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24. PRIVACY ISSUES OF ELECTRONIC MEDICAL RECORDS FROM THE PATIENT'S PERSPECTIVE

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Abstract

This research was aimed on addressing patients' perspective in medical field. A self-selection questionnaire was developed and distributed among patients at selected healthcare providers. Specifically we wanted to evaluate patients' opinions in big cities. From the results we have found that participants in both environments (big cities v rural regions) exhibit similar attitudes towards the security of their medical records. Habitants of big cities demonstrated higher trust in the Electronic Medical Records (EMR) which was presumably related to being more electronically adept.

Keywords

Privacy, Electronic Medical Records, Health Information Systems.

1. Introduction

Not much is known about the patient perspective in regards to the use of EMR. Although the benefits have been well researched as to what the healthcare sector thinks, the patients have generally been ignored (Sankar et al., 2003, Ryan & Boustead, 2004, Walsh, 2004, Whiddett et al., 2006, Bomba & de Silva, 2001).

Little knowledge has been dispersed to the general public which has caused a lack identity at who is responsible with their medical record. Rindfleisch, 1997 stated that the responsibility falls upon the healthcare provider and the doctors to protect the medical record. This may be quite a load on the doctors but in the results obtained from this research doctors were primarily seen as the responsible party above all other parties. This does not deviate greatly from previous research.

This is no different with the topic asking if patients know, or do not know, what is within their medical record (Hunter, 2003). There have not been many previous studies which have asked this very question. Firstly, the main problem that needs to be considered is that the definition of EMR and even normal medical records are not adequately explained and described. As such, it is hard to know if you understand something if you cannot even begin to define it. Therefore it is assumed that since the definition lack clarity, patients do not know what is in their medical records. One study that did ask this question found that "no one knew exactly what was stored in the medical record" (Hunter, 2003).

The lack of previous research continues to haunt the hypotheses as there is little about the patients' knowledge or preference towards EMRs. Due to New Zealand's high level of computerization (Didham et al., 2004), the prevalent technology used is the electronic records. That may reflect in the patients' opinions.

As well as knowledge of which system is used, patient preference and views on security have been poorly documented. Although there have been much studies commenting on the high costs of implementing EMRs, this can be seen as a provider problem rather than a patient problem. One study done by Chhanabhai & Holt (2006) mentioned that patients, in general, don't look too highly on EMRs and are apprehensive about digitization.

A question that has never been covered in past studies, here and abroad, is whether the participants know how much of their medical record they can change. As the general population has (presumably) poor knowledge of this, it is assumed that participants perceive they have low control over the change that they can do to their medical record.

A general consensus among previous studies has been that patients always seem to have a fear of their medical information being leaked. In an article written by Endsley et al. (2006), they stated that 91% of American patients were worried about the privacy of the medical information. This is an overwhelming portion of the public which makes privacy a key issue. Also, an interesting question is how this fear spreads among the generations.

Patients' perception on the length of time that their medical record is held for is also lacking. Usually patients assume that their information is held for their lifetime.

Everybody is interested what his/her medical record contains. But a related question is not very often tested: Whether the younger or older generations want to access their medical records online. The younger generation has grown up surrounded by technology and thus learn to use it at an early age. The older generation is introduced to this technology later in life when their ability to learn is diminished compared to that of the younger people.

The processes of collection, storage, and access have all eluded the patients as they possibly see it as secure anyway or not necessary to know. In fact Hunter (2003) mentioned that most people have no idea what kind of security measures are in place put their trust in the healthcare professionals to ensure good security.

Certain professions have always been under scrutiny on the way they have handled medical information. Others are trusted with almost every aspect whereas others are explicitly forbidden access. Governmental agencies have always been questioned about the power they have in regards to personal information. Medical records are no different. Whiddett et al. (2006) stated that 84% of doctors said that government collection of information will cause privacy issues and threaten its safety. As such, there is a slight unwillingness to share with government agencies. Of course, this is from a doctor's perspective but what does the greater population of patients think.

