Patients’ attitudes towards sharing their health information

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Summary
Objectives: The current policies of the governments of Australia and New Zealand encourage the use of electronic information systems to exchange patient information between various stakeholders. This research investigated (1) the attitudes of patients toward sharing their medical information and (2) whether patients considered themselves to be well-informed about the uses that are made of their information.

Methods: A questionnaire survey of adult primary-care patients was conducted in five clinics within a medium sized New Zealand city. Outcome measures were the proportions of respondents willing to share different categories of their information with different classes of recipients. Patients’ evaluations of their knowledge about the uses made of their information were also collected.

Results: Over 200 responses were collected from five clinics. Respondents’ attitudes toward sharing their information were found to be influenced by three factors. (1) Identity of recipient: whilst respondents were generally willing to have their information shared between health professionals, they were increasingly unwilling for it to be distributed to other stakeholders, such as administrators, researchers or other government departments. (2) Level of anonymity: respondents were more prepared to share anonymous information. (3) Type of information: respondents were increasingly unwilling to share their information as it takes on a more personal nature. Respondents were also found to be very poorly informed about the use of their information, 90% of respondents indicated that they had either incomplete or no knowledge of how their information was shared and 79% had no knowledge of the uses of their National Health Index (NHI) number. The findings also indicate that respondents would prefer to be consulted about the distribution of their information.

Conclusions: These findings indicate that many respondents were unwilling to have their personal information distributed other than for purposes of clinical care and a
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Knowledge before this research:
- Sharing of patients’ health information between organisations is widespread and becoming more common.
- Patients sometimes object to the uses that are made of their health information.
- There has been very little research into, or knowledge about, the attitudes of typical patients towards the sharing of their information.

This study has identified that:
- The results were similar to findings of UK studies, which show that the attitudes of the respondents were influenced by several factors which include:
  - the identity of the recipient, this is the most influential factor;
  - anonymity, patients are more willing to share anonymous data;
  - type of information, patients are increasingly unwilling to share their information as it takes on a more personal nature.
- Approximately one-third of the responses indicated that the respondents would like to be consulted before their information is shared with other organizations.
- The respondents felt that they were poorly informed about the ways in which their information was shared between organisations.

1. Introduction

The right to personal privacy is an important principle within many cultures [1]. However, the increasingly sophisticated use of information and communications technologies is constantly threatening to erode people’s privacy [2]. Within the healthcare sector there is a need to constantly balance patients’ requirements for personal privacy against the potential benefits that may accrue to society as a whole from the more widespread use of their personal information. This issue is particularly relevant in developed countries which have been seeking to use information technology to improve both the quality of care provided for patients and organisational efficiency. Within Australia and New Zealand, two key strategic aims have been the introduction of electronic health records (EHR) systems and the enhancement of electronic communications links between the primary care sector and secondary care institutions [3–6]. These aims are similar to the strategy of the UK Department of Health [7]. Part of the New Zealand strategy includes expanding the use of the National Health Identifier number (NHI) [8]. Initially, the NHI was developed for use as a unique identifier for all patients entering the secondary care system, but the intention is to extend its use into primary care.

Whilst studies have shown that EHRs do increase the accuracy and accessibility of patients’ records, the potential threats to the confidentiality of the information that they contain and their implications for patient privacy are more controversial [9] and large scale health information systems have often been fraught with problems [10,11]. A classic example of this occurred within the British National Health Service when doctors boycotted an inter-organisational network designed to improve the exchange of information on the grounds that it threatened patients’ privacy [12,13]. Research in New Zealand into clinicians’ attitudes towards the use of information contained within EHRs indicated that some of the potential uses were unacceptable and would also lead them to withhold information [14]. These concerns are not unfounded, for example, Anderson [15] cites a number of cases where patient privacy has been breached in the USA and, in a survey of Australians, Mulligan [16] found that 1.9% of respondents reported harm arising from unauthorised disclosure of their information by health services.

