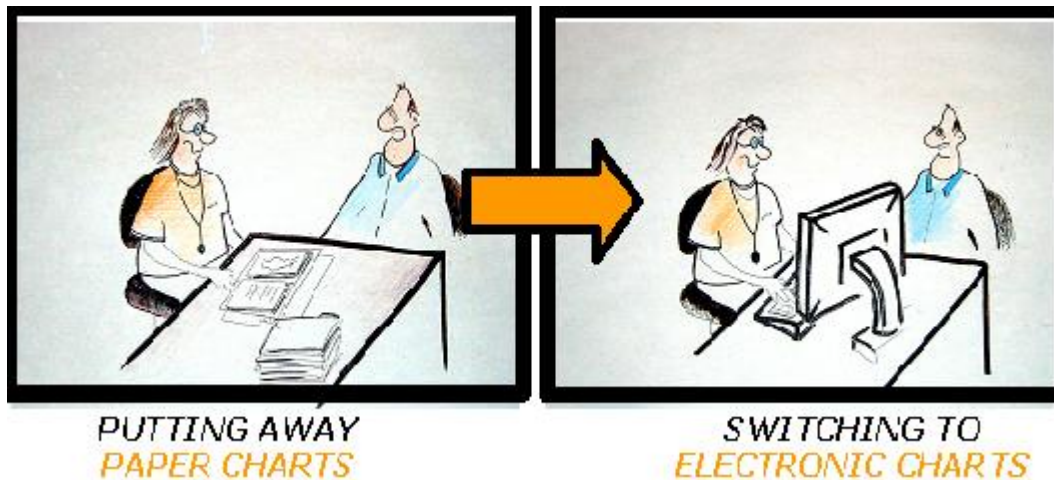


**CASE STUDY: MID-MAIN MEETS THE EPR**

**RESULTS FROM THE PRE-EMR PATIENT INTERVIEWS**

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**FIELDWORK SUMMARY- PHASE 1**

- Timeframe of interviews: 10<sup>th</sup> Nov 2004 – 15<sup>th</sup> Dec 2004.
- Consisted of: 5 “rounds/sessions” of interviews (each Wednesday).
  - In total: 22 interviews (duration varies from 10-45 min.).
  - Each interview was recorded after receiving verbal consent from each patient.
  - The material in this report is based on 16 of 22 interviews that have been transcribed thus far (interviewees names were not requested and all information has been handled in confidence).
  - Time spent in the field: ~12 hours.
- Only 4 patients refused to be interviewed (one was a student studying for his exam, the other one did not speak English, the third one was in too much pain, and finally the last one explained that she had been waiting for a long time...).
- Patient demographics vary. Ages: 17-76 years old. The fieldwork includes a broad population, from students, patients with different occupations, patients with disabilities or retired patients.
- Observations followed each session in order to explore and acquire more knowledge about the interaction and communication between and within healthcare personnel and patients.

The aim of this report is to summarize the data that was collected during the first phase of this study which addressed patients' perspectives about the implementation of the EMR prior to the implementation of the EMR. The report is structured in the following way:

- The Patients' Perspective
  1. General reflections on patient perspectives
  2. Benefits
  3. Concerns
  4. Expectations
- Suggestions for Patient Education Topics
- Last Words

A few sample quotations are included in the report in order to provide a taste and flavour of the types of comments that were made during interviews.

## **THE PATIENTS' PERSPECTIVE**

Please note that the order of the issues included here represents how frequently (or infrequently) these issues were mentioned. Hence, the issues mentioned by most of the patients appear early in the document, while those mentioned by fewer patients are placed at the end.

### **General reflections on patients' perspectives:**

In general, the various comments from the patients can be divided into three groups, following three types of perspectives:

#### **1. Positive and encouraging perspective:**

Most of the patients would fit into this category, in that they view the transition to an EMR as a positive development. Frequently, patients mentioned the benefits first, and it took them a while before they managed to come up with some concerns.

- *"Go for it and join the digital age!"* [C3:151204].
- *"I find that it would make it a lot more progressive, both for the patient and the doctor"...*

#### **2. "What-does-this-have-to-do-with-me" perspective:**

Several patients viewed the transition process as an organizational issue that happens "behind the scenes." They were not interested to know how their doctor retrieved the information about them as long as they could see and talk to their doctor.

- *"I don't care one way or another!"* [P10]...
- *"whatever works the most efficiently for their system"* [P5]...
- *"This will probably be beneficial for my doctor, but I don't understand how this will affect me"* [P20]...

### 3. Opposition/resistance to the EMR:

This attitude was expressed by very few patients, and it often relates to the concerns about sharing information between the various healthcare providers. Is it interesting to note here that these patients who opposed/resisted (or were not in favour) of the idea of going to an EMR were those who had an unfortunate personal experience with the health sector.

