agreement rate for government organisations to over 90% agreement rate for clinical staff in a hospital, which can be explained in terms of increased trust. This paper did not explore the antecedents of trust in any detail, but Mayer et al.'s (1995) factors of ability, benevolence and integrity would seem to provide a good starting point, as clinical staff would clearly rate highly on these attributes.

The relatively poor levels of trust indicated by the survey findings for the various ancillary health workers, such as the Allied Health workers, Community Health workers, pharmacists and laboratory workers is a potential cause for concern given the increasing role that such professions are playing in delivering healthcare. This is an important issue given to the increased focus on clinical teams and the on providing care for chronic diseases in the community. In future research we intend to investigate the underlying factors which make people reluctant

to share their information with these groups with the intention of identifying strategies to address patients' concerns.

Patients' reluctance to share their information can be overcome by reducing their perceived risk. The biggest impact is achieved by removing the patient's name and address; people are much less concerned about what happens to anonymised data and an additional 25% of respondents were willing to share such information. We were surprised that there was so little difference in people's attitudes to sharing information identified by record number and totally anonymous information, and we intend to explore this point in more detail to ensure that respondents fully appreciated the difference between the two. If the simple removal of name and address is found to resolve many patients' concerns, it will help to simplify many policy issues relating to the secondary use of patient information and have implications for the future organisation and structure of the public health service.

In situations where anonymous data is not appropriate, limiting the total amount of information which is shared can lead to an increase in the acceptability of practices in some situations, but the impact is not nearly as big as other factors. At the most, releasing just summaries or subsets of data to people or organisations only leads to an additional 7% of respondents being willing to share their information in a particular situation, and in some situations, limiting the amount of information has virtually no impact on respondents' decisions. This finding also has policy impact as it shows that, at least from the patients' perspective; there is little advantage to the development of 'summary care records' (Greenhalgh et al. 2008) so investment in this area will need to be mainly justified from the perspective of the users of the records.

The final conclusions from the analysis is that, at least for the range of uses explored in this project, people's attitudes are mainly influenced by the perceived risks and the perceived benefits have little influence. However, it is acknowledged that all of the uses which were considered were for the public good and would at least lead to a better public health service, which is an institution with which most New Zealanders identify strongly. In contrast, research which investigated Canadians' attitudes to the use of patient information (Willison et al. 2007) found that whilst 89% of respondents approved of using it to track communicable diseases, only 35% of respondents felt it was appropriate to allow companies use the information to better target their advertising to doctors. This would seem to imply that further investigation would be appropriate before information is released outside of the public health service.

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