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Using a patient held record for home based palliative care patients: A case study research project

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Abstract

A paper based patient held record (PHR) was introduced by the study region's district nursing service and hospice palliative care co-ordinators to promote continuity of care for home based palliative patients. The inquiry has employed a case study research approach to gain greater understanding of the use, challenges and impact of this initiative from those who had or used the PHR. Through the use of semi-structured interviews and focus groups, patients, lay carers, and clinicians from the main groups providing community palliative services were asked about their views and experiences in relation to use of the PHR.

The research suggests a PHR can bring a positive impact for palliative patients and their lay carers, particularly where used for sharing information with the patient and family, and between clinicians and services. When used for this purpose the PHR can assist clinicians to collaborate and co-ordinate care and to promote patient centred and empowering care. However, the findings also reveal that lack of engagement by clinicians with the PHR can lead to frustration and disappointment, particularly for those most connected to and invested in its use, carrying the potential to disrupt both therapeutic and professional relationships.

The study revealed conflicting goals regarding the purpose of the PHR. Most clinician's appeared to focus their use of it on promoting efficiency, primarily in the direction of value for the clinician and service. In contrast, most lay participants viewed their PHR as a tool to assist self-care and improve their chances to experience continuity. The results reveal that some well embedded ideologies, routines and rituals currently operating within the health sector have the power to constrain or restrain partnership and innovation. However, the position of the patient and family in their home appears to offer a degree of counteraction of power and agency which some patients and family had employed to influence and co-construct the use and function of their PHR with their home visiting clinicians.

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List of Abbreviations

CSFGD	Cancer services focus group doctor
CSFGN	Cancer services focus group nurse
CSR	Case study research
DNFG	District nurse focus group
DNS	District nurse service
FG	Focus group
GP	General practitioner
GPGF	General practitioners focus group
HCP	Health care professional
HFGD	Hospice focus group
HFGD	Hospice focus group doctor
HFGNC	Hospice focus group nurse community
HFGNI	Hospice focus group nurse inpatient
NZ	New Zealand
PCC	Palliative care co-ordinator
PHO	Primary health organisation
PHR	Patient held record

Chapter One – Introduction to the Study

Introduction

The focus of this study is an inquiry into the use of a paper based patient held record (PHR) within home based palliative care. Patient held record is a generic term to describe any format of record held by the patient (or their parent or primary caregiver) which contains information relevant to their health. Other terms commonly used include; personal health records, ‘log books’, ‘shared care diaries’, ‘patient travelling records’, ‘patient passports’, and ‘shuttle sheets’ (Gysels, Richardson, & Higginson, 2006; Ko, Turner, Jones, & Hill, 2010; Matthews & Byrne, 2009). These records tend to be either ‘heath care professional (HCP) focussed’ or ‘patient focussed’, the former primarily for communicating clinical information between clinicians, supporting HCPs to synchronise their patient care with each other and monitoring disease progression, whilst the latter focuses mainly on educating patients and assisting them to manage and navigate their own health and care journey (Finlay & Williams, 2002; Finlay & Wyatt, 1999). A PHR may consist of the patient’s full clinical record or that associated with a particular condition (for example cancer), treatment course (for example, course of home based intravenous antibiotic therapy), or health provider (for example their district nursing clinical file). Alternatively they may simply be a summary of aspects of the patient’s fuller clinical record held by their health provider.

As a nurse leader within the district nursing service (DNS), I led a project to implement a PHR for home based palliative patients within the study region. This research, undertaken in 2007 to complete my Master of Philosophy qualification, provided an opportunity to critically analyse the use and impact of the PHR. The following thesis presents the approach and findings of the inquiry.

Background to the study

In 2005 the region’s DNS and hospice palliative care co-ordinators (PCCs) introduced a PHR as a component of their shared home based palliative care. Its introduction arose from a liaison meeting between the two services where those present spoke of their wish to enhance continuity of care for their common patient group. The particular goals expressed were: reduce documentation and care activity duplication, foster best practice symptom management, and reduce incidence of communication breakdowns between people and

services. It was suggested that a single nursing assessment and care plan, developed, contributed to, and co-ordinated by both teams could make a positive contribution to these goals, particularly if accompanied by each team's 'delivery of care' documentation and placed with the patient. Hence the project became more broadly focussed on introducing a palliative care PHR.

A project team, made up of myself and several district nurses and PCCs, collaborated to create the desired PHR template, agree the required contents, consult with our wider teams and with palliative patients and lay carers, develop and then implement the processes required to establish use. Implementation also included a combined DNS and PCC education session regarding the aim and use of the PHR, including the shared assessment and care plan tools.

The paper based PHR implemented contained clinical information that was primarily focussed for clinician use. Both services also elected to maintain a facility held file in which to note a brief summary of clinical information for the clinician to review prior to the home visit, thereby assisting them to feel prepared. The facility held file was also necessary for documenting any 'over the phone' clinical care and advice provided (such as when the patient or lay carer phoned overnight or after hours requiring support and advice). The PHR was intended to contain information relevant to the patient's palliative condition and management and be available for patients, their lay carer(s) and HCPs to read, use, and write in. Whilst HCPs other than district nurses and PCCs were under no obligation to use the PHR during their contact with the patient, it was hoped that they would chose to do so.

The New Zealand (NZ) Palliative Care Strategy (2001a) recommends the development and evaluation of projects that seek to improve communication between HCPs and their patients and families and to promote integrated palliative care services. Similar goals are expressed in both the NZ Health Strategy (2000) and the NZ Primary Health Care Strategy (2001b), in particular, the need for services to develop more co-ordinated and complementary ways of working together. In addition, the NZ Ministry of Health document "Reducing Inequalities in Health" (2002) recommends health services implement mechanisms that increase peoples' control over their own lives, improve the ability for services to adapt to changing circumstances, and actively involve users of health care services.

Aim of the study and research approach

In keeping with these recommendations, this study has sought to explore the use of the described PHR within this region, primarily to identify and gain understanding regarding (i) impact(s) and practices associated with its use, (ii) factors considered to influence these, and (iii) opportunities and or issues for service improvement in relation to its use. These three aims are incorporated into the overarching research question - What are the impacts of using a PHR for home based palliative care patients?

A case study research (CSR) approach was selected for the inquiry. This approach is holistic in that it uses multiple sources of evidence, seeks to explore phenomena within, rather than removed from, their real life context and is an in-depth investigation into the defined and bounded case. The overall goal is to gain understanding of the case, the context surrounding the case, and the interaction between the case and context. The design does not require elimination or control of variables making it useful for research within settings, and with participants, prone to rapid and frequent changes in circumstances, such as the palliative care arena. Described as a strategy rather than a methodology, CSR can be situated within a positivist or interpretive paradigm. The theoretical framework underpinning this CSR inquiry incorporates constructivist, constructionist, and interpretivist principles, in particular that the making of meaning is both an individual and collective act and that an unlimited number of constructions regarding the same reality can simultaneously exist. Stake's (1995), (2005) and 2010) directions for conducting CSR align with this stance and therefore, have been utilised for this study. The inquiry is intrinsic in nature in that the case itself, (the use of this particular PHR for this particular patient group within this particular study region) is the primary focus of interest; the goal is to gain understanding of its use and impact from the perspectives of patients with the PHR as well as their lay carer(s) and the main groups of HCPs supporting their health needs.

Overview of chapters

This first chapter has outlined the focus and aim of the study, the researcher's background and involvement in the topic, and the research approach for the inquiry. Chapter two introduces contextual aspects associated with the study, including the role of the patient clinical record, the extended health care team, the concept of continuity of care, and challenges for its achievement within palliative care.

Chapter three provides a summary of research findings from investigations into both the theoretical and actual use of paper based PHRs within a range of settings. These studies demonstrate mixed results and a caution that interventions aimed at improving continuity can in fact have unintended and less positive impacts. Chapter four provides an outline of the CSR approach and methods selected to perform this research inquiry along with the theoretical framework underpinning and directing its implementation. Strategies for attending to ethical factors, rigor and reflexivity are also outlined.

Chapter five presents the findings from the patient and lay carer semi-structured interviews in relation to three themes that emerged from the data; use of their PHR, patient/lay carer perspectives regarding their PHR, and factors influencing engagement with their PHR. Chapter six presents the findings from the four HCP focus group discussions in relation to three emergent themes; using the PHR, drivers, barriers and challenges for use, and the perceived and or experienced impact of the PHR. Chapter seven outlines linkages between the findings of the two participant groups, particularly with regards to influences on the use and perceived function of the PHR and perceived impacts associated with its use. These linkages are located and discussed in relation to relevant literature. Key recommendations arising from the findings are presented along with a description of the study's limitations.

Conclusion

Positioned within an interpretivist paradigm, this study does not seek to generate theory or universal explanations. Instead, the aim is to gain richer and fuller understanding of the use(s) and impact(s) of a PHR for home based palliative care within this region, along with factors that appear to influence this and aspects that require improvement. Whilst any knowledge generated will be context specific, it may also be of tacit value to other settings, offering readers the opportunity to judge the findings for transferability and instrumental value to their own settings and practice. To assist the reader in this process, the following chapter provides an outline of contextual factors considered relevant to this study.