Whiddett et al. (2006) also mentioned that patients are more willing to share their information with health professionals than researchers. In this context, we have simplified the term „health professional” to mean: the doctor. Doctors are a lot more active with a patients' care as well as more visible. Researchers on the other hand are typically not as visible to a patient and even if they are researching for a large-scale future good, there may be little benefit for the current patient.

It was said that patients are less willing to share information with people who they cannot identify (Whiddett et al. 2006). These would be professions which are not directly involved with the patients' care. In the case of the directly-involved group, we chose the Doctors,

Surgeons, and Nurses as we thought these professions were most „visible to patients as these are the people that advise them over their health condition.

Lastly, there is a question involving couriers and other handlers of medical records. These people have no right accessing a patients' personal medical record for any reason unless given proper consent. This question has not been asked in previous research possibly due to its very obvious nature. But when considered, that is the point of this question. It is to establish a “base” in which other results can be compared to or to see if the sample can be „trusted”.

This paper presents the research problems related to the patients' perception of EMR, formulates the research hypotheses, outlines the research methodology, presents the results, and comments on it.

2. Research Problems

Listing of gaps in the field of EMR identified above allowed us to formulate a numbers of research questions. The full discussion of these questions is presented in (Chan, 2008).

- H1:** When given a list of professions and groups, patients will mostly perceive that responsibility of their medical record is in the hands of their doctors.
- H2:** Patients believe they do not know what is contained within their own medical record.
- H3:** According to the patients, electronic record systems are used in the healthcare provider.
- H4:** Patients believe they cannot change anything in their record.
- H5:** According to the patients, physical paper records are preferred to electronic records.
- H6:** According to the patients, physical records are more secure than electronic records.
- H7:** Patients do have a fear of their medical information leaking.
- H8:** What causes the fear that medical information will be leaked?
- H9:** Patients feel that medical information is safe within New Zealand.
- H10:** Patients believe that their medical information will be held indefinitely.
- H11:** Patients have not heard about the Privacy Act and Health Information Privacy Code.
- H12:** Of the patients that have heard of the laws, they know very little of the details.
- H13:** Patients feel their privacy is adequately protected by the current privacy laws.
- H14:** Younger patients have less knowledge of privacy legislation in New Zealand when compared to the older patients.
- H15:** The younger generation of patients has more desire to access their records online.
- H16:** Patients have no knowledge of the medical information collection procedures.
- H17:** Patients would like to know the medical information collection procedures.
- H18:** Patients have no knowledge of how, who and where their medical information is stored.
- H19:** Patients would like to know who stores their medical information.
- H20:** Patients have no knowledge of who has access to their medical information.
- H21:** Patients would like to know who has access to their medical information.
- H22:** Patients do not want to give government agencies access to their medical records
- H23:** Patients would rather give doctors access to their medical records than researchers
- H24:** Patients would rather give professions that are directly involved (e.g. doctor/surgeon, nurse) with the patient care access to their medical records
- H25:** Patients do not want to give couriers and other patients access to their medical records

3. Research Methodology

The context of this research was done within the environment of a healthcare provider. The logic behind this is that when choosing participants who are currently in contact with the healthcare system as it is now, they will have more fresh, specific and detailed knowledge of the problem in their minds. Patients of all ages were sought after as a range of opinions would greatly improve the generality of the data collected. Age and Gender was not discriminated against. There was no favouritism or pressure towards any gender or age as it was a choice of the potential participants to fill out the „Self-Selection” questionnaire or not. Also it is important to note that this study was intended of a verification type. There have been studies done of this type within the New Zealand environment but it has been done in smaller cities (Whiddett et al., 2006, Ryan & Boustead, 2004). As no study of this type has been done within Auckland, this study is seen as a confirmation of the previous results for New Zealand’s largest and arguably most representative city.