From the patient’s perspective, confidentiality is essential to the patient–physician relationship. Unless a patient can be sure that personal information will not be distributed against their wishes, they may be reluctant to disclose sensitive information that may be crucial to their correct treatment.
or they may refrain from seeking treatment. However, there is a lack of research from the patients’ perspective. A recent review of the literature identified nearly 6000 articles related to issues of patient privacy, but the vast majority of them were written from the practitioners’ perspective or addressed legal or regulatory issues. Only 6% of the identified articles were written from the patients’ perspective and of these only 110 (2%) were based on research. Furthermore, most of this research focused on specific groups or particularly sensitive issues, such as adolescents who are concerned about their information reaching their parents or people who are having HIV tests; very little work has addressed the attitudes of ordinary patients.

Some research into attitudes of patients or the public towards the distribution of their information has been undertaken in the UK in association with the National Health Service’s Electronic Record Development and Implementation Programme (ERDIP) [19], such as the Patient Electronic Record: Information and Consent (PERIC) project [20] and the ‘Share with Care’ project [21]. In Australia, the issues of confidentiality of patient information and consent for access has been addressed as part of the HealthConnect project [22,23]. These projects have recognised the increasing levels of concern about personal privacy among the general public and have started to address the issues of consent for access to patient information and to explore the development of electronic systems to control access (e-Consent systems) [24,25]. However, the exploration of the attitudes of patients has not received the attention that it would seem to warrant.

New Zealand has a very high level of computerisation in primary care [26], and the strategies proposed by the government will lead to a significant increase in the amount of personal health information which will be transferred between various organisations. The research reported in this paper explores the attitudes of New Zealanders towards sharing their personal health information. This knowledge is needed to ensure that the design of future health information systems will be acceptable to patients.

This paper focuses on five issues:

- the extent to which patients would like to be consulted about the distribution of their information;
- how well New Zealanders are informed about how their health information is used.

2. Methods

The patients’ perceived knowledge of information sharing practices and their attitude towards the distribution of their personal health information to various classes of people or organizations was assessed using a short questionnaire which was designed to take approximately 10 min to complete. A condensed version of the questionnaire is shown in Appendix A.

The questionnaires were distributed by the receptionists in five clinics serving primary care patients. Questionnaires were offered to all of the adult patients who attended the clinics. In each practice, the survey was intended to run for a period of three weeks or until 100 questionnaires had been distributed. Patients were asked to complete the questionnaires and either to return them to a collection box in the clinic or to return them to the researchers using a pre-paid envelope. Patients were requested not to complete more than one questionnaire, however, the research team made no attempt to monitor the distribution of the questionnaires by the receptionists or to identify either non-respondents or repeat respondents. Patients self-selected by taking and returning the questionnaire.

The five clinics were chosen to ensure a broad range of situations and respondents. In addition to conventional single doctor and multi-doctor primary care practices, the survey was undertaken at a health centre run by a Maori Iwi (tribe) to ensure a good representation of Maori respondents, and at a clinic specializing in sexual health issues, which was perceived as handling more sensitive issues.

The questionnaire was divided into sections which covered:

- basic demographics: age, gender and ethnicity;
- attitude towards sharing identifiable and non-identifiable information;
- detailed attitudes towards sharing identifiable information;
- whether patients’ attitudes to sharing information differ depending on the recipient;
- whether patients’ attitudes to sharing information differ depending on whether the information is identifiable or non-identifiable;
- whether patients’ attitudes to sharing information differ depending on the type of information;
- the extent to which patients would like to be consulted about the distribution of their information;
- how well New Zealanders are informed about how their health information is used.
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- perceived knowledge of information sharing practices and NHI number.

The questionnaire concluded with an open question which invited respondents to comment on who can see their medical records.

2.1. Attitude towards sharing identifiable and non-identifiable information

This section asked patients to indicate their attitude toward their information being shared with different classes of people or organizations. Four broad classes were used in this section:

1. health professionals;
2. health administrators;
3. health researchers;
4. other organizations (e.g. health insurers).

Respondents were first asked to indicate whether they were happy to have their non-identifiable information shared with each of these four classes, they were then asked to consider the situation where the information was identifiable and contained their name and address. Four response options were given for each situation:

1. Yes (i.e. happy)
2. Maybe, if asked first
3. No (i.e. not happy)
4. Don’t know

2.2. Detailed attitudes towards sharing identifiable information

This section gathered more detailed information about respondents’ attitudes towards sharing their identifiable information. Respondents were asked to indicate their attitude towards the distribution of their personal health information for each of the following four categories of information:

1. general information (e.g. name, address, occupation, etc.);
2. limited information about their current health problem (e.g. condition and treatment) but excluding potentially sensitive problems;
3. limited past medical/health information excluding potentially sensitive problems;
4. full current and past medical/health information including potentially sensitive problems.

