

# Patient Attitudes towards Improving Their Care by Carrying Their Own Medical Information: A Qualitative Analysis

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## Abstract

**Objective:** To elicit patients' views on information exchange between their doctors and whether they could contribute to their care by carrying their own health information. **Background:** Patient-held health records are increasingly popular as a resource for making medical information available to patients. Giving clinicians access to these records can aid them in making treatment decisions. This research is currently trialling paper and electronic versions of a portable patient-held health file. Patients carry these tools to doctors' appointments where clinicians record data for communication to other doctors or the patient. The project hypothesises that increased availability of patient information will enhance the safety and quality of health service delivery and improve health outcomes. **Methods:** Qualitative semi-structured interviews were conducted with ten patients. Participants were evenly distributed in terms of gender, were aged 60 years or greater and all visited at least two specialist doctors and one general practitioner (GP). **Results:** Patients who were currently active in decision making about their own health tended to already record some health information. They were receptive to carrying their own information and thought they should take some responsibility for their own health. Other patients who were more passive in making decisions about their health did not perceive a need to carry their own information as they felt that their doctors communicated regularly and adequately. **Implications:** An understanding of the information needs of a target population needs to be taken into account when designing patient-held health records. Differing attitudes of patients to their own health and engaging with their own health information may impact on the utilisation of a patient held health file (PHF).

## Objective:

Firstly our objective was to elicit patients' opinions about the technologies, detail, accuracy and timeliness of the ways their doctors currently exchanged information about them. Secondly, we sought patients' opinions about whether they could themselves carry portions of their medical record and present it to their doctors during their appointments. Broadly our study objective was to inform the design of a PHF.

## Background:

Recent increases in patients' access to their medical information has been brought about due to one facet of governmental policies that aim to deliver patient-centred health care that includes encouraging patients to take a more active role in their own health self-management (see Chronic Disease Self-Management Program USA <http://patienteducation.stanford.edu/programs/cdcmp.htm>; Department of Health UK 2001). Patient-held health records (PHRs) may increase the availability of clinical information for use by clinicians in decision making. Involving patients in their own health care maintenance is believed to increase the safety and quality of their care. Increasing the availability of information has been shown to increase safety and quality in areas including medications, diagnostic testing, inter-professional information exchange and patient-provider communication (Bates, Cullen, Laird et al. 1995; Kaelber and Bates, 2007).

PHRs are either paper diaries or electronic tools to which both patients and health practitioners contribute information. One example of such a paper based record is the New South Wales (NSW) Department of

Health's 'My Health Record' (<http://www.health.nsw.gov.au/qcp/mhr/>). Patients are advised to carry this booklet when attending any health service, doctor or hospital. Patients are encouraged to incorporate its use into their interactions with health professionals. Electronic versions of similar patient-accessible health records are also becoming internet based. These records have been described as "...electronic application[s] through which individuals can access, manage and share their health information...in a private, secure and confidential environment." (Markle Foundation 2003: 14).

These systems vary in the extent to which the contents of the record and access to it are controlled by both patients and health care providers and the extent to which they are integrated with hospital or surgery based records (Halamka, Mandl and Tang 2008). Functionality of these records may include access to organisationally located records, information about medications and conditions, and tools for encouraging patient self-management (Pagliari Detmer and Singleton 2007). The multifaceted benefits of electronic personal health records are that they:

"...have the potential to empower patients through greater access to personal data, health information, and communications tools, which may aid self care, shared decision making, and clinical outcomes. They may increase patient safety through exposing diagnostic or drug errors, recording non-prescribed medicines or treatments, or increasing the accessibility of test results or drug alerts." (Pagliari et al 2007: 331)