The data collection tool was a questionnaire which was designed to be completed within 30 minutes. The questionnaires were distributed to four different healthcare providers and then asked for consent from either the Practice Manager or Head Doctor. When consent was given, the questionnaires were passed out to the receptionists in the selected healthcare providers who subsequently distributed among the patients. The receptionists were asked to offer the questionnaire to all of the patients who attended the clinics, regardless. In total, 100 questionnaires were provided to the healthcare providers to give to potential participants. We received back 37 questionnaires. This relatively low response rate could relate back to the small window of time (3 weeks) given to each healthcare provider to pass out the questionnaires. In addition to this, the length of the questionnaire could have been a major deterrent in accepting to participate. Prior to finding four willing healthcare providers, we approached many but were rejected and one of the main reasons was the length of the questionnaire.

The use of four healthcare providers was both a practical decision as well as for the desired variety of responses. Practically the research was easier to perform as the collection tasks were divided up for each researcher to perform. Different providers in different geographical locations within Auckland would attract different types of people usually due to the close proximity to their homes. In splitting up the samples to four different providers, the total sample aims to try and capture the diversity of the general population.

The questionnaire was split into three major sections which were:

- General Knowledge about EMR
- Knowledge of the Law related to EMR
- Patients’ Wants

The questionnaire also ended up with a small demographics section asking for the patients’ gender and age.

The returned questionnaires were entered into a Microsoft Excel spreadsheet for easier processing. All the answers and comments were directly entered as they were recorded or noted on the questionnaire sheets to preserve the heart of each answer or comment. In addition to this, the data was entered into SPSS for statistical analysis. It was found that of all the cells possible in the data (4699 cells) there were a total of 459 missing values. As this totals to be 9.8% of the total data, the missing data can be safely ignored or replaced. The

main problem seems to stem from two entries, where 75.2% and 62.3% of their data missing. A remedy for this could be the removal of these entries.

4. Results and commentary

The purpose of this study was to find out the patients perceptions on medical records and its privacy. This was done through a survey of patients at healthcare providers. A set of hypotheses were created to test the survey data and the results were gathered. Full discussion of the results is presented in (Chan, 2008). In this part of the paper we are outlining the major findings related to the key research questions listed earlier in the text.

Although the benefits of using EMR have been well researched as to what the healthcare sector thinks, the patients have generally been ignored. As it was said before, due to this we have made the assumption that because of New Zealand's high level of computerization, the prevalent technology used is the electronic records. This is further backed up when the patients were asked what system they believed their healthcare provider was using. Around 69% of the participants mentioned that their providers used electronic systems.

Closely related to this are the issues of patient preference (traditional or electronic records) and their views on security (both of which have been poorly documented). From the previous studies we learned that patients, in general, don't look too highly on EMRs and are apprehensive about digitization (Chhanabhai & Holt 2006). It comes as a surprise then to see that the study results have shown that 81% of the participants preferred electronic records over the physical records. This is at odds with previous research and maybe seen as a change of attitude towards the „new” system. People may be starting to warm to the new electronic system more than when previous research indicated or it could possibly be due to an unknown geographical reason specific to Auckland.

The same percentage of patients believed that electronic records were more secure than the traditional system. As no previous studies have asked this question, it is hard to prove whether this percentage has grown or not. A possible cause could be that many patients have suffered complications or problems with their providers using the traditional system that in turn lowered their perceived security of it.

Lack of the logistics of handling patients' records was also confirmed by our research. The logical conclusion could be that the participants would perceive they have low or no control over the change that they can do to their medical record. Data collected from this research has shown that this isn't the case. A majority of patients believe they can actually alter their medical record (which they can). Even so, a third of the participants conformed to this hypothesis which can be seen as substantial. Generally, the most known fear in relation to medical records is the fear of leaking. This may result from the above mentioned fact that there is a lack of the knowledge of medical records handling logistics. Oddly enough, the opposite can be said of the opinions of participants within this study. The bulk of the respondents (68%) said that they were not scared of their information being leaked. This is hard to believe and departs from previous studies. This could come down to the fact that a majority of the patients surveyed were older than 40. It is well known that the older generation are more trusting than that the younger generation and this could be evidence of this. They would also have less knowledge of the dangers of using electronic systems as they generally have less contact with it. Another point that can be made is that this study is done in New Zealand. It has been shown previously that the New Zealand culture is much more laid-