These categories were chosen to align with the categories used in the PERIC study in the UK [20]. The exact interpretation of the term ‘potentially sensitive problems’ was left open to the respondents, but it was qualified by the phrase “such as sexually transmitted diseases, mental health, etc.”.

The various classes of people and organizations with whom primary care practices in New Zealand exchange patient information were identified from a review of the literature and from case studies of two medium sized practices [27]. The following 12 classes of people or organizations were used in the questionnaire:

1. self;
2. immediate family members;
3. doctor/practice nurse at clinic;
4. receptionist/manager at clinic;
5. hospital doctor/specialist/nurse/other GP;
6. emergency personnel;
7. pharmacists;
8. community healthcare workers;
9. government health agencies;
10. other government agencies (e.g. police);
11. healthcare researchers;
12. private health insurers.

For each category of information and for each class of people, respondents were asked to indicate how willing they would be to have their information shared. Respondents were asked to indicate one of the following four response options: Yes; Maybe, if asked first; No; Don’t know.

2.3. Perceived knowledge

Two questions were used to evaluate the respondents’ perceived knowledge. The first asked how much they knew about who could see all or part of their medical notes. The second question asked how much they knew about their National Health Index number (NHI), which can be used to correlate information about a patient from various sources. Responses to these questions were recorded on a 3-point Likert scale which consisted of: Nothing, Something, A lot.

2.4. Analysis methods

Data from the returned questionnaires were analysed using descriptive statistics and percentages calculated for each question. The results are used indicatively for showing trends. The significance of these trends was tested using non-parametric statistical tests such as the Wilcoxon signed rank test or the Friedman test. The Wilcoxon signed rank test was used to compare responses from two situations, such as respondents’ attitudes towards sharing identifiable and non-identifiable information. Friedmann test was used to compare responses from multiple situations, such as attitudes towards shar-
ing information with several classes of recipient. Since the respondents self-selected the sampling was non-random so the statistical analyses of the results provided here are indicative only.

3. Results

3.1. Response rates

A total of 203 questionnaires were returned out of the 263 which were distributed, giving an overall response rate of 77%, which was similar for all clinics. However, not all patients who visited the clinics during the sample period were offered questionnaires and some patients did not accept them, which means that the response rate as a percentage of people visiting the clinics during the data collection period is unknown.

Some of the questionnaires were returned without being fully completed, and the rate of missing responses tended to increase towards the end of the questionnaire. This may have been caused by several factors such as a lack of time, by respondent fatigue or by the increasing complexity of the structure of the questions. The variations in the sample size that are reported in the following statistical tests are due to such missing data.

3.2. Basic demographics

The overall demographic profile of the respondents is shown in Table 1. Clearly, the profile of the respondent population does not match that of the general population of New Zealand which is also shown in Table 1 [28] with younger female respondents being over-represented and older patients being under-represented. However, the predominance of female patients within the 18–60 age band is in line with previous research into GP attendance in New Zealand [29] which is also shown in Table 1.

The ethnicity of the sample was dominated by New Zealand Europeans (72%) and Maori (27%), with responses from other ethnic groups being too small to use for analysis. Maori were over-represented in the respondents, as they only comprise 15% of the New Zealand population aged 18 and over [28].

A series of chi-square tests were used to examine whether the respondents’ attitudes towards sharing information were related to any of the demographic variables but no statistically significant relationships were found ($p > .01$ in each case).

3.3. Attitude towards sharing identifiable and non-identifiable information

Fig. 1 gives a comparison of the total respondents’ attitudes towards sharing their identifiable and their non-identifiable information with the four classes of people. The figure clearly shows that their responses were influenced by the class of recipient, and it also shows that respondents were more willing to share their information if it was not identifiable. The differences in the overall response depending on who would be the recipient were found to be highly significant using a Friedman test for both identifiable information ($N = 175$, d.f. = 3, $\chi^2 = 145$, $p < .001$) and non-identifiable information ($N = 174$, d.f. = 3, $\chi^2 = 154$, $p < .001$). For each class of recipient, the difference in response for identifiable and non-identifiable information is statistically significant using the Wilcoxon signed rank test ($p < .001$ in each case, see Table 2 for details).

