Patient perceptions of carrying their own health information: approaches towards responsibility and playing an active role in their own health – implications for a patient-held health file

Rowena Forsyth BA (Hons) PhD,* Carol A. Maddock MA (Health Promotion Europe), DCR(T),† Rick A. M. Iedema MA (Applied Linguistics) PhD (Linguistics)‡ and Marissa Lassere MBBS(Hons) GraDipEpi PhD§

*Research Fellow, Centre for Values, Ethics and the Law in Medicine (VELiM), The University of Sydney,

†Health Promotion (Europe), DCR(T) Cancer Communications Researcher, Tenovus, Gleider House, Ty Glas Road, Llanishen, Cardiff, Wales, UK, ‡Professor of Organizational Communication, Director of the Centre for Health Communication, Centre for Health Communication, Faculty of Humanities and Social Sciences, University of Technology, Sydney and §Professor of Medicine (Conjoint), Faculty of Medicine, University of NSW, Sydney, Australia

Abstract

Correspondence

Rowena Forsyth BA (Hons), PhD
Research Fellow
Centre for Values Ethics and the Law in
Medicine (VELiM)
Level 1
Building 1
Medical Foundation Building K25
The University of Sydney
NSW 2006
E-mail: rowena.forsyth@sydney.edu.au

Accepted for publication

19 December 2009

Keywords: health information, patient empowerment, patient participation, personal health records

Objective To elicit patients' views on whether they could contribute to improvements in their care by carrying their own health information to clinician encounters; and to consider the implications for the development of a patient-held health file (PHF).

Background Increasing rates of chronic disease lead to health care being delivered by multiple care providers often at distributed geographic locations. As a way of increasing the availability of patient information to care providers our project will trial a PHF. Patients carry these files to doctors' appointments where clinicians record data for other doctors or the patient. Increasing the availability of patient information is anticipated to enhance the safety and quality of care delivery and improve health outcomes.

Study design Qualitative semi-structured interviews were conducted with 10 patients. Participants were evenly distributed in terms of gender, aged 60 years or greater and visited at least two specialists and one general practitioner.

Findings In this exploratory study, patients who were currently active in decision making about their own health already recorded some health information. They were receptive to carrying their information and thought they should take some responsibility for their health. Patients who were more passive in making decisions about their health did not perceive a need to carry their own information and felt that their doctors communicated adequately.

Conclusion Patient-held health files provide an opportunity for patients to access their health information. Such files have the potential to improve health outcomes for patients who adopt both active and passive roles in relation to their own health and engaging with their health information.

Introduction

Increasing rates of chronic disease are placing a large burden on health service delivery world-wide and have significant impact on individuals' quality of life and their family.¹ The Australian Government identified that in 2001, 78% of National Health Survey respondents had one or more long-term health conditions. Among those aged 15 and over, the prevalence was 87%.²

Recent reconceptualization of the traditional notion of health-care relationships as founded on the three assumptions of professionals as experts, health-care systems as the legitimate gatekeepers of socially supported health services and patients as both compliant and self-reliant³ has led to patients taking a more active role in their own health than ever before.

Involving patients in decision making about their own health care has been shown to improve health-care outcomes including better treatment choices, improvements in care quality,⁴ and be beneficial for patients' and their families experiences of health events.⁵ Despite these espoused benefits, evidence suggests that shared decision making has not yet been widely adopted by many health-care professionals due to time constraints, patient characteristics and clinical situations.⁶ In addition, variability exists in the extent to which patients aged over 60 years desire to adopt an active role in decision making regarding their health care including discussions with practitioners, and decisional control.⁷