- *“It is bullshit. Cause it doesn’t work anyway...if I have to go to the hospital, in an emergency ward, the doctor is unable to get my entire chart- he’s too busy to go through it and find out exactly what’s happening. He’s gotta be in direct contact with my doctor to begin with. I had so many misdiagnoses” [P4]...*
- *“What differences does it make; the doctor will still be using time for looking (searching) for information. Whether it is paper or electronic information, there’s no difference” [P15]...*
- There were a few patients who were worried that we are rapidly and increasingly becoming dependent on technology, and that “there is no way back” after the transition to electronic charts. For example, one patient said *“I think that we already lean on them too much...I think there is too much of it [computers] out there in the first place...If they fall apart now, what’s gonna happen to us? We depend on them quite a bit for everything” [P10]...*

#### Benefits:

- **Better and faster access to the most updated information.**
  - In addition, assisting doctors to remember all the various information was seen by some patients as a benefit: *“But I found that, because he [P1 pervious doctor] was an older gentleman...his memory wasn’t the fullest...So what he would do, is he would type in right there on the spot...And the last time I came in to visit him, he knew exactly what happened the time before, it was all there. He didn’t have to go searching through papers and files, cause he just click click- and it comes right up...No matter what kind of information he was looking for, he was able to pull it up and knew exactly where we had ended at” ...*
  - *“there has been times where I had to remind [my doctor] of tests that had been done, but that’s understandable, because, I’m only one out of 35 patients, or whatever” [P3]*
  - Various patients believed that EMRs will probably save a lot of time for doctors.
  - Several patients also mentioned the advantage that digital information can be accessed independently of a person or a paper-record, and that the EMR can be accessed by several people simultaneously.
- **Efficiency: Easy search and retrieval of information.**
  - Several patients pointed out that less time is being spent on paperwork, and more time can be available for patients.
  - Better organization and structure of information have been identified as potential benefits of the EMR by patients: *“everything in one screen” [P15]...*
  - *“[With computers] you cannot lose or misplace anything” [P7].*

- *"I've had that happen once or twice where they couldn't find the file in the doctors' office, so it's a good idea [...] cause with computers, it's there where you saved it!"* [P14].
- Having the prospective benefit to **share information among the various healthcare providers**. *"Easier to be transferred to other doctor's offices, instead of using fax machines and having to find certain papers"* [P14]...
- **Space factor**: saving room (this point was mentioned by many patients).
- **Better quality of electronic charts**: Records cannot be destroyed as easily as paper charts. *"Having all the information in the computer, we're talking about at least 100 years"* [P]...
- **More convenience, easier and faster to write on the computer** than using a paper.
- **Environmental perspective**: using less paper implies saving trees (this benefit was mentioned by several patients).
- **Handwriting**: easier to interpret doctor's handwriting.
- Providing the possibility to generate data (e.g. statistical information) for further **research** (e.g. preventive medicine).
- **Long term storage**.

### Concerns:

When patients hear about the implementation of the EMR in general, and specifically installing computers in physicians' offices, they often related this to having access to the Internet, which for many patients is often associated with hackers.

P1: *"If you got a computer, then it's accessible to an out or an inline. What's gonna stop somebody from paying somebody to access that, change things, find out information so that they are ahead of time, so they can damage control basically"* [P]...

- **Privacy & Access to medically sensitive information**:
  - In general one can say that it is not clear for many patients *who* will have access to *which* parts of information.
  - One of the comments: *"to open up access to information that doesn't need to be accessed, gives people power"* [P5]...
  - This concern was mentioned by most of the patients.

- **Hackers:**
  - Several patients claimed that it will be easier to access computer files, and more likely to happen, than people breaking into the office to get paper files.
  - Other patients who pointed out the concern of someone breaking in and gaining access to their files accompanied this with comments such as: *“but I don’t know if this information is useful [...] It’s about my disease”...“I’m not as concerned about it as I would be with my bank” [P8]...*
  - *“It’s easy to access for hackers, but that’s just one of the prices you pay to keep the paper flow going” [P3].*
  
- **Confidentiality of information:**
  - The issue of sharing information across organizational borders, as well as national borders was very often mentioned.
  - *“I’m very conservative...I want the information to stay between me and my doctor” [P]*
  - The example that was often referred to in talking about privacy and confidentiality of electronic medical records was: “The Patriot Act,” which refers to the decision that has been taken by the Ministry of Health to contract out the administration of British Columbia’s Medical Service Plan (MSP) and PharmaCare to a U.S. linked company (recently there were several articles in the media, with headlines such as *“British Columbians’ personal information is being exposed to the long arm of the FBI”*).
  - *“As long as the info stays in Canada and in the hands of health institutions, I don’t care. As long as it doesn’t have to go to the U.S.”.*
  