Chapter two – The case study context

Introduction

A CSR report should portray the nature of the case, particularly its activity and functioning, the informants through whom the case is known, the case's historical background, physical setting, and other relevant contexts. In addition to describing the boundary of the case in relation to its surrounding context, this 'thick description' is necessary to enable readers to both vicariously experience the case and make tacit connections to their own settings (Perry, 2011; Stake, 2010). In addition, little can be known about what a given piece of behaviour means without a description of the context in which the behaviour took place and without an attempt to see that behaviour from the position of its originator (Caronna, 2010).

This chapter briefly outlines contextual factors considered to have prompted and or influenced the PHR implementation project. These factors include the role and position of the clinical record within the health care system, the extended health team model, and the impact of this model on all clinicians having the most current clinical picture of the patient available at point of care. The concepts of continuity of care and palliative care are briefly summarised along with a description of some challenges faced by palliative patients, particularly with regards to factors that can promote discontinuity. An outline of the vision for palliative care in NZ is also provided followed by a description of the study region's interpretation of this and the local project to enhance continuity for home based palliative patients through the use of a PHR. The chapter concludes with a brief outline of the PHR concept and its use both nationally and internationally.

The clinical record, the extended health team and the sharing of clinical information

Accurate information is vital for safe and efficient clinical decision making. Accordingly, patient clinical records are "a cornerstone of the health care information system"; an indispensable tool for organising and summarising health care and for sharing information between HCPs (Milliat-Guittard et al., 2007, p. 475). In most care settings patient clinical records are held by the service providing the patient care; their contents constructed through multiple patient and service contacts and therefore promoting informational continuity for that patient within that particular service (Agarwal & Crooks, 2008). However, the extended

health team (HCPs from more than one service contributing to care) is now a common feature of the health system with each service tending to compile and hold a clinical record regarding that patient. Consequently, a full clinical picture of the patient is unlikely to reside in a one single record. Separate and fragmented record keeping makes seamless information transfer between clinicians and organisations impossible (Rigby et al., 1998). Furthermore, patients can become frustrated and annoyed at having to repeat information when their clinicians lack knowledge about their case (Cotter, 2007).

Although the extended health care team is a necessary feature of a modern health system, challenges arise from “increased specialisation, differentiation and fragmentation between different care organisations” (Bodenheimer, 2008, p. 807). Whilst all members of the extended team are likely to share the common goal of providing quality care, many do not operate from within the same organisation and employment circumstances or professional practice models and care delivery systems; their services are likely to have different structures, processes, values and priorities. Such differences can impact on the potential for providers to “communicate symmetrically with each other” (Helleso & Lorensen, 2005, p. 818). In addition, different models of care and record keeping with each service can perpetuate divisions between professions and organisations.

Evidence suggests that cohesive service delivery can only be achieved by the extended health team through “good communication and shared clinical perception of a patient’s problems and needs, hence seamless care is difficult to achieve without seamless transfer of information” (Rigby et al., 1998, p. 579). For shared care to be effective and efficient, organisational and professional barriers to this need to be overcome. Clinical information systems are key to enhancing continuity where more than one provider is involved, particularly through the use of integrated clinical records that both patients and all providers can access and contribute to (Agarwal & Crooks, 2008; Cotter, 2007; Helleso & Lorensen, 2005; Milliat-Guittard et al., 2007).

The call for strategies to address discontinuity by promoting broader and more timely sharing of information is echoed widely in contemporary health care literature (Protti, 2009). Several studies that explored the level of integration and adequacy of communication between primary and secondary care teams highlighted that both clinicians and service users had found communication between services to be too slow, incomplete or absent (Farquhar et al., 2005; Goodare & Nadim, 2006; McCann, 1998). Each of these studies led to the introduction of a

PHR in order to improve the content and speed of communication between services and put the patient at the centre.

Continuity of Care

Continuity of care is a commonly used term within the health sector and users seem to assume it has a consistent and well-understood meaning (Helleso & Lorensen, 2005). The term appears to encompass both an aim and a philosophy affecting the delivery of health care to individuals and their families. However, whilst continuity is described as a critical determinant of quality health care it is also considered to be a complicated concept consisting of interrelated dimensions (King et al., 2008; Uijen, Schers, & van Weel, 2010).

A significant research programme commenced by the Canadian Health Services Research Foundation in 1999, and in 2000 by the United Kingdom's National Co-ordinating Centre for Service Delivery and Organisation Research and Development, brought much needed clarity to the concept of continuity (Freeman et al., 2007). From this work, continuity has been defined as the experience of a co-ordinated and smooth progression of care from the patient's point of view, where discrete aspects of care are effectively linked through a common individualised management plan that adapts to patient need. As such, continuity "links past care to current health care and provides a known pathway for future care" (Freeman et al., 2007, p. 51). To achieve this services need: excellent clinical information transfer and co-ordination between HCPs and services, effective communication between HCPs and the patient and or their family, flexible care that adjusts to the needs of the individual and their family over time, care from as few HCPs as possible, and the provision of one or more named individual professionals with whom the patient can establish and maintain a therapeutic relationship (Freeman, Shepperd, Robinson, Ehrich, & Richards, 2001; Nair, Dolovich, Ciliska, & Lee, 2005; Parker, Corden, & Heaton, 2010).

Similarly, the Canadian research identified two core elements and three types of continuity; element one - that continuity can only exist as an aspect of care that is experienced by an individual, and element two - that care is received over time. Both elements need to be present for continuity to exist; however, their presence alone does not constitute continuity. The three types of continuity suggested were: (i) informational continuity - the use of information regarding prior events or circumstances to assist current care decisions and to link care between HCPs and health events, (ii) relational continuity - the development and

maintenance of a therapeutic relationship between a patient and one or more HCPs, aimed at linking past, current care, future care, and (iii) management continuity - the use of a complementary, consistent, and collaborative approach to ensure care delivery is flexible and adapts to changing patient need (Haggerty, Reid, McGrail, & McKendry, 2001).

As an experience rather than an attribute, characteristic or process, continuity is distinguished from other related concepts such as care co-ordination and integrated care (Reid, Haggerty, & McKendry, 2002). However, experienced continuity is also an outcome, produced by the system or organisation, by individual HCPs, and by the patient and or carers interaction with their health services, with relational, informational, and management factors the processes that produce this outcome (Baker et al., 2005). One or more processes may be needed to produce experienced continuity, depending on a number of factors such as patient preference, developmental stage, or particular health care need. As such they are not three distinct types of continuity, but rather intertwined dimensions "that link to create a coherent whole" (Reid et al., 2002, p. 4). Saultz (2003) argues that informational continuity provides the foundation on which management and relational continuity is built.

Overall, continuity of care is not an isolated or one-dimensional attribute. It is characterized by collective attributes yet is also a personal and individual experience that will mean different things for different individuals and in different contexts (Haggerty et al., 2003). In addition, due to the experienced nature of this phenomenon the presence of relational, informational, and management features alone may not guarantee continuity, for "continuity is how patients experience integration of services and co-ordination" and therefore is most meaningful when viewed from the perspective of the service user (Dolovich et al., 2004; Haggerty et al., 2003, p. 1220; Ware, Tugenberg, & Dickey, 2003). The next section of this chapter focusses on palliative care as the context for the implementation of the PHR.

Palliative care

Palliative care is defined as "an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification, impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual" (World Health Organization, 2002). Both a philosophy and framework for care, palliative care affirms life, regards dying as a normal process and seeks to neither hasten nor prolong death. Using a team approach, a

support system is offered to help people live as actively as possible until death and to help both patients and their families cope during the illness and in their own bereavement (E. Davies & Higginson, 2004)¹. The verb palliate, which means to alleviate, give temporary relief, lessen severity or to improve the quality of something is derived from the Latin term, 'palliare' - to cloak or cover. The term denotes a sense of wrapping the patient and family with support in order to preserve and enhance quality of life, provide protection from suffering, promote dignity and a patient centred approach to care, all with the goal of positively influencing the course of the illness (Institute for Clinical Systems Improvement, 2011; Pastrana, Jünger, Ostgathe, Elsner, & Radbruch, 2008). Once considered to apply only to those who were dying the scope of palliative care is now much broader, extending its philosophy and framework of care into the earlier stages of life limiting disease management for both malignant and non-malignant illnesses. Hence, palliative patients exist on a dynamic continuum between stable and actively dying (Leach, 2010; McIlpatrick, 2007).

Challenges for continuity within palliative care

Most palliative patients and their families are likely to face the following eight domains of issues as a minimum: disease management issues, physical challenges, psychological, social, spiritual and practical issues, loss and grief, and end of life care or death management (Howell, 2007). Multifaceted and complex needs are likely to surface within most if not all of these domains which can rarely be addressed by a single discipline and service alone. Consequently, an interdisciplinary approach within palliative care is advocated (Blackford & Street, 2001; Gysels et al., 2006; McDonald & McCallin, 2010).