back and trusting of others. This could contribute to the low level of fear. In more detailed analysis we can see that a majority of the older generation (77%) did not fear for the privacy of the medical information. For the younger generation, due to the smaller sample size, it is harder to tell. Although the majority did fear some kind of leak (54%), the difference is not large. This could be the beginnings of evidence that the younger generation are less trusting, but more samples need to be obtained. Statistically, it is shown that there is some evidence against there being similar results between older and younger generations (P-Value = 0.068).

Even with the low level of fear, something must trigger this fear in the participants who did say they were scared of leakage. Although much research have queried the patients about whether they fear for the privacy of the medical information or not, there has not been the question of what causes this fear. There were three main fears that emerged when the participants were asked what causes the fear. They were information falling into the wrong hands, future problems, and the openness of electronic systems. The first fear was that their personal medical information would fall into the wrong hands. This information is very personal and patients wish that their information to be only given to those who definitely need it. The next fear falls in line with the patients' future aspirations. They fear that an unauthorized leak of information may cause future employment issues which could limit their job options. Similar to this is also the adverse affect it may have on the patients' social status and their future social situations. Lastly is the perceived problem of openness. There is a perception that when using an electronic system, it can easily be „hacked by outside intruders and they can gain unlawful access. This is what is meant by openness, the ease at which someone in another geographical location can access what is not theirs. These can be seen as typical problems where personal information must be protected from hackers using their information to negatively affect their future.

Typically, in this field of research, there has not been much done within the New Zealand context. And because of this, it is hard to compare the results of this research to any previous work. When looking at the data collected, we can see that 70.6% of the participants believed that medical records were safe within New Zealand. This is roughly equivalent to the amount of people who did not fear information being leaked (68%). Again, this could come down to the trusting nature of the New Zealand culture or the dispersion of age within the participants. This can be an encouraging sign, as a participant would not think that their records are safe if some negative event involving their medical record privacy had occurred. It would be safe to say that with the high belief of safety, the providers are adequately protecting the records in the eyes of the patients.

Patients usually are not aware how long their medical record could be stored for. An answer to this question could enlighten us about the patients. knowledge of the Privacy Act or HIPC, as the actual period of time held is mentioned within them. As the results showed, almost all of the patients thought that their medical information was held for long periods of time. This is understandable as patients may assume that their information is held for their lifetime. Oddly, there was one respondent who thought that their medical information is never held at all.

There is very little previous research done on knowledge of the privacy regulation within New Zealand especially in the relation to medical records. Our general hypothesis was that this knowledge is low. The participants were asked whether they had heard of the Privacy Act 1993 or the Health Information Privacy Code 1993 (HIPC). Contrary to the hypothesis made, 75% of the patients had heard of the Privacy Act. So a basic, possibly vague recognition of

the act was found. This hazy understanding is evident when asked what was actually contained within the Privacy Act. Of the participants who mentioned that they had heard of the Privacy Act, a significant 60% could not mention anything that was contained within it. The prevalence of the Privacy Act in media articles could possibly contribute to the high levels of acknowledgement of the act, but low levels of actual comprehension of the law.

Unfortunately the same results were not found about the HIPC. Even with the relatively poor familiarity with the Privacy Act, the results with HIPC knowledge were even more inferior. Around 10% of participants had heard of the HIPC but none could detail any of its contents. These findings could be due to the fact that the HIPC does not get as much media coverage as the Privacy Act and therefore is less well-known. As people generally do not actively go in search for new legislations, the HIPC could then be confined to a life of less recognition compared to its older sibling, the Privacy Act. Although specific knowledge is poor, what maybe more important is the feeling of security the patients feel from these implemented laws. The results were not highly conclusive as a majority of the respondents mentioned that their medical records were protected "Adequately" with the current legislation. Although there is a very slight lean towards patients' perceiving their information to be well protected, it is hard to say whether this is just sampling bias or a true representation of the population.