- **Safety of medical records:**
  - Some patients expressed their concerns about the fact that it might be easier to steal files from a computer, rather than stealing paper charts. However, these concerns were often accompanied with comments such as: *“this will happen here [in the realm of paper charts] or there [with EMRs]”[P1]...* Another patient said: *“it’s probably safer than just having them lay around in doctors garages and basements. I think it makes more sense to have it on a computer” [P2].*
  - **Virus attacks** on computers were a concern to some patients: *“the first thing that came to my mind was, “what if there is a virus and [it] will erase all the files” [P8].*
  - **Technical problems** (in terms of system-crash) and **backup routines** were also of concern to some patients.
  
- **Eye contact with doctors:**
  - *“it’ll probably feel more official than having the doctor flip through papers and make notes” [P2].*
  - Concerns of losing eye-contact with the doctors and feeling, to some degree, left “outside” the decision process were raised by some. One patient explained to me that when his/her doctor puts the paper file in front of them, it is easier for the patient to

see what the doctor is writing down, and the patient feels that he/she has more access to the information in his medical files [P2].

- **Training for the doctors:**

- Very few patients were concerned that their doctors will face many complexities with getting used to computers and/or the system, and emphasized the importance of providing their doctors with adequate training.
- Other patients were concerned that their doctors will be so busy learning about the new system (the EMR), that they will have less time for the patients. *“Everyone can learn the skills [that are needed for using computers], but getting proficient at it, is a different story. I kinda like my doctor to really focus on ‘the doctor part’”* [P10]...

- **Authenticity (validity of the source of information):**

- Very few patients mentioned the fact that with computers (and digital files), there is no “original copy.” The issue of being able to print several copies of the same document concerned some of the patients. They gave examples of using documents from the medical record for insurance companies or in the court, and expressed their concerns about the fact that there must be a mechanism to signal that the information is valid, and had been confirmed by a doctor/author. *“Everyone can print anything from the computer... Somebody has to sign it in order to make it a valid document that contains valid information which should be confirmed by the doctor”* [P10]...

- **Financial:**

- A few patients mentioned financial concerns, reflecting upon the idea that too much money is being spent on the implementation of IT, and could be spent on other critical problems in the health sector. *“I’m concerned that so much money is being spent on IT”... “this money had been taken from other areas and would have probably been spent on other things in the health sector”* [P15].

- **Unemployment due to the expectation that the computer will “replace” the administrative staff:**

- *“So there will be quite a few people without a job again”* [P6]... This concern was brought up by only one patient, but I included it in the report as it reflects upon the relationships that patients have with healthcare personnel at the Mid Main.

**Expectations:**

- Several patients had the expectation that information will be shared among the various healthcare organizations. Often, they provided the example of being transferred to specialists, hospitals, or other healthcare providers, and expecting that their medical record will be accessed from there (and not only by their GP). This expectation was often accompanied by concerns of *who* will/should have the access to the records.
- A few of the patients who also mentioned the expectation of sharing digital information between the various healthcare institutions expressed their concern that not all the

healthcare providers are “computerized”. For example, one patient commented that “*The problem is that I don’t think that my rheumatologist is computerized. His file is still on paper so...if it’s papers from there and it gets here, then it needs to be typed into the computer. Instead of just filing it in the paper-chart...They’ll have to retype it right?*” [P8]... This comment shows how patients who are not familiar with computers do not understand how electronic and paper-based information can be shared. Other times they think that ‘sharing information’ means printing out papers and sending it by mail.

- Several patients expressed that it will probably take some time to get used to having their doctor sitting with a computer, but that this is just a matter of time, and adapting to the new technology. Two patients gave me the example of the bank-machine when they first came onto the market. An example of one of the comments: “*Well, I guess that everybody now is going to computers...I guess it’s the same with the bank when they switched to bank machines, I resisted to go to bank machines cause I knew the teller already and the manager, and going to the bank machine you don’t know anybody...and it’s a machine. And later on, I adapted to it, so that when you’re in a rush you can just go to any corner and to the bank machine*” [P8].
- Some patients felt the EMR would help the patient to deal with medical conditions (e.g. diabetes) in a better way (independently from the doctor): *maybe it’ll help me to cope with it [diabetes] in a better way. [...] Maybe it [the computer] can remind me how to do things* [P6].

## SUGGESTIONS FOR PATIENT EDUCATION TOPICS

The following section includes lessons that were learned from the following fieldwork, and the information here is based on the interviews with patients.