As noted earlier, the involvement of multiple disciplines and services can bring challenges for continuity. Patients and families can feel overwhelmed and confused as they attempt to keep track of all who are involved in their care, in particular, knowing who to contact, in what circumstances and the processes required for doing so (Devlin & McIlpatrick, 2009; Stajduhar, Martin, Barwich, & Fyles, 2008). Multiple providers also impact on the opportunities for patients and families to develop and maintain therapeutic relationships with the various members of their health team. Such relationships are important for assisting patients and lay carers to feel recognised and involved, secure and confident in their own ability to cope and to gain a sense of confidence and reassurance, not only in the skills and expertise of the health

¹ Initial for first name has been used for different authors with the same surname in accordance with APA 6th ed.

professionals with whom they have a positive relationship, but also that their health care team will be there to support them when needed (Docherty et al., 2008; Funk, Allan, & Stajduhar, 2009; Linderholm & Friedrichsen, 2010; Stajduhar et al., 2008).

A person requiring palliative care may move rapidly between primary, secondary, home, clinic, hospital, and hospice based services – depending on their physical and emotional needs. Effective inter-team, service, and discipline communication is crucial to prevent discontinuity at these transitions; however, the greater the number of disciplines and services involved, the more difficult this is to achieve (Devlin & McIlpatrick, 2010). Evidence of ineffective communication, co-ordination and co-operative planning between and across all services, lack of awareness, consensus or value regarding each other's roles and responsibilities, coupled with varying levels of palliative care confidence, knowledge and expertise and conflicting models of care and service across different care settings have been identified and contribute to this challenge (Dudgeon et al., 2009; McDonald & McCallin, 2010; Meier & Beresford, 2008; National Institutes of Health, 2005; Shipman et al., 2008).

Unplanned transitions can commonly occur within palliative care, often attributed to acute exacerbations or crises driven management arising from inadequate advanced care planning, services working in a ‘silenced’ fashion or where there is not one designated person providing the role of co-ordination across all services and the journey of care. Such occurrences further add to the challenge of promoting continuity (Abarshi et al., 2010; Kristina Thomas, Hudson, Oldham, Kelly, & Trauer, 2010). Delays in end of life prognosis, planning and timely referrals to palliative care services can also lead to unplanned and crisis driven transitions. Such delays can be associated with lack of experience and or confidence in determining the point at which the focus needs to shift from curative to supportive and palliative care (particularly in the case of health decline associated with non-cancer related conditions) or physician reluctance to form and communicate such prognoses to patients and families (Barclay & Maher, 2010; Boyd & Murray, 2010; Delamothe, Knapton, & Richardson, 2010; Fins, Peres, Schumacher, & Meier, 2003; Seymour, French, & Richardson, 2010).

As patients move between care settings, their current health information is often not readily available in a timely manner. While this is an issue for all settings, it is of particular concern for the management of acute symptoms occurring after hours. Clinicians providing after-hours support are less likely know the patient and have limited or no opportunity to access such information from the patient's usual health team (Brumley, Fisher, Robinson, & Ashby, 2006;

De Bock et al., 2011; Worth et al., 2006). Lack of information at point of care can bring delays in care, duplication of assessments, tests and interventions, conflicting recommendations leading to lack of a consistent and coherent approach to care, increased use of hospital and hospice inpatient services, poorly informed discharge planning, and lack of follow up (Dumont, Dumont, & Turgeon, 2005; Marsella, 2009; McIlpatrick, 2007; Neergaard, Olesen, Jensen, & Sondergaard, 2008). Lack of information at point of care can also lead to patients and or lay carer(s) having to repeat their story to various HCPs and to be responsible for accurately transferring information that will impact on their clinical management. This is both a burden and concern for those who have decreased cognition due to the effects of their illness or medication and can impact on their ability to accurately describe current medications, names of other HCPs involved in their care, tests completed, and other vital aspects of on-going care (Latimer, Crabb, Roberts, Ewen, & Roberts, 1998).

Contemporary health care trends have brought a shift towards more home based palliative care, including end of life care; such an approach relies on the presence of lay carers and their ability to cope with and contribute to such care (Linderholm & Friedrichsen, 2010; Stajduhar et al., 2008). Lay carers are placed in the position of taking on more and more aspects of care that historically would have been provided by nurses, either in the home or within a care facility and the level of burden this places on lay carers is well documented (Andershed, 2006; Funk et al., 2010; Glajchen, 2004). Factors such as loss of employment or financial security, lack of information, support and education, disrupted family and social relationships, and the psychological impact of diagnosis and disease management can greatly inhibit the ability of patients and families to function in this self-care role, seek out necessary services and cope with impending death (Conkling, 1989). Impact(s) and experience(s) of discontinuity further add to this burden; all of the issues described above carrying the potential for patients and their families to experience increased suffering, discomfort, stress, anxiety, distress, insecurity, loss of control, vulnerability, and fear. Such factors have also been linked to patients and carer(s) feeling overwhelmed and no longer able to manage home based palliative care (Stajduhar et al., 2008; Keri Thomas, 2003).

Addressing the continuity of care issues outlined above requires well-coordinated and integrated responses, with all providers following a common approach and services delivered in a timely, uninterrupted and coherent manner (Anderson & Parent, 2004). Effective communication is considered a key aspect for this; however, whilst much information is gathered by various HCPs as they evaluate patients for their specific services, it is often not

transmitted to those who will be following the patient during the next phase of care. Better methods are required for gathering, documenting, and transmitting such information in a consistent and organised fashion to ensure information critical to proper planning and patient functioning is easily accessible to all those involved in patient care.

Palliative care in New Zealand

The NZ Palliative Care Strategy (2001a, p. 7) vision is that “all people who are dying and their family/whanau have access to quality palliative care services that are culturally appropriate and are provided in a co-ordinated way”. The need for co-ordination within and across palliative care is repeated throughout the document along with a call to address issues such as lack of integration and inflexibility of services, noting that

“Generally there appears to be little co-ordination or integration of services among providers (for example, in some places there are poor relationships between hospice staff and district and hospital nurses). Family members and people who are dying are reportedly having to navigate their own way through the different services, thus acting as the co-ordinators of their own care” (Ministry of Health, 2001a, p. 48).

The Palliative Care Subcommittee of the NZ Cancer Treatment Working party (2007, p. 4) define general practice teams, along with district nurses, residential care staff, Māori health providers and allied health teams as the providers of generalist palliative care and specialist palliative care as that provided by “clinicians who have undergone specific training and/or accreditation in palliative care/medicine, working in the context of an expert interdisciplinary team of palliative care health professionals”. They also recommend: (i) that the primary care team provides the continuity for the patient during their illness, (ii) that specialist palliative care services operate as a consultancy service to primary care providers, on the basis of assessed need, rather than simply because of diagnosis or prognosis, (iii) where specialist palliative care services are required, an integrated approach that recognises the roles and responsibilities of both generalists and specialists be used, and (iv) an integrated framework with defined and formal linkages to key services is essential for effective palliative care.

The local model of palliative care

The local palliative care model has evolved through on-going efforts by the region’s hospice and key partners to implement the above principles and recommendations. In 2002 an interdisciplinary working party envisaged a palliative care partnership aimed at optimising the

skills, resources and expertise of both generalist and specialist services, so as to provide the best possible palliative care to the community. The model of integration that emerged is built upon formal collaborative agreements and arrangements between the region's hospice and District Health Board (DHB), Primary Health Organisation (PHO), general practice teams, needs assessment co-ordination service, DNS, hospital-based palliative and oncology services, residential care facilities, and a university based specialist psycho-oncology service.

Within this model the hospice provides both community and in-hospice based specialist palliative care services. Included in the community component are PCCs (implemented as a nursing role), a chaplain, social worker, pharmacist, and several specialist palliative care physicians. The PCCs provide oversight and co-ordination of all home based palliative patients receiving assistance from the hospice, including regular home visits to the patient and regular liaison with their district nurse, general practice team and other key members of their wider health team. In addition to medical management for in-hospice patients, the hospice physicians support general practice, providing outpatient specialist assessment, diagnostic and treatment advice for referred patients. The general practice team provides all primary services for their patients, including their generalist palliative care, drawing assistance from the hospice team as required.

The palliative care contribution of secondary care services includes the hospital based specialist palliative care team (for advice and support for hospital in-patients), specialist cancer services (for palliation chemotherapy/radiation treatment), and the DNS who provide the nursing management for patients with palliative needs requiring more regular and time intensive support than the general practice and PCC can deliver. This management includes, but is not limited to, regular nursing assessment, identification and management of symptoms, syringe driver therapy, hygiene and other personal cares, continence management, skin and wound care, and psychological support. The DNS and hospice collaboratively provide after-hours acute support for home based palliative patients. Both services operate twenty four hours a day, seven days a week, enabling such needs to be supported regardless of the patient's location in the region. The region's needs assessment and co-ordination service and local support services are also key contributors, providing home management and personal care support to palliative patients or residential care based support where necessary.

The local project to enhance continuity for home based palliative patients

A shared desire to enhance continuity of care for home based palliative patients prompted the DNS and hospice PCC collaborative project to implement a PHR in 2005, thereby enabling all HCPs involved in each patient's end of life care to have access to a more complete clinical picture than previously available.