In light of the positive contributions that empowered patients have made to their care,⁸ health organizations have sought to harness patients' expertise and encourage patients to become more active in their own care. One dimension of this involvement, patient self-

management, focuses on patients setting goals and action-planning for their health in ways appropriate to personal circumstances, usually in partnership with clinicians.⁹ Formalized self-management programmes include the Chronic Disease Self-Management Program (CDSMP) in the USA (<http://patienteducation.stanford.edu/programs/cdsmp.html>) and the Expert Patient Programme in the UK.¹⁰ Criticism of these programmes centres on their limited reach beyond white, middle-class populations¹¹ and their restrictions on power that patients can exercise.¹² However, whilst the programmes reinforce the bio-medical paradigm they also acknowledge patients' individual illness experiences.¹³

This paper considers these tensions in light of recently developed patient-held records (PHRs). After providing some background about PHRs, we present the details of our project and report the results of qualitative interviews conducted with patients about their attitudes towards carrying their health information. These interviews were conducted for the purpose of contributing to the design of the specific PHR being developed and trialled by our project. We felt that current PHRs had failed to adequately incorporate patient and key stakeholder preferences into the design of such technologies to date. Our results point towards patients favouring different modalities of engagement with health information thus structuring how they may use a PHR, and necessitating a design that can accommodate divergent preferences. Whilst acknowledging the limitations of our study due to our small sample size, we offer our results as demonstrative of issues highlighted by the use of these relatively novel technologies and hope to contribute our analysis as the basis for future investigation.

Patient-held records

Many of the government-led approaches suggested above have promoted patients becoming more active in their own health management. One way in which patients are becoming more empowered is through accessing their medical information. Many patients are also being encouraged to monitor their health information in the form of paper or electronic diaries. One study found that such diaries were valuable in providing insights into the ongoing health routines and coping strategies of older people leading to a detailed picture of participants' 'health histories'.¹⁴

Dickey and Petitti¹⁵ found that the paper 'health diary' they developed led to significant improvements in medical practitioners' compliance with recommendations for delivery of preventive services. Importantly, the study recognized that the diaries functioned as a 'tool to build cooperation between patients, providers and nursing staff'. Thus, while care delivery may be improved directly by the availability of information for use in clinical decision making, such records may also enhance communication between patients and clinicians.

The usefulness of personal health records for patient self-management has been explored in areas including oncology,^{16–18} blood pressure monitoring^{19–21} and mental illness.²² Williams and colleagues¹⁸ found that whilst the records did not impact on communication between patients and care providers, they were significantly helpful for patients to feel more in control by reducing difficulties in monitoring their progress and in preparing for appointments. Patients in Essex and colleagues' study²² valued being consulted about the information written and found the record of their treatment useful. The study showed increasing patients' autonomy in interactions with care providers, and the record-aided communication between professionals.

One example of a health record that patients carry to appointments with health-care providers is the New South Wales (NSW) Australia's Department of Health 'My Health Record' (<http://www.health.nsw.gov.au/initiatives/>

[myhealthrecord/index.asp](http://www.health.nsw.gov.au/initiatives/myhealthrecord/index.asp)). Launched in 2002, this record aims to help patients keep track of information about their conditions and to improve communication between individuals and their care providers (<http://www.health.nsw.gov.au/initiatives/myhealthrecord/index.asp>). Patients, carers and health practitioners all contribute information to the booklet. Patients are advised to carry the booklet when attending any health service, doctor or hospital. This diary's innovation is that it encourages patients to incorporate its use into their interactions with health professionals. The diary promotes empowerment of patients by giving them access to the information that doctors record in the booklet including medications, health conditions and allergies.

Patient motivation to maintain such records and carry them to their appointments arises from the record's ability to be the most comprehensive and up-to-date record of their health across multiple care providers. The attractiveness for patients of using them is that they maintain greater control of their information and can more knowledgeably interact with care professionals.²³ Patients' ability to review their information subsequent to appointments can prompt greater recall, potentially encouraging them to search for more information via the internet, libraries and support groups. Further, by accessing this information, patients may have a more complete picture of their health and physicians' advice.