Fig. 1 shows that there is a noticeable increase in the number of respondents who are willing to share

<table>
<thead>
<tr>
<th>Table 1 Demo graphic profiles of respondents</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age group</td>
</tr>
<tr>
<td>Male</td>
</tr>
<tr>
<td>Female</td>
</tr>
<tr>
<td>Total</td>
</tr>
</tbody>
</table>

Values in parentheses and italics are numbers of respondents.

<table>
<thead>
<tr>
<th>Table 2 Influence of identifiable versus non-identifiable information for each class of recipient</th>
</tr>
</thead>
<tbody>
<tr>
<td>Recipient</td>
</tr>
<tr>
<td>Health professional</td>
</tr>
<tr>
<td>Health administrator</td>
</tr>
<tr>
<td>Researchers</td>
</tr>
<tr>
<td>Other organisations</td>
</tr>
</tbody>
</table>
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Fig. 1 Patient responses for sharing identifiable and non-identifiable information.

Table 3 Changes in response category for each class of recipient

<table>
<thead>
<tr>
<th>Recipient</th>
<th>Unchanged (%)</th>
<th>One category change (%)</th>
<th>Two categories change (%)</th>
<th>Other direction (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Health professional</td>
<td>61</td>
<td>28</td>
<td>8</td>
<td>3</td>
</tr>
<tr>
<td>Health administrator</td>
<td>57</td>
<td>27</td>
<td>11</td>
<td>5</td>
</tr>
<tr>
<td>Researchers</td>
<td>48</td>
<td>39</td>
<td>11</td>
<td>2</td>
</tr>
<tr>
<td>Other organisations</td>
<td>60</td>
<td>30</td>
<td>8</td>
<td>2</td>
</tr>
</tbody>
</table>

their information if it is non-identifiable, and it also illustrates that the number of responses in the 'Maybe, if asked first' category remains relatively constant. These changes could arise from different patterns of behaviour. One possibility is that the three response categories respresent a continuum of opinions and that some respondents change from 'No' to 'Maybe', and a similar sized group change from 'Maybe' to 'Yes'. The second possibility is that the changes are due to some respondents changing their responses directly from 'No' to 'Yes' (a change of two categories), whilst the cohort responding in the 'Maybe' category remains fairly stable. Table 3 presents a summary of the percentage distributions of the magnitudes of the changes in responses between sharing identifiable and non-identifiable information. These results show that the majority of the changes in attitude only result in a move from one category of response to the next which implies that the response category 'Maybe' is in fact an intermediate position on a continuum of opinion.

3.4. Detailed attitudes towards sharing information

Figs. 2 and 3 detail the percentage distributions of respondents’ willingness to share the least sensitive and the most sensitive categories of information with different recipients. The results for the other two categories of information fall consistently between these two extremes. The order of presentation of the classes is the same in both figures, which have been sorted into the order of acceptability of sharing of sensitive information. Statistical analysis of the responses confirms that the patterns were influenced by both the recipient and the nature of the information. Within each of the four categories of information the Friedman test showed that there were highly significant differences in response depending on who would be the recipient (p < .001 in each case, see Table 4 for details).

A Freidman test also showed that for all but one of the classes of recipient, there were statistically significant differences in respondents’ attitudes

Table 4 Influence of different classes of recipient for each category of information

<table>
<thead>
<tr>
<th>Category</th>
<th>N</th>
<th>Chi-square</th>
<th>d.f.</th>
<th>p</th>
</tr>
</thead>
<tbody>
<tr>
<td>General</td>
<td>154</td>
<td>541</td>
<td>10</td>
<td>&lt;.001</td>
</tr>
<tr>
<td>Current</td>
<td>123</td>
<td>585</td>
<td>11</td>
<td>&lt;.001</td>
</tr>
<tr>
<td>History</td>
<td>121</td>
<td>599</td>
<td>11</td>
<td>&lt;.001</td>
</tr>
<tr>
<td>Sensitive</td>
<td>122</td>
<td>619</td>
<td>11</td>
<td>&lt;.001</td>
</tr>
</tbody>
</table>

2 For Fig. 2, patients were not asked about their attitude towards accessing to their own general information.
Fig. 2  Patient responses for sharing general information with various classes of recipient.