On admission to their service the region's hospice already gave patients a small booklet, outlining how the hospice would work in partnership with their general practice team including a summary of their joint plan to care for the patient and family. This booklet had a small section for clinicians to note key points arising from their patient visit, however, the project team felt it was not large enough for the more detailed record of each patient interaction sought for the proposed PHR. Therefore, it was decided that on admission to the DNS, palliative patients would be given a larger folder to accommodate the more detailed care delivery documentation and joint nursing care plan. The hospice booklet containing useful historical information would then be slotted into a section of the new PHR.

A standard A4 medium sized ring binder was used with dividers between each of the different sections of information stored in the folder. The first page listed key points regarding the purpose and use of the PHR as well as explaining that patients may choose not to have one. The new folder was trialled with a small number of district nurse patients. Feedback from these patients, their families, district nurses and PCCs regarding ease of use, lay out and contents led to minor adjustments to its contents and the layout of the shared care plan. The finalised PHR was then launched to both services at a shared education day. Education to general practice teams was approached in a more informal manner, with the PCCs demonstrating the PHR to each general practice team during their usual liaison discussions. Whilst clinicians other than district nurses and PCCs were under no obligation to use the PHR during their contact with the patient, it was hoped that they would chose to do so. However, education sessions for other services and clinicians likely to come in contact with the patient did not occur, although patients and family members were encouraged by the district nurses to take their PHR to all health care appointments (including hospice or hospital admissions) and offer it to their HCPs in those settings to use and write in.

The DNS opted to use the PHR as their main patient care record and to keep a summary patient 'DNS base file' for noting brief key points, intended to act as a 'communication between shifts' tool. If care was provided over the phone rather than a home visit, the

telephone based care would be documented fully in the DNS ‘base file’. In contrast, the Hospice PCCs continued to document their assessment and care delivery information in the Hospice’s multidisciplinary team electronic patient information system, as well as writing in the PHR. Hence the Hospice PCCs experienced quite a degree of clinical documentation duplication. As the PHR was also the main patient care record for the DNS, upon discharge its contents were retrieved and filed in the wider hospital services clinical records department. Families could request a copy of any contents if they wished.

At the end of a six month trial period, the project team facilitated a combined DNS and PCC forum to review the strengths, weakness, benefits and disadvantages of the PHR. Both services confirmed their support for continuing the use of the PHR and the shared assessment and care plan tools within it for home based palliative care patients.

The patient held record concept

Patient held records have been in use for many years in a number of countries and areas of health care including: antenatal, child health, rehabilitation, primary and community care, long term condition management, mental health, cancer, and palliative care. Although the World Health Organisation has advocated use of a medical passport since 1964 (Liaw, 1993), the use of PHRs is becoming more prominent due to changing ideology regarding patient access to their own health information and attention to continuity of care (Brunero, Lamont, Myrtle, & Fairbrother, 2008; Detmer, Bloomrosen, Raymond, & Tang, 2008; Finlay & Williams, 2002; Fisher, Bhavnani, & Winfield, 2009; Forsyth, Maddock, Broadbent, Ledema, & Lassere, 2008; Greasley, Pickersgill, Leach, & Walshaw, 2000; M. Johnson, 2011; S. Johnson & Mayor, 2002). A number of countries have health policies which recommend the use of PHRs, either in paper based or electronic format (contained on a computer data base, a mobile electronic device such as a ‘smart card’ or web-based), particularly for those with complex health needs with multiple staff and services involved in their care (Cornbleet, Campbell, Murray, Stevenson, & Bond, 2002; Lecouturier, Crack, Mannix, Hall, & Bond, 2002; National Health Service Modernisation Agency, 2003; Ross & Lin, 2003; Tang, Ash, Bates, Overhage, & Sands, 2006; Waegemann, 2005; Wibe, Hellesø, Slaughter, & Ekstedt, 2011).

Within Australia and NZ the use of a PHR also appears to be expanding, particularly within primary health care (PHC), diabetes, stroke care, cancer, and palliative care (Barrett, 2003; Capital and Coast District Health Board, 2009; Forsyth et al., 2008; Hornsby Kuringai Ryde

Division of General Practice, 2005; Matthews & Byrne, 2009; G. Mitchell, Douglas, Connor, Bucetti, & Clifford, 2009; New South Wales Health Department, n.d.; Waikato District Health Board, 2009; Wairarapa District Health Board, 2008; Waitemata District Health Board, 2009). Despite the rise in calls for electronic PHRs paper based formats continue to be the most common (Niederkorn, 2009).

Pragmatic issues such as efficiency have also prompted PHR use (D. Johnston et al., 2007). In 2004, in response to concerns that scarce services and resources were not being maximised due to fragmentation and duplication, the West Coast PHO and DHB implemented a PHR along with several other initiatives aimed at promoting cost effective and cohesive interdisciplinary diabetes services (Atmore, 2007). A similar goal for efficiency prompted one community health service to implement an integrated PHR, aimed at reducing the “10 or more different sets of concurrent paper based notes for the same patient – none of which linked with anyone else” (Wairarapa District Health Board, 2008, p. 21).

Descriptions of PHRs from across the above range of settings highlight variation in content, format and use. These variations appear to be associated with two factors: (i) the primary aim or function for which it was introduced, and (ii) the nature of the PHR lead developer(s) or champions (e.g. if they were HCPs, service users, patients, nurses, or a combination of all). ‘Health care professional focussed’ PHRs tend to emulate facility held clinical records and are likely to include at least some or all of the following information: key patient and health care assessment, care planning, care delivery, care evaluation, treatment, follow up, monitoring, medication information and instructions, sections for health care staff and patient/primary carer notes. In addition, the function, format and content of ‘HCP focused’ PHRs appear less likely to be shaped, determined and personalised by the patient and/or their primary lay carer and more by the HCPs using and documenting in them. In contrast, ‘patient focussed PHRs’ tends to have a less structured content and format, encouraging patients/lay carers to shape how they use them, particularly those which are established by the patient/family themselves. Some PHRs attempt to deliver both ‘HCP and patient focussed’ aims and functions (Finlay & Williams, 2002; Finlay & Wyatt, 1999; Niederkorn, 2009; Rawlings, 2007).

Conclusion

The chapter has provided an outline of key factors considered of contextual relevance to this CSR project, including the concept of continuity of care and the nature and philosophy of

palliative care internationally and within NZ and the study region. The emergence of the extended health team and the challenge for promoting collaboration and informational continuity when multiple clinicians and services are involved in patient care has also been touched on, particularly in relation to those with complex health needs such as palliative patients and their families. The chapter has concluded with a brief description of the PHR concept and its use both internationally and within NZ. The following chapter presents arguments regarding theoretical benefits and risks associated with PHRs and a summary of research findings from 23 studies that investigated the actual use of paper based PHRs within a range of settings.

Chapter three – Studies exploring patient held record use

Introduction

Although reasonably widespread in some areas, both positive and negative perspectives regarding PHR use continue to be outlined. This chapter presents a brief overview of such perspectives, arising from studies which have explored theoretical patient access to their facility held medical records, theoretical use of a PHR and emerging opinions regarding the topic of personal health records. The arguments raised highlight the need to explore the experiences and perspectives of those who have actually had and used a PHR in order to ascertain whether these theoretical impacts were found to occur. The second section of this chapter provides a summary of research findings from 23 studies that investigated the actual use of paper based PHRs within a range of settings. The chapter concludes with a rationale for the research and a suggested approach for further research into the topic.

Theoretical views regarding the use of a patient held record

Potential benefits

Proponents suggest a PHR may improve communication and timely information transfer, clarify treatment goals, reduce inconsistencies in care, assist to harmonise care activities between HCPs, and enable after hours clinicians to access necessary clinical information no matter where they are seeing the patient (Farquhar et al., 2005; Goodare & Nadim, 2006; Rawlings, 2007). All of these aspects carry the potential to prevent investigations or explanations being repeated unnecessarily, assist with emergency consultations, improve co-ordination of care and symptom management, reduce direct medical costs, and enhance quality of care. Advocates also suggest PHRs could provide patients with more, accurate and less contradictory information, thereby assisting them to participate in their care, monitor their own progress, prepare for appointments, communicate with and ask questions of their HCPs, and generally promote enhanced self-management (Gilhooly & McGhee, 1991). Use of a PHR can also remove the burden from patient and families to be solely responsible for accurate verbal transfer of detailed clinical information (Hooker & Williams, 1996; McCann, 1998) and may be helpful for mobile populations (Schoevers, van den Muijsenbergh, & Lagro-Janssen, 2009; Witry, Doucette, Daly, Levy, & Chrischilles, 2010).

Proponents of a PHR also note the opportunity for patients to pick up inaccuracies and gaps in care (e.g. tests and follow up recommended but not performed), thereby enhancing health care efficiency and quality of care (Niederkorn, 2009; Reti, Feldman, & Safran, 2009). On a more psycho-social note, a PHR may improve communication about illness within the family, with the notes providing a focal point to initiate discussion about difficult topics (Gilhooly & McGhee, 1991). Overall, PHRs may reduce the imbalance of information, and hence power, between patients and clinicians, fostering increased communication and trust between patient and HCP, enhancing patient involvement and control, and enabling patients to feel more supported, less uncertain and anxious (Reti et al., 2009; Tenforde, Jain, & Hickner, 2011). Introducing a PHR, with the associated need to establish collaborative arrangements for its use, offers a useful preliminary step towards introducing shared electronic health records (Letrilliart et al., 2009).