Conversely, some studies have raised doubts about the efficacy of health diaries. One study²⁴ investigating paper diaries, electronic devices and telephone data capture of symptom recording found that despite specific instructions to patients to complete entries at particular times of day, many of the entries were completed late. Entries in the paper diary had the highest auto-correlations indicating that patients often completed multiple entries within a short space of time either retrospectively or prospectively. Such recording undermined the reliability of the data.

Evidence of increases in internet use and electronic information storage for personal activities is demonstrated by patients' willing-

ness to store and share their medical information on websites. Internet searching for health information has become a popular means by which individuals gain greater understanding of their conditions and interact with others coping with the same condition. However, one study²⁵ found that whilst health consumers find the internet a convenient source for quickly finding health information they give little credit to the information they find. Another study²⁶ found that women using the internet to search for information integrated online advice with advice from friends, family and physicians in their decision making with greater weight being given to physicians' advice over the other sources.

Health-care delivery sites are increasingly adopting computerized medical record keeping systems with the aim of improving the quality and efficiency of health-care service delivery.²⁷ Reflecting this trend, PHRs are also becoming internet based.²⁸ 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 their degree of integration with hospital or surgery-based records.^{29,30} Functionality of these records also varies and may include access to organizationally located records, information about medications and conditions, and tools for encouraging patient self-management. The multifaceted potential benefits of electronic personal health records include patient empowerment through increasing access to health information and communication tools as well as increasing patient safety through identifying diagnostic or drug errors and accessibility to drug alerts.³¹

Such records can act as both passive and active technologies. Passively, the PHRs are an information repository – clinicians, diagnostic professionals and patients may all contribute information to the record. By placing information in the record they make it available to others; however the record itself does not necessarily direct whether the information will be acted upon. The record becomes an active technology when clinicians and patients access the information and make decisions about care progression.

An advantage of these records arising from their web-based nature is that clinicians at geographically distributed locations may access the information remotely at times convenient to them without needing to consult patients face-to-face. In addition, many records enable patients and doctors to have email contact which may increase patients' access to care, enhance patient education and improve adherence to treatment plans.³²

But while PHRs are becoming increasingly popular, the literature does not venture far towards addressing how patients feel about carrying their own health information. Let us therefore now turn towards our exploratory study of how patients may (like to) access their medical information and contribute to the exchange of information between their health-care providers. We have intentionally chosen to use the term 'information exchange' rather than 'information transfer' to promote a dialogic use of information whereby patients contribute to their encounters with medical professionals.³³

Methods

The research reported in this paper is from 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. We use the term patient-held health file (PHF) to refer to the specific PHR developed by our project. Our PHF encompasses only a subset of the range of possible functionalities of PHRs. The functionality included in our PHF reflects our practical and resource limitations and its intention to be used as a record carried by a patient (electronic or paper format) to encounters with health professionals and used during consultations rather than accessed remotely via the internet outside of consultations. The information contained within the record, while able to be read by the patient, is directed towards clinicians. Clinical information may include doctors' contact details, patients'

medical conditions, allergy alerts, medications, test results and visit summaries. The purpose of these records is to facilitate communication of medical information about a patient between general practitioners (GPs) and specialist physicians. We anticipate that such a record will improve patients' outcomes by enabling health-care providers to access up-to-date, accurate information about patients' current conditions supported by data from other clinicians providing care to the patient.

Concurrent to the development of our PHF, we sought stakeholder perspectives on the organizational, professional, socio-cultural and technical features that would influence the effective use of a PHF by patients and health-care providers. In doing so, we aimed to understand current practices surrounding the use of patient information in clinical settings and how our PHF would be incorporated into existing information exchange routines.

Semi-structured interviews were conducted with patients, specialist doctors GPs, IT and legal professionals. Interview schedules for each group differed according to the aspects of PHF use most relevant to that group. The topics of the patient interviews were concerned with how patients currently understood their conditions, how they interacted with care professionals, whether they maintained records about their health and whether they sought information about their health from external resources such as the internet. Interview transcripts were read and reflected on between interviews and the wording of questions revised for subsequent interviews. Interviews were intended to be as neutral as possible in their questioning and did not assume patients desired to access their medical information or improve interaction with their care providers.