The qualitative interviews reported on here were conducted within a project designing a PHR that will be trialled over a four year period as a randomised controlled trial. In order to distinguish our record from other PHRs we refer to ours as a patient-held health file (PHF). We use the term PHF to mean a record carried by a patient (either in electronic or paper form) to encounters with health care professionals. The information contained within the record, while able to be read by the patient, is directed towards clinicians. This information tends to be clinical in nature and may include patients' doctors' contact details, medical conditions, allergy alerts, medications (both current and historic), test results and visit summaries. This information is not a replica of the information contained in the patient's file held by care facilities. In many ways it will reflect aspects of these organisationally held records but is likely to be a summary of them. The PHFs are intended to be adjuncts to these organisationally located records. The purpose of these records is to facilitate communication of information about patients between GPs and specialist physicians on occasions when information exchange has not occurred. We anticipate that the use of such a record will improve patients' outcomes by enabling health care providers to have access to up-to-date accurate information about patients' current conditions supported by data from other clinicians providing care to the patient. This supporting data may be useful in providing insight to other practitioners about clinicians' diagnostic processes.

## **Methods:**

The research reported in this paper is from qualitative semi-structured interviews conducted with patients at a tertiary public hospital in Sydney, Australia. Approval to conduct the research was granted by the South East Sydney Illawarra Area Health Service (Central Network) Human Research Ethics Committee. The interviews are part of a larger data set that includes interviews with specialist doctors and GPs. The purpose of these interviews was to elicit stakeholder opinions about the possibility of a PHF currently being designed and trialled by the project. The focus of the interviews was on processes of information exchange between specialist doctors and GPs with regards to their patients. Within the patient interviews the participants were specifically asked about their interactions with different doctors, whether they thought their doctors exchanged information about them and what their response would be if they were asked to carry a subset of their medical information. Ten patients (six outpatients and four inpatients) were interviewed. Participants were evenly distributed in terms of gender, were aged 60 years or older and all visited at least two specialist doctors and one GP. The interviews were transcribed by a professional transcriber and checked for accuracy by one of the researchers (RF). A thematic analysis was undertaken using NVIVO software.

## Results:

In the interest of brevity only a small portion of our results can be presented here. The results are grouped in three themes: interactions with doctors, maintenance of own records and attitude to the PHF. All names are pseudonyms.

### Interactions with doctors

Five patients (Margaret, Trevor, Elizabeth, Juan and Nora) indicated their preference for taking an active role in making decisions with their doctors about their health care. Margaret commented:

"Methotrexate, I'd been on it for ten years and it had been at the same dosage and then I had to put it up a bit ...and then a couple of years later I had to put it up again and then it got down to months and I had to put it up again... so then I spoke to the Doctor and I said "I can't see the point in just going up and up and up in increasingly shorter distances, it's obviously my body's got used to it or something. It's not as effective as it has been" and I wanted to talk about options you know or how much Methotrexate can a person have safely... that was when we decided on the dosage of having it by injection... and that meant I didn't have to put it up yet again. We just stayed on the same dose but having it put straight into the blood stream and it has been more effective." (Margaret)

In contrast, four other patients (William, Pauline, Beryl and Steve) preferred to accept of the instructions given to them by their doctors. William and Beryl stated:

"He [the doctor] tells me what I take and I just take it." (William)

"I'm quite happy to do what they tell me if it suits me" (Beryl)

### Maintenance of own records

Two of the patients (William and Edward) currently did not keep any records about their own health. Seven of the patients (Margaret, Trevor, Elizabeth, Pauline, Juan, Beryl and Nora) did maintain some records of their own health including lists of their medications, blood pressure and blood test results. Trevor, Elizabeth and Steve all kept a file at home in which they put copies of blood results and doctors' letters. Juan was an exceptional case in that he recorded a great amount of information about his health. He said that he was able to predict changes in his blood results and that through his own diligence he had been able to reduce his medications:

"I use my own background in engineering to do my own statistics...What I do is I get a copy of the blood test result and I ask for any indicators there even if it's good or bad or out of the range to explain a reason why it could be. Find a reason and then I change my routine. So next time I try to get it within the range...these days [I can] probably even guess very accurate what the results are going to be based on my activities, mostly physical activities...if you have a condition, mine is dermatomyositis which require monitoring of how you're going with your blood test result or medications. You should know when the medication was changed. You should know on which date it was changed and for what reason... I can get a piece of paper, bring it to you and I can tell you when it was changed from 25 [mg] to 20 to 15, 12½, 12, 10, 7½, 5, 2.5." (Juan)