Concerns and potential risks

Less positive perspectives in relation to proposed PHR use include the risk that patients may find their PHR to be a burden or experience distress from reading it; they may misunderstand its contents unless information is focussed and channelled by doctors, therefore requiring longer consultations for explanation, and increased time demands on clinicians to read through and write in the PHR as well as keep their own clinical notes (Finlay & Williams, 2002; Fisher & Britten, 1993; Liaw, 1993). In one study exploring the theoretical option for patients to hold their own medical information, half the patient participants were concerned about losing or forgetting to bring their PHR to appointments and slightly less than quarter felt concerned that reading it would “plunge them even deeper into this disease that they would just as soon forget” (Milliat-Guittard et al., 2007, p. 478). In a similar study, 13% of cancer patients declined to have a PHR due to concern it would make them anxious (Drury et al., 2000). Concerns about marginalisation through reduced direct verbal communication to the patient, particularly for those with cognitive decline, have also been expressed along with concerns that a PHR could “expose” different views held by various members of the health team and varying approaches to care delivery, all of which could cause confusion and anxiety for patients (Ayana, Pound, & Ebrahim, 1998, p. 334). Asking patients or their carers to prompt HCPs to read and document in their PHR it could cause discomfort for them, particularly if the HCP appeared disinterested or uncommitted to its use. Concerns over antagonising their HCP could make patients/lay carers feel vulnerable and a sub-optimal response from their HCP could provoke distressing feelings for them (Finlay & Williams, 2002).

The risk for PHRs to encourage litigation or doctor shopping, arising from the patient – doctor relationship being adversely affected by what was read in their notes or because patients no longer feel tethered to a facility that held their notes, have also been expressed, along with concerns that PHRs could promote hypochondria, problems with confidentiality, and mis-use of their health information such as for drug seeking activities (Liaw, 1993; McGhee, Hedley, Jones, & Cheng, 1991; Tang et al., 2006; Witry et al., 2010). Specific concerns associated with potential implementation of electronic PHRs included concerns over accuracy of the record, particularly in relation to the patient's right and ability to change its contents, concerns about who would enter data into the record and maintain its currency, concerns about managing access to potentially sensitive information, and challenges associated with ensuring different providers with different IT systems could still view and ‘upload’ information to the PHR (Binnersley, 2009; Detmer et al., 2008; Dickerson & Sensmeier, 2010; Reti et al., 2009; Simborg, 2009; Tang et al., 2006; Weitzman, Kaci, & Mandl, 2009; Witry et al., 2010).

Studies investigating the impact of using of a paper based patient held record

As noted earlier, the above arguments arise from theoretical considerations. To gain further clarity regarding the experiences of patients, families and HCPs with actual use of a PHR, a review of literature specifically related to research inquiries into outcomes associated with their use was conducted. CINAHL, Medline, Ebscohost, Pubmed, Ovid, Web of Science, and Google Scholar were searched for articles using the search terms ‘patient held’, ‘personal’ or ‘client held’, ‘patient access’, ‘health record’ and ‘medical record’ and meeting the following conditions: (i) a paper based formal record given to the patient that contains key patient and health care information and sections for additional clinical notes or patient/family notes to be recorded, and (ii) the patient is given this record to keep and to take to health appointments, help manage health care tasks, circumstances and communication.

Publications dated from 1985 through to December 2011 were selected. Reference lists were also searched for additional relevant work. During the search for literature it was noted that research studies into the use of a patient held or patient accessible records have moved in more recent years to those associated with electronic or web based PHRs.

The number and categories of publications found, along with those subsequently excluded is shown in Figure one. This Figure also indicates the health care arena in which the PHR was used and the primary focus of the PHR (as able to be determined from the description

provided in the article), according to the three categories described in the previous chapter. The research approach and participants involved in each study are also noted. Summarised findings of these studies are presented within the following themes: patient and lay carer perspectives, HCP perspectives and differing views of function and purpose.

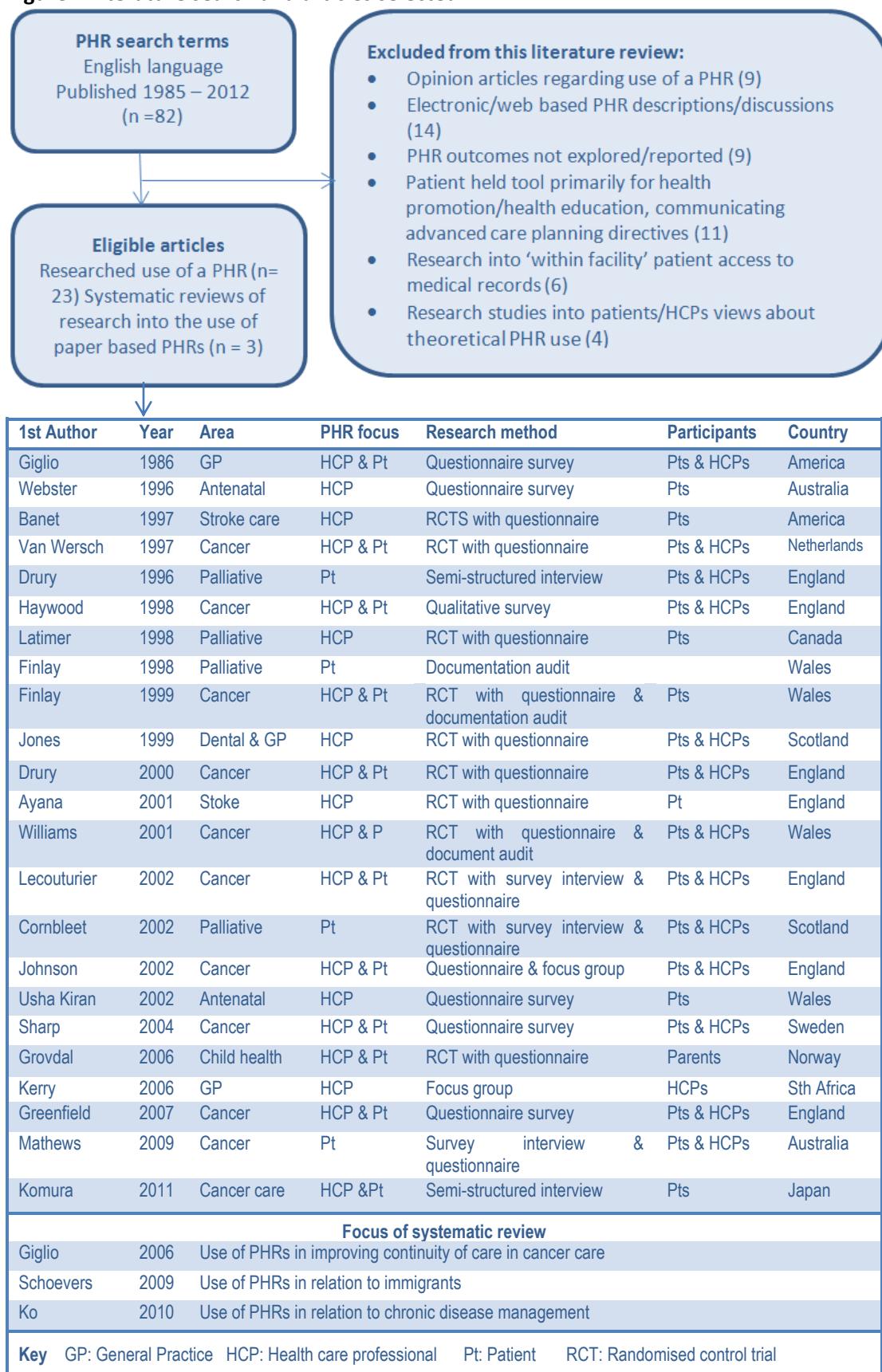
Patient and lay carer perspectives

Patient and lay carer use of their patient held record

In the majority of studies patients and lay carers reported reading their PHR, with the exception of three studies (Kerry, 2006; Latimer et al., 1998; Webster et al., 1996). In just under half of the studies reviewed patients/lay carers had also written in their PHR (Bjerkeli Grovdal, Grimsmo, & Ivar Lund Nilsen, 2006; Cornbleet et al., 2002; Drury et al., 2000; Finlay, Jones, Wyatt, & Neil, 1998; Finlay & Wyatt, 1999; Greenfield & Jones, 2007; S. Johnson & Mayor, 2002; Komura et al., 2011; Matthews & Byrne, 2009; Sharp, Laurell, Tiblom, Andersson, & Birksjo, 2004; van Wersch et al., 1997; Williams et al., 2001). In one study evaluating 50 palliative care PHRs, 41% (n=495) of all entries were made by patients, 11% (n=133) by relatives and 43% (n=526) by HCPs, with some containing “rich reflective comments by patients about their condition and situation and written replies from staff” (Finlay et al., 1998, p. 397). Another study found that 53% (n=36) of patients/lay carers wrote in their PHR (Lecouturier et al., 2002).