It has always been said that the young and old do not think alike. In this research, this is put to the test as we hypothesized that the knowledge of privacy legislation and attitudes towards online access of records are affected by the age group they belong to. We assumed: young: <20 years old, old: 60+ years old. A finding from the Australian Privacy Commission annual report (The Wallis Group, 2007) was that the older generation was found to have more knowledge of privacy laws than the younger participants. The reasoning of this question being asked in this research was to see if the same results can be replicated. We assumed they will as New Zealand and Australia are situated in close proximity to each other and show a similar culture. This data is seemingly replicated with the results gained from this research. The „old" age bracket has a substantially larger group who has heard of the Privacy Act, around 84%, compared to that of the „young" age bracket which was around 55%. This could mean that the older generation does have a better „general" knowledge of privacy laws than the younger generation. One must remember that due to the small sample size, the results may not completely represent the full picture. What needs to be done is to collect more samples of patients in the „young" age bracket to allow for more accurate results. When considering just the HIPC, the results are a lot more equal. Even if, statistically, the results showed that there was no evidence against the two age brackets being different it is interesting to note that of the small group of patients who had heard of the HIPC, they all belonged to the „old" age bracket. This could be the subtle beginnings of the older generation knowing more, even about the unfamiliar HIPC. What are needed are more samples to either prove or disprove this. When the responses for both Privacy Act and HIPC are combined, it shows that there is no evidence against there being a difference between the groups. As such, these sets of results show that there may not be the same difference experienced in Australia amongst the old and young as in New Zealand. This is interesting as the HIPC results have a seemingly large effect of the outcome due to its relatively similar results for both age groups. Again, what are needed are more samples to bolster the accuracy of the results.

Perhaps more predictable were results related to the issue of whether the younger or older generations want to access their medical records online. The younger generation has grown up surrounded by technology and thus learns to use it at an early age. The older generation is introduced to this technology at an older age where their ability to learn is diminished

compared to that of the younger people. This serves as a basis for the hypothesis which questions which generation has more desire to access their records online. Percentage-wise, the younger generation seems to have great desire for online access in which 91% said they would like access compared to that of the older generation which was only 45%. Statistically, there seems to be strong evidence against the null hypothesis and that means that it is very likely that the groups are not the same ($P\text{-Value} = 0.012$). As such, this would mean that there is a difference between the opinions of the young and old generation in regards to the desire to access their records online. This difference in attitude towards the technology can be seen every day. Although this is rather extreme and that not all people classified in the „older” generation reject and fear technology, it adequately represents the sample in this study.

Information about the perception of how the medical records are collected, store and accessed brought the following results: Of the three procedures, the percentage claiming that they knew the procedural information ranged from about 8% to 19%. This is low compared to the percentages that associated importance of privacy to these phases, ranging from 85% to 94%. It is odd that with such poorly informed patients and such high importance placed on privacy that this information is not more actively sought after. It is even more surprising that the providers are not doing what they are obliged to do and inform the patients of collection, storage, and access procedures. This might not be the complete picture as well. It may so happen that it is human memory at fault as this information is expected to be explained once and only once and as such, gets forgotten through time. Another problem is that the knowledge that the participants say they have of the procedures may not be what we are thinking of. Collection, storage, and access procedures are all very broad definitions which can be taken in very different ways. It is not clear if they know what the procedures are, even if they stated they did, as there was no follow up question asking what they actually know. So because of this, we must take their word and assume they do actually know, if they stated so.

Obviously, the doctors should be responsible for handling medical records and the research confirmed that (94.6%). Governmental agencies have always been questioned about the power they have in regards to personal information, and our survey confirmed that only 37% of patient would, accept that. Doctors are a lot more active with a patients care as well as more visible. Researchers on the other hand are typically not as visible to a patient and even if they are researching for a large-scale future good, there may be little benefit for the current patient. As such, the participants of this questionnaire gave big differences in the responses between doctors and researchers. Whereas participants almost unanimously thought that doctors should have viewing and access rights to their medical records, only below 20% said that researchers should have those same rights. As mentioned before, the doctors are more likely to be given access than researchers based on the data collected in this study. This is possibly due to the reasons given above where the doctors are more active in the patients care and is „visible” compared to that of researchers.