A theoretical sampling technique³⁴ was employed to recruit patients for interview who were consistent in age and specialist doctor attendance with those who would be participating in the forthcoming trial of the PHF tools. Interviews were conducted with 10 patients (six outpatients and four inpatients). Participants were evenly distributed in terms of gender, were

aged 60 years or older and visited at least one GP and two specialist doctors.

A thematic analysis^{35–37} that inductively identified patients' attitudes towards their medical information, learning about their health conditions and their experiences of interacting with health professionals was conducted. The interview transcripts were electronically coded using NVivo software. The most prominent themes to emerge are those that we have chosen to report in this paper. All participant names are pseudonyms.

Results

Advantages and disadvantages of a PHF

Accessibility in case of an accident or emergency

The most frequent response was that patients thought that having their medical information available for health-care professionals in urgent situations would be the greatest advantage of them carrying their information:

If people did have something that they carried everywhere they went, if you had an accident and they [health professionals] could see immediately ... 'you're on Methotrexate, we better not give you anything with aspirin in it or that's going to cause a lot of problems'. (Margaret)

If you fall over in the street ...you're usually too dopey to be able to tell an ambulance officer what's going on... I just think it would be a help no matter where you end up especially in [an] emergency where you see so many doctors. (Beryl)

Solution to rising forgetfulness

Beryl and Elizabeth identified occasions when either they or their medical practitioner may forget details of their health as times when having a typed or written record of details about their health would be useful.

Well I guess as I get older I will become more forgetful so if I could remember to take it with me then it doesn't matter that I've forgotten to mention that I have an Ophthalmologist for instance. It will be there...apart from me forgetting I suppose it would also – in case the specialist forgets. I mean it's there as a reminder. (Elizabeth)

Important resource while travelling or moving

The benefit of having an accurate medical history with them when they changed medical practitioners was mentioned by Margaret, Trevor, Pauline and Juan. All patients referred to travel or changing their residence as instances of potential risk due to being dependent on people who might not have easy access to their medical history:

If I was away on holidays or maybe overseas, and I could walk in with it and I had a problem they would be able to help me quicker than having to go through all the tests and things. (Trevor)

Well the advantage is that they have it all ready in case you have to move out of your city and go somewhere else or you go on holidays. If you carry your history with you in a couple of pages then any Doctor anywhere in the world will know exactly what to do. (Juan)

Greater patient control

Margaret and Juan mentioned that it was important to them to have some control over their own health. Juan mentioned the significance of 'responsibility':

You learn to understand your conditions and what factors can have an influence which is a must. If you don't know, you can't take responsibility or you rely on the doctors.

Patients were asked whether they could identify any disadvantages with them carrying their own medical information. Juan and Beryl stated that they did not perceive any disadvantages. Nora, Trevor, Elizabeth and Pauline believed there could be disadvantages if they were separated from their medical information. Nora thought that theft was an issue and that it might be possible for a thief to buy medication that was contained in her record:

If you got mugged and you had it on a little disc ... somebody could use it to ... to their own advantage. You know maybe to get tablets.

Pauline identified misplacing her record as a disadvantage; however, she was not concerned that the information could be used by another person:

[A] disadvantage would be losing it and somebody picking up all your information which really wouldn't do them any good but still.

Patients' preferences for paper-based or electronic PHF

The participants were also asked about whether they would prefer to carry their information as paper documents or as electronic files. When talking about an electronic version most patients imagined a CD-based tool. Elizabeth, Pauline, Steve and Nora exclusively stated their preference for carrying their information in an electronic form. Pauline justified her technology-based preference in terms of her own physical capabilities:

I'd prefer an electronic one...you'd put it on a disc and just put it into the computer. Carrying [paper] files around is not real crash hot I don't think...and in my case, I can't carry heavy things.