Seven of the patients (Margaret, Trevor, Elizabeth, Pauline, Juan, Steve and Nora) also sought information about their conditions and medications either from the internet, health-related books or from their doctors. William and Beryl did not currently search for information about their health. Beryl explained:

"I try to just go along day by day. I don't worry about reading what's going to happen in the future...I mean Dr [name] explains so much. I'm happy with that. Somebody gave me a book in hospital one day and I was reading it through and it just went on and on until I said "no I can't take anymore". I just shut the book and handed it back. I don't want to know all that." (Beryl)

### **Attitude to the PHF**

When asked whether they thought that patients could play a role in carrying their own information to their doctors' appointments, five patients (Margaret, Elizabeth, Juan, Beryl and Nora) gave a positive response. They said they felt comfortable with carrying information and for Juan, it gave him the opportunity to take responsibility for his own health, something he felt that would improve other people's health if they adopted a similar practice:

"In my case, I'm absolutely thrilled that I can take full responsibility and based using my background, my engineering background, I can understand the statistics and you can see trends going so I've been giving classes to the specialists and like a big picture... I think the majority [of patients] I think they delegate their responsibility to the Doctor and because its very easy and I think they're absolutely wrong. They are never going to improve if they don't do it. If you ask me, personally, I think they're never going to get out of it. They're never going to move forward if they delegate the responsibility to the Doctor." (Juan)

In contrast, Pauline, Steve and Edward were more negative when asked about carrying their health information. Steve commented:

"If I had to I probably could but I would probably lose the lot of it you know on the way but as I said go back to knowing the doctors, they would have it all in advanced all the time you know because they know what I'm like you know. ...I'm not a person that could accept full responsible of myself that's a fact you know...Only unless I really had to... I could say "oh yes I'm sick" and that would be about the top of my information I could give...I've got a lot of faith in my doctors and I don't want to take the responsibility off them. And as I said they've studied hard to be a doctor so they know, I don't." (Steve)

The above results indicated that our patients could be viewed as adopting two positions. On the one hand five of the patients (Margaret, Trevor, Elizabeth, Juan and Nora) all stated that they liked to take an active role in making decisions with their doctors about their health. All of these patients read additional information to do with their health and currently maintained some records of their own health. Some of these patients also carried with them a list of their medications which they updated as necessary. These patients were optimistic about the possibility of the PHF and said that it was something they would feel comfortable carrying and presenting to their doctors.

In contrast, four others (William, Beryl, Steve and Edward) took a more passive role in their interactions with their doctors and decision making about their health. They were more accepting of doctors' directions and trusted that their doctors had an expertise that they should not question. For many of them, they were not interested in knowing details about their health beyond what medications or treatments they should receive. They rarely read any additional information about their health and almost none of these patients maintained any records about their health. These patients tended to be more negative about the PHF and felt more uncomfortable with the responsibility they perceived it placed on them. They were also less likely to envisage a need for such a tool as they considered data about their health to already be maintained by their doctors.

One patient, Pauline, was an exception to these trends. Whilst she kept a list of her medications and actively sought additional information about her health, when it came to interacting with doctors, Pauline adopted a more passive role. She was also optimistic about the PHF and expressed a preference for an electronic version of the tool.

## **Implications:**

The results presented in this paper demonstrate the divergent positions that patients adopt in relation to their health information. As such, the extent to which patients engage with the information contained on the PHFs is likely to be variable. The success of our tools will be measured in terms of indicators such as hospitalisations and will not rely on whether patients read the information or not. As such the burden placed on patients will be minimised as their role will be only to act as transporters of the PHF tool. This will increase the likelihood of improvements in care for a greater number of patients including those with limited English language and literacy skills since the success of the PHF relies on contributions made to it by the doctors.

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