On the topic of being „visible”, we reiterate our next hypothesis about patients’ willingness to share information with people who they can identify (Doctors, Surgeons, and Nurses) and lack of that with those not directly involved with the patients’ care (Administrative Staff, Receptionist, and Researchers). Although they may have some direct contact with the patients for other purposes, they would not normally give patients healthcare advice. The results show that the directly-involved group have higher acceptance by patients for access to their medical records. Even when taking the average percentages of each profession from both groups, the directly-involved group average percentage dwarfs the non-directly involved group, 82% to 20.7%. This large difference is evidence that directly-involved professions

tend to have much better acceptance to access patient medical records than other not-so-involved professions.

Finally there was a hypothesis involving couriers and other people who have no right accessing a patients' personal medical record for any reason unless given proper consent. All of the participants believed the courier and other people should not have viewing and access rights to their medical record. This is as expected as allowing access to untrustworthy people seemingly removes all security measures put in place. The part that is of interest is the question of consent. Between 80% and 85% said that couriers and other people needed to seek their consent before being allowed to view their record. The surprising part is that this value is not higher as all previous answers were all unanimous in saying that these two groups should not be allowed to view or access their medical record. The question itself may have been misunderstood by the participants. Maybe the participants thought that since they have already stated that these groups should not gain access, they assumed that they would not need to ask as they will just be denied. This is just pure speculation with no proof or evidence though.

This research has tried to replicate the results found in previous, albeit sparse, research. On top of this, this research has included extra questions which have not been asked before and tried to bring about new knowledge in the field of patient perspective in EMR. What has been found has been quite similar to previous research as well as finding completely new information. Differences have also been experienced which could bring about new future research.

Privacy has been a key issue throughout the EMR development stage but currently fails to adequately make patients feel as if they are safe. When patients do not feel sufficiently protected by these systems or laws, they will not revealed as much information as they would if they trusted the system/law from fear of improper disclosure. This could unwillingly lead to harm the patient in the long-term which is not in the best interests of anyone. But this study has suggested that this is possibly not an issue anymore. There is a high preference for the electronic system and a high belief that the electronic system is more secure which seemingly contradicts all previous research. This preference for electronic systems is a huge boost for providers to implement EMRs, if they are not already doing so. Perhaps the biggest indication is that the participants generally feel their medical record is safe within New Zealand. Although slightly contradicted by the fact that the same participants also fear their information leaking, this could be a sign of the changing times. The feeling of safety within a nation in which supposedly 52% of healthcare providers have implemented EMRs may mean that the fear of the electronic era is slowly disappearing and that EMRs, although still generally unknown, are becoming accepted.

This is only speculation and therefore calls for more research to be done to either prove or disprove this casual remark.

5. Limitations, Reliability and Validity

A major issue that may spring out is a small sample size. In total there were only 37 collected questionnaires which can be seen as quite small. The small number of samples could have a major effect on the effectiveness of the tests performed. As mentioned by the Chi-Square test, there were many occasions where the effectiveness of the tests could have been compromised due to the small sample sizes. Another issue that comes from the poor sample size is the

problem of generalization. As mentioned by Lee & Baskerville (2003), they found that a “small sample size limits ability to generalize”. It is hard to be able to generalize the data collected to an entire population when this population is only represented by a few.

There was mention in the previous research of Sankar et al. (2003) that most patient perspective studies are done with the „vulnerable” section of the population. Although they still give valid results, these may not be stretched to cover the entire population due to the possible different views on sensitive information. It may be best to get a more general random population for future tests.