In contrast, Juan and Beryl both stated they would prefer a paper-based record. Juan stressed the importance of brevity and population-specific appropriateness in his response:

Paper form. Just one page – two or three pages. It's your history there for the last twelve months...not everyone [has] got access to computers. And remember you're dealing with older people. Mostly patients who if having trouble with it are reluctant to go on the computer or they would rely on someone else.

Interestingly, Margaret's perspective combined both electronic and paper-based versions of the record:

I'd be happy to carry [an electronic version] I suppose. I'm always aware that technology can go wrong and cause a nuisance so I would like to have a paper version as well I think as a back up. I'm still not at the stage where I will rely entirely on technology for important matters.

Personal computer use in people's homes has recently become a reality, although many people over the age of 60 have not been brought up with the technology. This suggests a possible reason that some participants were unfamiliar

with concepts to do with electronic information technology; however, recent research has found that the internet is an important resource for senior citizens to access information about drug prescriptions and medical conditions.³⁸

Privacy issues and the PHF

Participants were asked whether they would be concerned about maintaining the privacy of their medical information in a portable form. None of the respondents were concerned in relation to their own information. Margaret mentioned, however, that she thought that patients with mental illness may be concerned about their status being revealed to others:

I mean if I had a psychiatric illness or something I might because people can often label you if you'd had something like that and I think privacy might be a concern then ... I've known people who have been knocked back on jobs because years ago they suffered depression ... but they've been normal for ten years but because they had a history of depression you know they're labelled.

Both Nora and Juan were not worried about other people accessing their information. They contextualized their health information within a broader framework of different types of personal information:

I mean privacy is – you have to trust as the same way you trust the doctor you have to trust the system... these days it doesn't matter, we're talking about health, we're talking about driver's license, credit cards, you're exposed left right and centre. (Juan)

Types of information to be included on the PHF

The respondents thought that a list of their medications and conditions were the most important types of information to be included on the PHF. Margaret identified specific details that she thought should be included:

It would have to include when the condition was diagnosed so it's known how a long a person has had it. What medications people are on, perhaps the dates, the years that they are on these. Whether it was a failure or a success ... and if you've had any surgery

Some patients perceived that they did not need to carry any more information than details of their conditions and medications. When Pauline was asked if she thought that she should carry test results or scans to her doctors' appointments she replied:

Well they usually have all that in their files and a lot of them are going computer now so they bring it up... they say 'I've got it on here'. (Pauline)

This quote demonstrates Pauline's perception of the comprehensive information contained in her medical records and the availability of this information to her doctors.

Patients' preferences with regard to transferring and viewing medical information

Patients were also asked about their current practices of carrying and viewing their health information. Of the 10 patients interviewed, two (William and Edward) currently did not keep any records about their health. They said this was because they felt that there was nothing that they needed to record.

Margaret, Trevor, Elizabeth, Pauline, Steve, Juan, Beryl and Nora did maintain some records of their own health. Of these patients, Trevor, Pauline, Beryl, and Nora kept a list of their medications while Margaret recorded her 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. Juan identified skills gained from his previous occupation as useful to him in maintaining his health information, something that was consistent with the findings of other research.¹³

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,

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.

Discussion – implications for PHF design and uptake

Although exploratory, the results presented above have important implications for conceptualizing how patients may interact with their own medical information. Their responses provide an understanding of the range of patients' preferences for the form and content of their information and how this may impact on their interactions with doctors.

In terms of contributing to the design of our PHF, we were able to gain insight into the way that our study participants currently sought and accessed health information. Crucially, we were able to appreciate these practices specifically in relation to the patient population that would be trialling these tools in our study. Our results warned us against assuming that all our participants would approach information use in the same way, a finding that is consistent with other research showing diverging patient engagement preferences.^{39,40} We were thus able to guide our design accounting for clear differences in how patients would use the PHFs, without assuming they would view their PHF-based information.