- Many **patients are familiar with the use of computers** (and/or other **technological devices**) in one way or another. They are either familiar with (exposed to) technology from their work, private use, or because they have seen computers around in the health sector. Therefore, as several patients said, “*I don’t have any problem with technology, cause I’m used to it*” [P14] ...
- In addition, many patients explained to me that, sooner or later, the increasing development of technology in the health sector would have happened anyway, as in other sectors (e.g. banks). “*It’s what happens, it’s where the future and the world is going to*” [P14]... Some comments were in fact as extreme as the following: “*yeah, I think that some day, you’ll go into your doctor’s office and you’ll have the computer in front of you and you’ll have to answer all the questions, and then you might see a doctor, or the computer will tell what’s wrong with you*” [P2]...
- Due to the fact that there were several patients who wondered whether the **old paper charts will be destroyed**, it is advisable to clarify that these will still be stored in the clinic. In addition, it might be good to explain to the patients that although we are “moving with times, and entering the *paperless* world,” paper charts will continue to be

used for a while. By mentioning to patients that it is a change that will be conducted gradually, we prevent having too high expectations from patients (and prevent comments such as: “*What are all these papers? I thought you said you are going ‘paperless’?*”).

- I also feel it is important to be cautious with the information that will be provided to patients. Many patients expect that the implementation of the EMR will allow the various healthcare organizations (e.g. hospitals, community clinics, pharmacies, etc.) to communicate electronically (rather than sending a letter or using the telephone). This benefit, which is the most obvious one to the patients, is the ultimate goal which the system will not be able to deliver. Furthermore, since it is obvious to us that it will take a while before we reach this stage, it is important to emphasize to patients that this is the *ultimate* goal. In order to develop more realistic expectations, one can rather try to move the focus over to the other advantages that will be obtained. For instance, we may want to emphasize that the EMR will enhance the way information is gathered, stored, distributed and used; increase access to the most updated information and decrease the time spent on handling activities; support clinical tasks as diagnostic and therapeutic decisions; help manage chronic diseases such as diabetes; etc.
- **Providing teaching and training sessions** to the doctors is paramount, as well as following a *gradual* transition to using an EMR in everyday practice.
- **Placing the screen:** It is advisable to place the screen so that it is in some sense accessible to the patient so that the patient will continue to feel that he/she is conceived as part of the process (just as they used to feel before the EMR).
- **Increase patients’ awareness** about the changes that will follow. However, keep in mind that there are several patients who simply do not view this change as something affecting them and believe that they do not need to know about the transition to an EMR (viewed as an issue that is “behind the scenes”).
- It is always advisable to inform patients about the **rationale** for implementing the EMR, and to introduce the various **benefits** that that will be gained from this transition. At the same time, it is advisable to **address concerns** that were presented by the various patients. Based on the interviews, patients were primarily concerned with the following issues: **privacy and access to information** (*who* will have access to *which* parts of the information), **and confidentiality, and safety of records** (technological problems, hackers and virus attacks).

## FINAL WORDS

While reading some literature about the history of EMRs, I found parts that describe the patients’ perspective in the early 1970s. It was revealed that **patients had little problem in accepting computers** as part of their healthcare delivery team. In addition, they found that patients were less intimidated by the computer than the doctors. According to my impression from the patients’ comments, I feel that this can be applied to our existing situation at Mid Main. As previously mentioned, most of the patients were positive and encouraging about the idea of digitalizing

medical records. Moreover, I noticed that patients readily mentioned several benefits, yet often took some time to reflect on their concerns.

**Based upon the interviews** that were conducted **with** the various **WOLF-users**, as well as the interviews with policy makers, we were informed that **there were no special sessions for introducing the EMR to patients**. The existing practice that the clinic followed was that it was the doctors' responsibility to inform their patients about the fact that they will start 'using computers'.

**Most of the patients described the EMR as a medium for restoring digital information.** This report provides a general overview of the benefits that patients were aware of, as well as their concerns and expectations. Patients are aware of the most important benefits that are implied in the transition to EMRs. If there is an interest, one can possibly summarize these benefits and include the ones that were not mentioned by the patients. This could help ensure that the various patients have similar levels of knowledge about the EMR. After looking in my notes which include a list of benefits that are related to EMRs, I must admit that the only point that was not mentioned by the patients was the possibility of improving clinical decision-making process (e.g. by producing computerized reminders that record and store abnormal results, allergies to medications, etc.)

- Improve patient management and compliance with treatment guidelines (though one can say that this was actually mentioned indirectly by few patients)
- Improve patient safety.

I hope you will find this report instructive and interesting, and that it can be helpful to the implementation of the EMR.