Small sample size may also limit the reliability and validity of the research. Questions which this was evident were the set of “young” vs. “old”. There were only 30% participants who were deemed „young” and as the results showed, there were not enough to distinguish a clear cut answer. It maybe so that there isn’t a clear cut answer, but with more sample we can determine this. There were problems with the small sample size affecting the effectiveness of the Chi-Square tests performed as there is a required minimum 5 samples per cell which was not adhered to.

There were also problems with missing values. This seemed to trace back to two participants who had over 80% of their answers missing. „Missing” in this sense simply means that they had not entered any values for the question. It may mean that they did not understand the question or that they did not have time to fill it out. Either way, there is not value there to use. So the data collected may be quite valid, but the reliability would need to be strengthening for this to be more definitive.

6. Conclusion and Future Research

Currently most information is being digitized. Although there may be a large cost that is necessary for conversion, in the long-run it is usually worth it. EMR’s are inevitable. As much as this is true, the speed at which it is moving makes it seem as it will never happen. It is hard to comprehend that with the medical field being so information intensive as it is, that the lag can be so bad when compared with, say the banking environment. It is rather paradoxical that although their job is to save lives, by being so lax or even rejecting the EMR systems, more lives could be lost. But not all the benefits are just about saving lives, there are also the more mundane issues like costs and time. The introduction of EMR systems can bring about a better quality of care, which in turn can bring down the currently exceptionally high medical error cost. With all the benefits such as lower costs and more importantly, saving lives, you would think otherwise.

But in order to benefit from such advantages, there must be a large initial investment in order to set up the necessary steps. This is usually too much for small clinics and because of this; EMR.s can seem to be only applicable and feasible for larger firms. What is more worrying though is the fact that even when a hospital can afford it, the nation as a whole cannot support it. Legislation is generally lacking in most countries, especially in the U.S. where there seems to be just a perplexing amalgamation of different state laws and federal laws, not one for the nation. With this lack or just confusion of regulation, patients are worried over the safety of their private information. Lack of knowledge and a tacit lack of government protection have caused such a precarious situation. As such people tend to hold back when revealing information which removes some of the benefits of converting to EMR.

What can be seen is that government has a large role to play in the further adoption of EMR systems. The effectiveness of EMRs and privacy legislation is seen to go hand in hand. Within New Zealand, the legislation is said to be highly effective in encouraging the use of electronic IS (Whiddett et al, 2006) and it shows as New Zealand is said to be second only to the U.K. in EMR use (Chhanabhai & Holt, 2006). The results in this study have shown that a majority feel that their medical information is safe and adequately protected by the New Zealand legislation. As established many times before, the security of patients' medical information is one of the key factors in further adoption.

What the problem is that privacy is a "people problem" and as such can only be solved by something that targets the people. Technology can support this, but the main problem is in education and legislation. Without the knowledge, people can't see the problem or solution, but without the legislation, people don't have the protection they so desperately want. Legislation needs to improve in order for the lives of patients to be safe.

In the results of the study performed in this research, it found many similarities to previous research on which this study has built upon. But there were some glaring differences which could be seen as the beginnings of a change. The concept of performing all the current medical record procedures electronically has always been met with distant optimism by both providers and patients. There has always been a slight mistrust in the electronic devices, so much so that it has seemingly slowed EMR adoption. But this seems to be changing. From the results gathered, patients seem to prefer and believe that electronic systems are better which disagrees with previous research. This research has found that, although there is still a poor knowledge of medical records in general, there is a desire to know more. As well as this, young and old have been found to have slightly different views on medical records as well as online access.

One participant appropriately summed up the possible perceptions of all people about privacy of medical information in a comment left on a questionnaire. "I realize I've made a lot of assumptions in the past. These questions have made me think!". The participants in general do not have much knowledge of medical records and as such make assumptions to aid their understanding.