We found that for our patient population, paper-based documentation is often preferable, both in terms of accessibility and comprehension, to computerized files. We anticipate that by understanding and incorporating sensitivity to existing preferences and practices of information

use into the design of our tools, our PHFs will be better utilized. It should be noted, however, that patients recruited to our trial have not chosen which PHF they prefer but have been randomly assigned to paper PHF, electronic PHF and control (no PHF) study arms.

In light of the literature presented in this paper's introduction, our interviewees' responses also led us to consider three ways in which our PHF tool (and other similar PHRs) point towards the possibility of them being a useful tool for empowering patients. First, whilst empowerment of patients through doctors' giving them information about their health has been shown to improve their health outcomes, advocates for this process have assumed that all patients desire greater comprehension of their health conditions and medications. A study⁴¹ of endometriosis patients found they often resented the responsibility imposed on them by the current climate of health self-management. The author identified this responsibility as a form of work which some patients adopt reluctantly. Consistent with this, another study¹³ conceptualized this as the 'labour of being an expert patient'. Similarly, a number of participants in our research said they would not feel comfortable with carrying their own medical information and thought it should only be handled by the doctors. Thus, it would be incorrect for us to assume that all participants in our research will take an active interest in reading the information contained within the PHF.

Contesting this assumption leads us to the second of our points about the way that our PHF may be considered a potentially empowering technology. Our study will focus its evaluation on reportable health outcome measures such as hospitalizations. It is possible that our PHF may become more useful and have a greater contribution to improving care than tools which only have an impact if patients fully utilize them. In our study, the PHF offers patients a choice with regard to the extent that they engage with their own health information. Outcomes may be achieved not only for patients who read their information but also for those who choose not to since the effectiveness of the

tool only relies on patients remembering to take their PHFs to their appointments and the use of and contribution to it by their doctors. The applicability of this technology to patients with a spectrum of preferences for involvement in their own health may increase the applicability of the technology for a greater number of patients including those with limited English language skills.

Lastly, an important focus of the PHF roll-out will be to change patients' perceptions of the occasions on which their PHF may be utilized. The intention of our project is not for the PHF to be an 'exceptional, in case of emergency technology' but rather an 'everyday technology' that patients produce every time they attend their GP or specialist(s).

Conclusions

A recent trend in health care has seen patients taking greater responsibility and becoming more active in decision making about their health management. This increased involvement emerged due to a widespread governmental policy of placing the patient at the centre of their health-care provision. As part of this policy, patients are increasingly accessing their medical information. Patients can now track their medical information through centrally stored electronic records that they maintain themselves. However, in our view, patients have not been sufficiently involved in the design of these devices to date.

Above, we reported on one facet of our project that centres on trialling a PHF that patients carry with them to their doctors' appointments. Whilst the content of the tool (clinical information) is aimed at clinicians, the patient is the crucial actor in their care network as it is they who carry and present the record to the clinicians to use and update. Patients' responses highlight the importance of incorporating specific populations' needs into the design of technologies they will use as well as identifying the challenging nature of engaging a diverse population in using a new technology.

Finally, our results confirm that not all patients seek to have understanding of and input into their own medical information. Importantly, the usefulness of our PHF will be apparent not only for patients who wish to contribute to the content of it but also for patients who do not want to engage with the information contained within it as the success of the PHF derives from its portability by patients and not their comprehension of its contents. We argue that this point needs to be appreciated by organizations and governments promoting the use of personal health records in order to maximize the benefits of these technologies for patients adopting differing positions in relation to their own health information.

Funding acknowledgement

This project was funded by the Commonwealth Government through the National Health and Medical Research Council (NHMRC) Australia (Grant number 455467).