Reasons offered for not reading their PHR included: poor vision, relatives reading it for them, considering its contents were not their business, or wanted to leave decisions and involvement to their HCPs (Drury, Harcourt, & Minton, 1996; Komura et al., 2011; van Wersch et al., 1997). Reported reasons for not writing in their PHR included: illness, relatives wrote in it instead, felt unsure, to uncomfortable or intimidated by it, felt their experiences were not the concern of other people, preferred to raise points in person with their HCP, not enough space, and preferred to write in their own notebook (Cornbleet et al., 2002; Drury et al., 1996; Finlay & Wyatt, 1999; Greenfield & Jones, 2007; Komura et al., 2011; van Wersch et al., 1997). Finlay and Wyatt (1999) also suggest that format may have influenced patients’ and families’ confidence and ease to write in their PHR, finding from their inquiry into both a structured and unstructured PHR format that patients with the unstructured style reported more positive factors in relation to their PHR.

Figure 1 Literature search and articles selected



Mixed results emerged regarding patients/lay carers taking their PHR to health appointments and or offering it to their HCPs to read and write in, with high rates, (Banet & Felchlia, 1997; Drury et al., 2000; Giglio & Papazian, 1986; Lecouturier et al., 2002; Usha Kiran & Jayawickrama, 2002; van Wersch et al., 1997), moderate rates, (Cornbleet et al., 2002; Matthews & Byrne, 2009) and low rates reported (Bjerkeli Grovdal et al., 2006; R. Jones et al., 1999; Webster et al., 1996). Reasons associated with low rates included forgetting to take it or considering it too personal to share (Drury et al., 1996; Komura et al., 2011; Webster et al., 1996). However, Giglio and Papazian (1986) found participants were more likely to transport a smaller sized PHR, perhaps due to convenience of fitting it in their carry bag.

Health provider interest and engagement with the patient held record

In the majority of studies reviewed patient/lay carer participants reported that some HCPs appeared disinterested, too busy or reluctant to use their PHR. Indeed, only six studies did not highlight this issue (Drury et al., 1996; Drury et al., 2000; R. Jones et al., 1999; Latimer et al., 1998; Usha Kiran & Jayawickrama, 2002; Webster et al., 1996). Such reluctance was frequently reported by lay participants as disappointing and some indicated it had discouraged their own use of their PHR (Finlay & Wyatt, 1999; Greenfield & Jones, 2007; Komura et al., 2011) and made them reluctant to transport, offer and promote its use at HCP appointments (Bjerkeli Grovdal et al., 2006; Cornbleet et al., 2002). Lay participants in two studies reported difficulties persuading staff to write in their PHR, associating this with disinterest on behalf of those HCPs (Ayana, Pound, Lampe, & Ebrahim, 2001; van Wersch et al., 1997). Several other authors also drew correlations between HCP level of interest and engagement with the PHR and lay participants' perceived value of their PHR and desire to have a PHR (Lecouturier et al., 2002; Williams et al., 2001).

Value obtained from their patient held record

Across the 25 studies reviewed four subthemes emerged regarding the value that patients/lay carers obtained from their PHR; these are outlined below.

Feeling more informed

The patient and family's sense and experience of being better informed by reading their PHR were frequently commented on. Lay participants in several studies indicated high regard for the sections in their PHR which were designed to provide clarity about their condition, signs and symptoms to monitor, who to contact, and other self-care advice (Greenfield & Jones,

2007; Haywood, 1998; Matthews & Byrne, 2009). Some lay participants noted that being able to read their PHR had improved their knowledge and grasp of their situation and of their/their child's/their partner's health (Banet & Felchlia, 1997; Bjerkeli Grovdal et al., 2006; R. Jones et al., 1999; Komura et al., 2011; Lecouturier et al., 2002; Sharp et al., 2004; van Wersch et al., 1997). Being able to read their PHR appears to have provided reassurance, a sense of increased control, and reduced uncertainty for some (Latimer et al., 1998; Sharp et al., 2004; van Wersch et al., 1997; Webster et al., 1996; Williams et al., 2001). The value of the PHR as an aide memoire was noted in many studies, as was being able to update at their own convenience (Greenfield & Jones, 2007; Matthews & Byrne, 2009; Williams et al., 2001), use it as a handy reference to keep track of past and future events, medications and treatment advice, or to assist them to answer HCPs' questions (Drury et al., 1996; Finlay & Wyatt, 1999; Haywood, 1998; S. Johnson & Mayor, 2002; Lecouturier et al., 2002).

Promoting communication with health care providers and family

A significant number of patients and family wrote in their PHR and this was highlighted as particularly therapeutic by some patients/lay carers (Finlay & Wyatt, 1999). Over half the participants in Johnson and Mayor's study reflected that their PHR had "provided an opportunity to write about their experiences, record their symptoms and monitor their progress" (S. Johnson & Mayor, 2002, p. 186). Overall, the PHR was found to be useful for informing their HCPs of their concerns, preferences, symptoms, and questions (Drury et al., 1996; Finlay & Wyatt, 1999; Greenfield & Jones, 2007; Komura et al., 2011); some indicated they had given their PHR to their HCPs to read specifically to avoid their repetitive questioning (Lecouturier et al., 2002; Matthews & Byrne, 2009). The PHR was also noted by lay participants in some studies to make it easier to question their HCPs and to promote dialogue (Bjerkeli Grovdal et al., 2006; Cornbleet et al., 2002; S. Johnson & Mayor, 2002; Webster et al., 1996). Some patients also found their PHR assisted them to talk about their condition and communicate their wishes for its management and end of life care to their families (S. Johnson & Mayor, 2002; Komura et al., 2011; van Wersch et al., 1997).

Promoting involvement with their own care

Lay participants reported that the increased understanding obtained from their PHR made it easier to be more active and to feel more involved in their own care (Bjerkeli Grovdal et al., 2006; Drury et al., 1996; Komura et al., 2011; Sharp et al., 2004); some indicated that they wrote in their PHR specifically to help them keep track of their own treatment, progress and

future events they needed to remember, prepare for and prompt others about (Finlay & Wyatt, 1999; Greenfield & Jones, 2007; S. Johnson & Mayor, 2002). Williams et al. (2001) also found that participants with a PHR expressed less difficulties preparing for their health care encounters than those without a PHR. In another study, one carer highlighted the value of being able to read notes written in the PHR from HCP encounters she had not been able to attend with her partner (the patient), thereby promoting a sense of involvement and reassurance for her (Sharp et al., 2004). Overall, the perceived value of the PHR may explain why some felt they should have received their PHR at time of diagnosis rather than later in their health care journey (Finlay & Wyatt, 1999; Greenfield & Jones, 2007; S. Johnson & Mayor, 2002; Latimer et al., 1998; Lecouturier et al., 2002; Matthews & Byrne, 2009).

The patient held record as a source of stress

Concerns that some patients/lay carers may find a PHR to be a burden, both in the practical and emotional sense are borne out by some studies, with varying proportions of burden, anxiety, distress, and concern associated with the use of a PHR reported (Drury et al., 1996; Drury et al., 2000; Finlay & Wyatt, 1999). In a study by Webster et al. (1996) 12% (n=18) of women expressed concern about carrying their record, predominantly in relation to risk they might lose it. In contrast, only 6.9% (n=5) of women from another antenatal PHR study found them a burden (Usha Kiran & Jayawickrama, 2002). A significant proportion (28%, n=11) of patients recovering from a stroke found their PHR to be “more trouble than it was worth”, however this was strongly linked to their difficulties persuading staff to write in it (Ayana et al., 2001, p. 1). A similar sense of burden associated with encouraging their HCPs to write in it was reported by some participants in two other studies, (Cornbleet et al., 2002; Williams et al., 2001) whilst the burdensome nature of self-reporting (writing in their PHR) was noted by 30% (n=15) of lay participants in a Japanese based study (Komura et al., 2011). However, Drury et al. (1996, p. 125) also concluded that “patients found written information in PHRs no more threatening to their coping strategies than verbal information, and they were able to interpret and select written information with discrimination”. Despite the above challenges, overall there was an indication that many patients and lay carers viewed having a PHR as positive and useful. Only one study found that the majority of patients (53%, n=91) preferred to no longer have a PHR (Williams et al., 2001).

Health care professionals' perspectives

Health care professionals' use of the patient held record

Thirteen studies incorporated HCP perspectives and in a number of these HCPs reported higher rates of PHR use than that suggested by lay participants' descriptions. 72% (n=34) of clinicians in the Sharp et al. (2004) study claimed they always or sometimes read what other HCPs had written in them and two-thirds (n=39) of HCPs in the van Wersch et al. (1997) study indicated they had made reasonable use of the PHR. However, only 52% (n=24) of clinicians in the Sharp et al. (2004) study reported sometimes or always reading the PHR notes written by patients/family members; this may have accounted for the significant difference in the lay participants' views about how often HCPs read their PHR (15 patients felt their HCPs read their PHR versus 24 clinicians who indicated they sometimes or always did). One study found that more community clinicians (82%, n=15) had used the PHR than inpatient clinicians (41%, n=10) (Cornbleet et al., 2002). Interestingly, whilst 73% (n=45) of HCPs in this study were aware their patients had a PHR, only a third felt that all their patients offered it to them to read and write in. From accompanying HCP comments, the authors concluded that these HCPs had felt it was up to the patient to offer their PHR for use. This perspective is echoed by Wersch et al. (1997) where HCPs reported they did not ask for the patient for their PHR if they felt the patient lacked interest in it, determining this on the basis of how much the patient had previously written in their PHR. A number of studies did reflect lower rates of HCP use, with several commenting that a high proportion of HCP participants had not seen or interacted with a PHR (Drury et al., 2000; Greenfield & Jones, 2007; S. Johnson & Mayor, 2002; Williams et al., 2001).