Fig. 3  Patient responses for sharing sensitive information with various classes of recipient.

towards sharing different categories of information ($p < .001$ in each case, see Table 5 for details). The exception to this general pattern is that patients generally wish to have access to all categories of their own information ($N = 148$, d.f. = 2, $\chi^2 = 0$, $p = 1$).

A review of the way that individual respondents changed their answers when considering different

<table>
<thead>
<tr>
<th>Table 5</th>
<th>Influence of different categories of information for each class of recipient</th>
</tr>
</thead>
<tbody>
<tr>
<td>Recipient</td>
<td>N</td>
</tr>
<tr>
<td>Self/patient</td>
<td>148</td>
</tr>
<tr>
<td>Doctor/practice nurse</td>
<td>154</td>
</tr>
<tr>
<td>Emergency personnel</td>
<td>145</td>
</tr>
<tr>
<td>Hospital doctor</td>
<td>150</td>
</tr>
<tr>
<td>Immediate family</td>
<td>143</td>
</tr>
<tr>
<td>Receptionist/manager</td>
<td>150</td>
</tr>
<tr>
<td>Pharmacists</td>
<td>142</td>
</tr>
<tr>
<td>Researchers</td>
<td>143</td>
</tr>
<tr>
<td>Community health worker</td>
<td>141</td>
</tr>
<tr>
<td>Government health agencies</td>
<td>128</td>
</tr>
<tr>
<td>Private insurers</td>
<td>144</td>
</tr>
<tr>
<td>Other government agencies</td>
<td>143</td>
</tr>
</tbody>
</table>
categories of information found that again most responses changed by only one response category rather than by two, indicating people moved from ‘Yes’ to ‘Maybe’ and ‘Maybe’ to ‘No’. Many respondents did not change their responses between one category of information and the next, with typically 80% of respondents giving the same answer for a particular class of recipient. However, for the full spectrum of information, i.e. from general information to sensitive information, only about 60–75% of respondents held a constant attitude, with responses varying depending on the class of the recipient.

3.5. Perceived knowledge

The responses relating to the respondents’ perceptions of their knowledge about the ways that their information is used are shown in Table 6. The results indicate that very few people consider themselves to be well informed about the ways in which their information is used and that knowledge of the NHI is very limited.

<table>
<thead>
<tr>
<th>Knowledge of sharing</th>
<th>Nothing</th>
<th>Something</th>
<th>A lot</th>
</tr>
</thead>
<tbody>
<tr>
<td>Knowledge of NHI number</td>
<td>85 (43)</td>
<td>92 (47)</td>
<td>19 (10)</td>
</tr>
</tbody>
</table>

Values in parentheses are percentages.

Firstly, the acceptability of sharing information appears to be strongly influenced by the nature of the recipient. The same overall pattern can be seen to apply to all categories of information. Respondents were generally happy to consider sharing all of their information with health professionals, especially if they were consulted first, with very few refusing to share their information. The majority of respondents were willing to share their information with health administrators and researchers, particularly if they were consulted first. Respondents were least willing to share information with other organizations, with over 50% of respondents not wishing to share their information with private health insurers or with government agencies.

Secondly, there appears to be an increased reluctance to share information as it takes on a more private nature. The distributions in the graphs clearly show that there is a hierarchy of categories of information, ranging from the general demographics to the sensitive history, which people are increasingly reluctant to share with anyone other than their doctor. These general trends become more apparent as the recipient of the information becomes less involved in directly delivering healthcare. These findings are in agreement with the Share with Care project [21] which found that 32% of respondents had at least some sensitive information over which they would like particular control.

Thirdly, respondents were more willing to share their information if their identity was removed. However, 60% of respondents expressed some reservations about sharing even anonymous information with people other than health professionals. This result is similar to findings in the UK [21] and Australia [30] which identified that many people desire some control over their data even if it is anonymous. This desire contrasts with some current practices which are permitted under the privacy legislations of the UK, Australia and New Zealand [25] which do not control the use of unidentifiable data. Consequently, in the interests of patient satisfaction, it may be appropriate to modify some current information sharing policies even if they are legal.