References

- 1 Department of Health United Kingdom. Improving chronic disease management, 2004. Available at: http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_4075214, accessed 17 March 2008.
- 2 Australian Institute of Health and Welfare. Incidence and prevalence of chronic diseases, 2005. Available at: http://www.aihw.gov.au/cdarf/data_pages/incidence_prevalence/index.cfm, accessed 17 March 2008.
- 3 Thorne SE, Nyhlin KT, Paterson BL. Attitudes toward patient expertise in chronic illness. *International Journal of Nursing Studies*, 2000; **37**: 303–311.
- 4 Powers PH, Goldstein C, Plank G, Thomas K, Conkright L. The value of patient-and family-centered care. *The American Journal of Nursing*, 2000; **100**: 84–86.
- 5 Rogers BM, Schultz CL. Empowerment of families during death, dying and bereavement: implications for health care. *Journal of Family Studies*, 1997; **3**: 25–45.
- 6 Gravel K, Légaré F, Graham ID. Barriers and facilitators to implementing shared decision-making in clinical practice: a systematic review of health professionals' perceptions. *Implementation Science*, 2006; **1**: 1–12.

- 7 Flynn KE, Smith MA, Vanness D. A typology of preferences for participation in healthcare decision making. *Social Science & Medicine*, 2006; **63**: 1158–1169.
- 8 Bodenheimer T, Lorig K, Holman H, Grumbach K. Patient self-management of chronic disease in primary care. *Journal of the American Medical Association*, 2002; **288**: 2469–2475.
- 9 Lorig K. Partnerships between expert patients and physicians. *The Lancet*, 2002; **359**: 814–815.
- 10 Department of Health United Kingdom. The expert patient: a new approach to chronic disease management for the 21st century, 2001. Available at: http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_4006801, accessed 17 March 2008.
- 11 Kennedy A, Gately C, Rogers A, EPP Evaluation Team. *Process Evaluation of the EPP Report II: Examination of the Implementation of the Expert Patients Programme within the Structures and Locality Contexts of the NHS in England (PREPP) Study*. Manchester, UK: National Primary Care Research and Development Centre, University of Manchester, 2005.
- 12 Wilson PM. A policy analysis of the expert patient in the United Kingdom: Self-care as an expression of pastoral power? *Health and Social Care in the Community*, 2001; **9**: 134–142.
- 13 Wilson PM, Kendall S, Brooks F. The Expert Patients Programme: a paradox of patient empowerment and medical dominance. *Health and Social Care in the Community*, 2007; **5**: 426–438.
- 14 Milligan C, Bingley A, Gatrell A. Digging deep: using diary techniques to explore the place of health and well-being amongst older people. *Social Science and Medicine*, 2005; **61**: 1882–1892.
- 15 Dickey LL, Petitti D. A patient-held minirecord to promote adult preventive care. *Journal of Family Practice*, 1992; **34**: 457–463.
- 16 Drury M, Harcourt J, Minton M. The acceptability of patients with cancer holding their own shared-care record. *Psycho-Oncology*, 1996; **5**: 119–125.
- 17 Finlay I, Jones N, Wyatt P, Neil J. Use of an unstructured patient-held record in palliative care. *Palliative Medicine*, 1998; **12**: 397–398.
- 18 Williams JG, Cheung W-Y, Chetwynd N *et al.* Pragmatic randomised trial to evaluate the use of patient held records for the continuing care of patients with cancer. *Quality in Health Care*, 2001; **10**: 159–165.
- 19 Cappuccio FP, Kerry SM, Forbes L, Donald A. Blood pressure control by home monitoring: meta-analysis of randomised trials. *British Medical Journal*, 2004; **329**: 145–153.
- 20 Mengden T, Hernandez Medina RM, Beltran B, Alvarez E, Kraft K, Vetter H. Reliability of reporting self-measured blood pressure values by hypertensive patients. *American Journal of Hypertension*, 1998; **11**: 1413–1417.
- 21 Yarows SA, Julius S, Pickering TG. Home blood pressure monitoring. *Archives of Internal Medicine*, 2000; **160**: 1251–1257.
- 22 Essex B, Doig R, Renshaw J. Pilot study of records of shared care for people with mental illnesses. *British Medical Journal*, 1990; **300**: 1442–1446.
- 23 Tang PC, Ash JS, Bates DW, Overhage JM, Sands DZ. Personal health records: definitions, benefits, and strategies for overcoming barriers to adoption. *Journal of the American Medical Informatics Association*, 2006; **13**: 121–126.
- 24 Lauritsen K, Degl' Innocenti A, Hendel L *et al.* Symptom recording in a randomised clinical trial: paper diaries vs. electronic or telephone data capture. *Controlled Clinical Trials*, 2004; **25**: 585–597.
- 25 Dumitru RC, Burkle T, Popatov S, Lausen B, Wiese B, Prokosch H-U. Use and perception of internet for health related purposes in Germany: results of a national survey. *International Journal of Public Health*, 2007; **52**: 275–285.
- 26 Sillence E, Briggs P, Harris PR, Fishwick L. How do patients evaluate and make use of online health information? *Social Science and Medicine*, 2007; **64**: 853–862.
- 27 World Health Organisation. Building Foundations For Ehealth: Progress of Member States: Report of the Global Observatory for Ehealth, 2006. Available at: http://whqlibdoc.who.int/publications/2006/9241563354_eng.pdf, accessed 18 March 2008.
- 28 Markle Foundation. Connecting for health. A public-private collaborative, 2003. Available at: http://www.connectingforhealth.org/resources/final_phwg_report1.pdf, accessed 1 October 2007.
- 29 Halamka JD, Mandl KD, Tang PC. Early experiences with personal health records. *Journal of the American Medical Informatics Association*, 2008; **15**: 1–7.
- 30 Tang PC, Lansky D. The missing link: bridging the patient-provider health information gap. *Health Affairs*, 2005; **24**: 1290–1295.
- 31 Pagliari C, Detmer D, Singleton P. Potential of electronic personal health records. *British Medical Journal*, 2007; **335**: 330–333.
- 32 Mandl KD, Kohane IS, Brandt AM. Electronic patient-physician communication: problems and promise. *Annals of Internal Medicine*, 1998; **129**: 495–500.
- 33 Lee RG, Garvin T. Moving from information transfer to information exchange in health and health care. *Social Science and Medicine*, 2003; **56**: 449–464.
- 34 Corbin J, Strauss A. Grounded theory research: procedures, canons, and evaluative criteria. *Qualitative Sociology*, 1990; **13**: 1.