The same participant continued with the poignant comment saying that "After working in the education sector I have worried about how flippant or easy records could be accessed relating to health issues, by some office staff. Thus I also have thought about with regards to [Doctor's] staff „code of conduct/ethics.". With the current paper record system that most providers are using, this may be the case. An office member can easily flip through someone's record and replace it with ease. It is true that having a „code of conduct" or legislation can mildly prevent this, but the introduction of EMRs can further assist this by having access controls which block access. This further supports the idea that legislation alone cannot adequately protect privacy. But the opposite is true as well as EMR systems and technology by itself cannot fully protect privacy too. But these should, by no means, be taken as true facts. At least the results should be used as a comparison for other research.

Currently, as this is seen as a small study, it is possibly implicitly said that this will lead, and may be the base of, more studies in the future. As legislation is seen as highly important to the future of EMRs, much more research needs to be done within this field to possibly find what is needed to boost the diffusion of knowledge as well as what knowledge is currently understood. Currently health privacy legislation is slowing down which is showing a

maturing of the law. At this stage, a more stable future for this may aid in its better propagation.

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Appendix 1

Descriptive Statistics of the Major Results

Note: All the answers indicate percentage

Age Group	%
Under 20	0.0
20-30	33.3
30-40	12.1
40-50	12.1
50-60	18.2
Over 60	24.2

Figure A1. Age Demographics

Question	Yes	No
Do you know what is contained in your medical record?	51.4	48.6
Would you like to know more about your record?	59.5	40.5
Do you think it is necessary to keep your medical record confidential?	88.9	11.1

Figure A2. General Information

Question	Physical	Electronic
Do you know what system your current healthcare provider uses?	31.0	69.0
Which system do you prefer?	19.4	80.6
Which system do you think is more secure?	19.2	80.8

Figure A3. Physical or Electronic?

Question	Yes	No
Are you afraid that your medical information could be leaked?	32.4	67.6
Do you think that medical records are safe in NZ?	70.6	29.4
Would you like to access your medical record online?	56.8	43.2

Figure A4. Safety of Records

Question	Yes	No
In relation to your healthcare provider, do you know what their procedures are when it comes to medical information collection?	13.5	86.5
Would you like to be informed of who collects your information?	73.0	27.0
Do you know how your medical information is stored?	18.9	81.1
Do you know who does this process?	8.1	91.9
Do you know where your medical information is stored?	8.1	91.9
Would you like to be informed of who stores your information?	68.6	31.4
Do you know who has access to your medical information?	13.9	86.1
Would you like to be informed of who accesses your information?	86.1	13.9
Do you know how long your medical information is stored for?	5.9	94.1
Would you like to be informed of how long your information is stored for?	82.9	17.1
Would you like to change the time limit?	26.9	73.1

Figure A5. Knowledge of Procedures

Question	Yes	No
Have you been properly informed when medical information has been collected from you?	39.4	60.6
Have you been told of the purpose of the medical information collection?	30.3	69.7
If so, have you been told who the intended recipients are?	18.8	81.3
Have you been given contact details of the agency collecting the information?	8.8	91.2
Have you been given contact details of the agency storing the information?	9.1	90.9
Have you been told how to access your collected medical information?	2.9	97.1
Have you been told that you can correct your medical record?	11.4	88.6
Have you done so before?	2.9	97.1
Have you ever been contacted about checking the validity of this information?	5.7	94.3
Have you ever been asked for access to your medical record for research?	8.3	91.7
Have you ever been asked for disclosure of your medical information?	22.9	77.1
Do you know the complaints procedure if you think your privacy has been breached?	17.1	82.9

Figure A6. Legal Requirements

Question	Yes	No
Have you heard about the Privacy Act 1993?	75.0	25.0
Have you heard of the Health Information Privacy Code 1994?	10.8	89.2

Figure A7. Knowledge of Privacy laws

Profession	Number agreeing
Your Doctor	94.6
Nurses	48.6
Diagnostic Staff	48.6
Surgeons	45.9
Administrative Staff	37.8
Government	37.8
Receptionist	37.8
Your Doctor's Colleagues	29.7
Courier used to move your information	27.0
Researchers	18.9
Other Patients	0.0

Figure A8. Responsibility of Medical Records