Although the New Zealand privacy legislation recognises the right of informed choice and consent, many healthcare providers assume that patients have given implied consent by seeking their services and do not always seek further clarification when distributing patients’ health information [25]. This implied consent is clearly not
always well informed consent as this research found that many respondents consider themselves poorly
informed about the uses made of their information. This suggests that more attention should be
directed towards ensuring that patients are fully aware of current information-sharing practices and
future developments so that their implied consent can be seen to be informed. However, as Coiera and
Clarke [24] note, the process of consultation for access to information needs to be managed care-
fully so that it does not place an undue burden on health professionals.

The findings of this research have implications for the design of e-Consent systems, which enforce
access control protocols for electronic health information. Coiera and Clarke [24] provide a useful
framework for dealing with issues of consent, they identify the following four general forms of con-
sent:

1. **General consent**, where a patient is assumed to have given blanket consent for their information
to be used. This is too open a regime to meet the preferences of the respondents in this study.

2. **General consent with specific denial**, where the patient can specify limitations on the dis-
tribution of their information. This approach might be suitable for the respondents’ attitude
towards sharing their information with health professionals, but it would be less suitable for
their attitudes towards sharing information for purposes other than for delivery of care as it
would probably require a large number of specific exclusions.

3. **General denial with specific consents**, where the patient denies all access to their health
data except in particular circumstances. This approach more closely matches the respon-
dents’ attitude to sharing information with health professionals and would probably require a large number of specific consents on an ongoing basis.

4. **General denial**, where access to information requires consent on each occasion.

This approach exceeds the privacy require-
ments of the respondents and also places
significant administrative burdens on health professionals.

It might be possible to meet the needs which
were identified in this research using a hybrid model
which adopts different forms of consent for the use
of information for different purposes.

**General consent with specific denial** could be
used to define access to information by health pro-
fessionals for the provision of care. By default,
this approach would permit easy access to infor-
mation within the clinical setting, a pattern that
was found to be widely accepted in this study. How-
ever, this form would also allow patients to restrict
access to particularly sensitive information if they
desired.

A variation on the **General denial with specific consent** form could then be used to define access to
information for other purposes. By default, access
to information could be denied for all purposes
other than the provision of care unless the patient
specifically grants access. This approach would
ensure that patients were well informed about how
their information was being used. It is not clear
from the findings whether patients would prefer
such consent to be applied to a single episode of
care or for a single consent to provide more general
access to their information, and this issue needs
further investigation. If some general consent is
provided in this way, it should not be applied to
any information for which a specific denial has pre-
viously been defined.

Since the implementation of e-Consent systems
is a relatively new area of research, further work is
needed to explore the practical implications of this
hybrid model.

### 5. Conclusions

In conclusion, these results indicate that many respondents would like limitations to be placed on
the distribution of their personal information par-
icularly for purposes other than clinical care. How-
ever, respondents’ views vary widely and are influ-
enced by several factors, this implies that it will
be difficult to define a simple protocol for sharing
information which can achieve widespread accep-
tance. This paper proposes a hybrid model of con-
sent in which the way in which consent is obtained
varies depending on the proposed use of the infor-
mation.

A sizeable proportion of the respondents indi-
cated that they would like to be consulted
before their information is released. However, the
research did not explore patients’ views about how
or when such consultation should occur and fur-
ther research should be undertaken clarify what is
required.

The results also indicate that patients are more
likely to agree to the distribution of their infor-
mation if their identity is removed. However, the
study did not explore the extent to which patients
would like their identity hidden or removed from
the information, the questionnaire only mentioned
removing names and addresses. Given the gen-
eral lack of knowledge about the NHI number, it is unclear whether patients would want their NHI number to be removed or encrypted as well. Further research should be undertaken to explore the extent to which patients would like their identity to be removed from or disguised within information which is used for purposes other than for their direct medical care.

These findings support the need to incorporate sophisticated and flexible access control mechanisms, such as e-Consent systems, into future information systems so that they may be adapted to meet the preferences of individual patients. Further research is needed to clarify the attitudes of patients towards the use of their information, the findings could then inform the development of future policies and protocols to ensure that these will meet the requirements of patients as well as the other stakeholders. Failure to meet patients’ privacy requirements could have a variety of unfavourable consequences, including, a reduction of trust in the patient–doctor relationship; increased concerns about confidentiality, privacy and security of personal health information; incomplete or inaccurate information being stored in shared records. Ultimately, the result of these problems may be a failure to achieve the expected gains in efficiency and effectiveness of healthcare which are expected to arise from the investment in integrated health information systems.