- 35 Morse JM, Field PA. *Qualitative Research Methods for Health Professionals*. Thousand Oaks, CA: Sage Publications, 1995.
- 36 Rice PL, Ezzy D. *Qualitative Research Methods: A Health Focus*. South Melbourne: Oxford University Press, 1999.
- 37 Pope C, Ziebland S, Mays N. Analysing qualitative data. *British Medical Journal*, 2000; **320**: 114–116.
- 38 Kaiser Family Foundation. *e-Health and the Elderly: How Seniors Use the Internet for Health Information: Key Findings from a National Survey of Older Americans*, 2005. Available at: <http://www.kff.org/entmedia/upload/e-Health-and-the-Elderly-How-Seniors-Use-the-Internet-for-Health-Information-Key-Findings-From-a-National-Survey-of-Older-Americans-Survey-Report.pdf>, accessed 7 March 2008.
- 39 Elwyn G, Edwards A, Wensing M, Hood K, Atwell C, Grol R. Shared decision making: developing the OPTION Scale for measuring patient involvement. *Quality & Safety in Health Care*, 2003; **12**: 93–99.
- 40 Marshall SS, Haywood KL, Fitzpatrick R. *Patient Involvement and Collaboration in Shared Decision Making: A Structured Review to Inform Chronic Disease Management – Report from the Patient-reported Health Instruments Group to the Department of Health*. Oxford: University of Oxford, 2005.
- 41 Secar K. *Health Self-Management Amongst Women with Endometriosis*. Auckland, New Zealand: Refereed paper presented to The Australian Sociological Association and Sociological Association of Aotearoa New Zealand, 2007.