Overall, findings suggested that HCPs wrote in the PHR less than they read it. Only one out of seven HCP participants in the Greenfield and Jones (2007) study had actually written in a PHR. Drury et al. (1996) found that 55% (n=24) of HCP participants reported always reading the PHR but only 36% (n=16) indicated they always wrote in it.

The perceived/experienced value of the patient held record

From the 13 studies incorporating HCP perspectives, two subthemes regarding clinicians' perceived/experienced value of the PHR emerged and are outlined below.

Patient focussed/empowering care

In most studies, HCPs expressed positive regard for the concept of a PHR, but also reflected that the PHR appeared to offer more benefit for patients and families than for HCPs. In particular, clinicians noted its value as an aide memoire for patients and a tool for informing and educating patients; promoting understanding of their condition and compliance with their treatment and medications, supporting self-management, and empowering patients to be more prepared and involved in their own care (Cornbleet et al., 2002; Drury et al., 1996; Giglio & Papazian, 1986; Greenfield & Jones, 2007; Haywood, 1998; Sharp et al., 2004; van Wersch et al., 1997; Williams et al., 2001). The value of the PHR as a tool for facilitating patient-HCP communication was also highlighted, including the manner in which it enabled patients/lay carers to make their feelings, preferences and current needs apparent to clinicians by noting them in the PHR, prompting conversations regarding these and other challenging subjects and (Drury et al., 1996; Greenfield & Jones, 2007; van Wersch et al., 1997; Williams et al., 2001).

Continuity of care

The value of the PHR for promoting continuity of care was also noted, including the manner in which it facilitated communication between HCPs and between services (Giglio & Papazian, 1986; Williams et al., 2001) and its usefulness for “passing information back and forth” where lots of disciplines were involved (S. Johnson & Mayor, 2002, p. 187) and without need to write additional and separate letters to what was written in the PHR (Sharp et al., 2004). Health professional feedback in one study placed particular emphasis on continuity, with the PHR reported to have contributed to harmonising care activities, information exchange, clinicians keeping abreast with the wider health team’s contribution to patient care and reduction in contradictory care advice and treatment (van Wersch et al., 1997). However, such perspectives are in contrast to lay participant perspectives, with only small numbers reporting that their PHR helped their HCPs communicate with other members of their wider health team, relating this to lack of HCP engagement with it (Bjerkeli Grovdal et al., 2006; Greenfield & Jones, 2007; Lecouturier et al., 2002; Matthews & Byrne, 2009).

Perceived barriers/challenges experienced with use

In addition to forgetting to ask see the PHR, HCPs reported a number of barriers that impacted both on their views of the value of the PHR and their decision to use them or not. System inadequacies, duplication and lack of time were most commonly reported and appear to have influenced lower engagement than patients desired even though the majority of the HCPs

affirmed the value of patients having a PHR (Cornbleet et al., 2002; Drury et al., 1996; Giglio & Papazian, 1986; Greenfield & Jones, 2007; Lecouturier et al., 2002; Sharp et al., 2004; Williams et al., 2001). As Lecouturier et al. (2002, p. 120) highlight, “professionals are adept at managing consultations to avoid interruptions by patients so that even articulate and normally assertive patients felt they could not ask their doctor to use it”. Only one study reported lengthened consultation times related to the use of a PHR but also noted some consultation times had reduced (Williams et al., 2001). A further factor impacting on use, and also likely to be a self-perpetuating cycle, was the view that PHRs could not be relied on as current and complete (Cornbleet et al., 2002).

Inadequate education and ‘marketing’ to all HCPs likely to contribute to care for those with a PHR was the second most common issue signalled (Bjerkeli Grovdal et al., 2006; S. Johnson & Mayor, 2002; Sharp et al., 2004). Furthermore, Cornbleet et al. (2002, p. 209) suggest such lack of awareness and involvement in development may have prompted “wariness and uncertainty as to what was being asked of them” for some clinicians, which in turn may have portrayed a negative perspective to those presenting their PHR. Alternatively, lack of awareness may have been interpreted by patients as professionals being too busy, or disinterested in using the PHR (Lecouturier et al., 2002). Ayana et al. (2001) point out the risk for such a situation to become a self-perpetuating cycle of low use, reflecting that if clinicians do not act as ‘champions’ of the PHR, their lack of engagement could promote patient disinterest in its use.

Concerns that a PHR could hinder verbal HCP-patient communication appear to have been borne out (Ayana et al., 1998; Ayana et al., 2001); slightly more patients with a PHR in the stroke services study reported having no or little idea of what was happening to them and were less likely to have been instructed in how to cope at home prior to discharge. One suggestion was that their HCPs felt it was unnecessary to provide verbal explanations as the necessary information was documented in their PHR.

Six studies discussed loss of the PHR. In one study 12% (n=12) of participants expressed a concern that they could lose their antenatal PHR but whether this occurred or not was not examined (Webster et al., 1996). Resolving loss of PHRs was the main focus of one action research focussed study; however participants in this study visited a number of different health care centres, each of which would issue another PHR if they left theirs behind and this was felt to be a factor contributing to loss (Kerry, 2006). Significant loss occurred in the stroke services PHR study (27%, n=6); the authors of this study drew attention to a number of

difficulties felt to be impacting on the success of that programme, suggesting that patient and family disinterest in using their PHR arose from these difficulties and that this, coupled with their level of illness and neurological disturbance from their stroke impacted on loss rate (Ayana et al., 2001). The remaining studies that commented on this aspect indicated loss rate between zero and less than 3% (Drury et al., 1996; Drury et al., 2000; Lecouturier et al., 2002).

Reluctance and or concerns about broaching the topic of introducing the PHR to patients, based on the premise that it signified health deterioration to the patient/family was expressed in two studies (Drury et al., 1996; Greenfield & Jones, 2007), whilst another reported HCP concerns about documenting sensitive or potentially distressing information in the PHR (Cornbleet et al., 2002). Concerns about invading patients' privacy by reading and writing in their PHR were also expressed (Sharp et al., 2004).

Differing views of the function and purpose of the patient held record

Both Cornbleet et al. (2002) and Lecouturier et al. (2002) note that patients and families appeared to hold different perspectives regarding the function and focus of the PHR from those expressed by HCPs and suggest this difference influenced each party's motivation to use and value the PHR.

For the patient it is mainly a way of getting their wishes and feelings into the debate about their management, and so a diary function creates the usual welcome sense of empowerment. For the professional, however, the information required is primarily technical ... while the patient's writings will be read and noted, this is not seen as an essential part of the consultation (Cornbleet et al., 2002, p. 211).

If a system is seen to be worthwhile, effort will be made to carry out activities to maintain that system. However, if both parties don't equally contribute to this value falls. Those putting in more effort begin to perceive maintaining the system as a burden that adds insufficient value to justify effort. Whilst appreciating the potential for their PHR to be a means of passing information between the different members of their team, the majority of patients in Johnson and Mayor's (2002) study stressed that the primary purpose of the PHR was to benefit them (the patient) and that efficient information sharing with HCPs was a secondary spin off, not a primary focus.

Rationale for the research

Clearly a PHR alone cannot address the challenges and impacts of fragmented health care environments (Ayana et al., 2001). However, it has been suggested that success is more likely where there is a clear and common view of the function of a PHR, a high degree of professional commitment to its use, and a group of patients who are motivated to have and use one (Cornbleet et al., 2002). In addition, a PHR may be valuable in settings where decisions are complex, or where HCPs may be more closely involved, perhaps requiring a process of joint decision making and consulting others depending on changing circumstances; HCPs practising in these circumstances may be motivated to use a tool to enhance communication and care co-ordination (Bjerkeli Grovdal et al., 2006; Drury et al., 1996; Gysels et al., 2006; Ko et al., 2010; Schoevers et al., 2009). However, Drury et al. (1996, p. 124) caution that “the differing information needs of patients and HCPs raises the potential ethical problem of a PHR imposing more responsibility on patients than they wish, or harmfully confronting a patient’s psychological strategies for dealing with their illness”. Given evidence of the negative impact that HCP disinterest generates for patients and family it would seem vital that PHRs are only utilised in circumstances where there is strong local support and commitment. Therefore, an inquiry into the use and impact of the home based palliative care PHR implemented in this study region is ethically required (Cook, Render, & Woods, 2000; Haggerty et al., 2003).

Furthermore, system or organisational changes intended to improve continuity of care can instead have less positive and unforeseen outcomes and “can produce new points of potential fracture” (Freeman et al., 2001, p. 34). Caution is advised along with monitoring for any resultant unintended effects or defects and, given the experienced nature of continuity, it is vital that consumer perspectives are central to any review of impact. It is suggested that experimental studies may not be the most appropriate methodology for investigating the impact of a PHR. Instead, based on evidence that “health professionals’ and patients’ attitudes, beliefs and preferences, expectation and satisfaction are the very components that determine the effective use of a PHR”, qualitative methods are likely to be of value (Gysels et al., 2006, p. 89).