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Appendix A. Questionnaire in condensed format

1.1 My age is completed years: 18 to 30 years 30 to 60 years More than 60 years

1.2 Sex: Male Female

1.3 If you tick one or more boxes for this question, your ethnicity is:
   - New Zealand European
   - Tongan
   - Maori
   - Niuean
   - Samoan
   - Chinese
   - Cook Island Maori
   - Indian
   - Other (such as Dutch, Japanese, Tokelauan). Please state:

For each of the following questions please answer by ticking one box only on each answer line:

1.4 How much do you know about who can see part or all of your medical records?
   - Nothing
   - Something
   - A lot

1.5 What do you know about the National Health Index (NHI) number?
   - Nothing
   - Something
   - A lot

1.6 I am happy for all of my personal health information to be shared by the following groups of people as long as the information is non-identifiable i.e. it does NOT contain my name, address etc.: Health professionals: (e.g. doctors) Yes Maybe, if asked first No Don’t know
   - Health administrators: (e.g. managers) Yes Maybe, if asked first No Don’t know
   - Researchers: Yes Maybe, if asked first No Don’t know
   - Other organisations: (e.g. insurers) Yes Maybe, if asked first No Don’t know

1.7.1 I am happy with all of my identifiable (i.e. with name and address etc.) personal health information being shared between:
   - Health professionals: (e.g. doctors) Yes Maybe, if asked first No Don’t know
   - Health administrators: (e.g. managers) Yes Maybe, if asked first No Don’t know
   - Researchers: Yes Maybe, if asked first No Don’t know
   - Other organisations: (e.g. insurers) Yes Maybe, if asked first No Don’t know

Please complete the following table by placing a mark in each box as follows:

✓ (for ‘YES’)
X (for ‘NO’)
† (for ‘Maybe, if asked first’)
— (if you don’t know or do not want to answer):
### A.1. General information

<table>
<thead>
<tr>
<th>General information e.g. name, address, occupation, NHI number, etc.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Immediate family members</td>
</tr>
<tr>
<td>Doctor/practice nurse at GP practice</td>
</tr>
<tr>
<td>Receptionist/Manager for GP practice</td>
</tr>
<tr>
<td>Hospital doctor/specialist/other GP (not your own)</td>
</tr>
<tr>
<td>Emergency personnel</td>
</tr>
<tr>
<td>Pharmacists</td>
</tr>
<tr>
<td>Community healthcare workers</td>
</tr>
<tr>
<td>Government health agencies (e.g. ACC)</td>
</tr>
<tr>
<td>Other Government agencies (e.g. WINZ, Police)</td>
</tr>
<tr>
<td>Healthcare researchers</td>
</tr>
<tr>
<td>Private health insurers</td>
</tr>
</tbody>
</table>

### A.2. Identifiable personal health information

<table>
<thead>
<tr>
<th>Limited information about your current health problem:</th>
<th>Limited past medical health information:</th>
<th>Full current and past medical health information (with sensitive information):</th>
</tr>
</thead>
<tbody>
<tr>
<td>e.g. type of treatment, type of condition, EXCLUDING problems that you consider to be potentially sensitive such as sexually transmitted diseases, mental health, etc.</td>
<td>Only your limited past medical/surgical history, EXCLUDING problems that you consider to be potentially sensitive such as sexually transmitted diseases, mental health, etc.</td>
<td>ALL your current and past medical/surgical history, INCLUDING problems that you consider to be potentially sensitive such as sexually transmitted diseases, mental health, etc.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Self</th>
</tr>
</thead>
<tbody>
<tr>
<td>Immediate family members</td>
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</tr>
<tr>
<td>Healthcare researchers</td>
</tr>
<tr>
<td>Private health insurers</td>
</tr>
</tbody>
</table>

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If you have anything further you would like to say about who can see your medical records, please write it on this page.

Thank you for taking the time to participate in this research project.
Patients’ attitudes towards sharing their health information

References