Conclusion

The findings outlined above suggest a PHR may facilitate both HCP-HCP and HCP-patient communication and partnership, and may also provide a meaningful tool for some patients

and families to assist them to cope with and navigate their health care journey, particularly those with complex and frequently changing health needs that require assistance from multiple HCPs across a range of services. In general, HCPs, patients and their main lay carers viewed having and using a PHR as positive and useful, although more so for patients/lay carers than HCPs. Some patients/lay carers found their PHR to be a burden or stressor, both in the practical and emotional sense, and many experienced an apparent lack of interest in their PHR by some HCPs. Barriers to HCP use also appeared to exist and there is strong evidence that HCPs' perception and use of the PHR significantly influenced patients' perceived benefit of, preference for, and ultimately use of their PHR. The literature cautions that interventions focussed on enhancing continuity of care can instead have detrimental outcomes and recommends monitoring for such occurrence. The following chapter presents the rationale for using CSR methodology for such an investigation and outlines the research approach, underpinning theoretical framework and methods employed.

Chapter Four – The research approach

Introduction

This chapter provides an outline of the selected CSR strategy and discusses its suitability for use in this research project's setting. A brief explanation of the philosophical stance underpinning the research approach is given; in particular that its theoretical framework aligns with nursing's epistemology of people centred social practice and human science, and is additionally shaped by constructionist, constructivist and interpretivist principles. The research design, developed according to Stake's (1995), (2005) and (2010) advice to inform and guide the data collection and analysis is also explained, along with the processes used for participant recruitment, data collection, and analysis. The chapter concludes with a discussion of ethical considerations pertinent to the project and the promotion of rigor, trustworthiness, and credibility throughout the research process and within this final report.

Research aim and approach

The aim of this inquiry was to study the use of a PHR for home based palliative patients within this region, primarily to: (i) explore the impact(s) of the PHR on this patient group and their HCPs, the sharing of information relevant to their care, and the co-ordination of that care, (ii) gain understanding about the range of practices associated with its use and influencing factors, (iii) identify service improvement issues or opportunities associated with its use. These three aims are incorporated into the overarching research question:

What are the impacts of using a PHR for home based palliative care patients?

Perspectives from each group of people most likely to come in contact with the PHR were sought in order to gain understanding of their experiences with the PHR, and their perspectives of its most significant features, benefits, challenges or problems.

Case study research

As palliative care is “dynamic, complex, patient focussed, context dependent and multi-professional”, research within this arena requires a methodology that can accommodate and adapt to rapid and frequently changing circumstances and other contextual complexities often associated with this field of care. In addition, the significance and impact of context on the use, perceived value and effectiveness of a PHR has been identified in the literature as an

aspect requiring further research inquiry (Gysels et al., 2006). Consequently, a CSR approach was chosen for this project.

Case study research is a comprehensive and holistic research strategy in both mode of inquiry and the understanding derived (Andrade, 2009; Anthony & Jack, 2009). Acknowledging that context shapes events in important ways, CSR explores a phenomenon within rather than removed from its real-life context, promoting intensive and in-depth study of the selected case(s) while also considering the larger context the case(s) exists within and the interaction between the case(s) and that context. The aim is to gain understanding of the case(s) both as a whole and as a sum of parts (Perry, 2011).

Studying human events and actions within their everyday circumstances, CSR offers an opportunity to “understand social phenomena through accessing the meanings that participants assign to them, and to focus on their cultural and historical context” (Fitzgerald, 1999, p. 75). Thus, CSR is useful for exploring not only the complexities of life in which people operate, but also how complex social interactions, structures and cultures impact on individual and collective beliefs and decisions (Anthony & Jack, 2009; Caronna, 2010). CSR design does not require control, manipulation, or elimination of variables or contextual influences, but instead can be adjusted to accommodate events which evolve during the research process. This makes CSR useful for inquiries where there are multiple influencing variables, where historical and contextual conditions are an important aspect of the phenomenon of interest; and where the researcher has little or no control of the phenomenon or its surrounding context (Hentz, 2007; C. Jones & Lyons, 2004; Stevenson, 2004). Hence, CSR is well suited to research within the palliative care setting and for studying practices and change within health organisations (Caronna, 2010; Walshe, Caress, Chew-Graham, & Todd, 2007).

Within CSR, the case must be a specific, recognisable, functioning entity that can be linked to life or social context, bounded by space, time, event or activity, and have working parts and purpose. The case may have subsections, dimensions and domains, each with their own context, and all of which influence the case (Bergen & While, 2000; Hentz, 2007; Walshe et al., 2007). The case also must be distinguishable from particular events, behaviours or actions so that its boundaries can be congruent with, and explicit within, the research question and data collection methods used. Phenomena with vague or porous boundaries are not suitable for CSR (Cutler, 2004). A person, event, programme, organisation, critical incident, intervention, social situation, or community may be considered a case (Stake, 2010; Yin, 2009).

A hallmark of CSR is that it can draw on a variety of data sources such as interviews, document analysis, various modes of observation and the use of quantitative data. The goal is to explore the case through many lenses in order to deliver a rich and thick description that provides a comprehensive outline of the case within its context and which highlights the inherent variables and complexities (P. Baxter & Jack, 2008; Cousin, 2005; Hancock & Algozzine, 2006; Stake, 2010). However CSR has no agreed set of data collection methods, instead methods are selected both on the basis of their ability to shed light on the research question posed and to operate despite the presence of any contextual constraints (Gibbert & Ruigrok, 2010; Hentz, 2007; Luck, Jackson, & Usher, 2006).

Described as a research strategy rather than a methodology, CSR is primarily a choice of what is to be studied and how to approach that study. Therefore, it tends to be classified according to the purpose or focus of the study; single or multiple, intrinsic or instrumental, holistic or embedded, exploratory or explanatory, descriptive or evaluative (Bergen & While, 2000; Cousin, 2005; Cutler, 2004; Stake, 2005). In addition, CSR can be situated within a positivist or interpretive paradigm. Indeed a suggested strength of CSR is that it provides a bridge between the paradigms, offering researchers openness to select from a wide range of quantitative and qualitative methods in order to inform their inquiry in a pragmatic fashion (Luck et al., 2006). Regardless of this pragmatic value, a theoretical perspective with which to frame the study, shape the research design, and focus and guide the overall investigation is recommended (Cousin, 2005; Schwandt, 2003).

Theoretical stance underpinning the research framework

Guided by the argument that the selected research paradigm “should be congruent with the discipline’s larger paradigm” (Munhall, 2007, p. 45), the theoretical framework of this CSR project aligns with the philosophical underpinnings of nursing practice, particularly its epistemology of people centred social practice and human science (Hussey, 2000; Jackson, Daly, & Chang, 2004). As such, this project has focussed on discovering meaning, understanding and interpretation rather than causal explanation, prediction, verification and control (Munhall, 2007). However, as qualitative research does not subscribe to a single and unified theoretical and methodological concept, simply positioning the research as qualitative in nature provides insufficient detail to focus and guide the overall investigation. Consequently, constructivist, constructionist and interpretivist principles have also been incorporated into its theoretical framework (Denzin & Lincoln, 2008; Flick, 2009; Patton, 2002).

Constructivism and constructionism

Rather than finding or discovering knowledge, individuals construct knowledge “as they engage with the world they are interpreting” in order to make sense of their experiences and of phenomena (Crotty, 1998, p. 43). As the making of meaning is an individual act, the same reality can be interpreted in different ways, depending on the context and nature of the interaction between the individual and the object or phenomenon. Therefore, an unlimited number of constructions regarding the same reality can simultaneously exist (Crotty, 1998; Patton, 2002). Whilst considered to be an individual act, knowledge construction does not occur in isolation; instead, members of a social setting are actively involved in collective meaning making according to their culture of shared understandings, practices, language, conventions, symbols, values and beliefs. As we are preceded by, embedded into and inhabit these institutions, they are conduits through which we interpret and construct meaning. However institutions are also relative to time and place and as such are in a constant state of revision (Flick, 2001; Patton, 2002; Schwandt, 2003). Hence, constructivism focuses on the meaning making activity of the individual mind whilst constructionism focusses on the collective generation and transmission of meaning (Crotty, 1998).

Drawing together the threads of constructivism and constructionism, Stake (2010, p. 18) posits that two realities exist “simultaneously and separately within every human activity”; the reality of personal experience and the reality of group and societal perspectives and relationships. These two realities connect, merge and overlap but are still distinctly different, hence what happens collectively cannot be considered the sum of each personal experience, nor can what happens individually be derived from separating the collective experience.

Interpretivism

Humans act on the basis of the meanings they attribute to their acts and the acts of others. To understand an individual’s behaviour, one must seek to understand their point of view, and particularly the meanings they attach to the events of their lives (Bryman, 2004; Grant & Giddings, 2002). However, each human action has more than one level of meaning; that of surface meaning and that which signifies deeper meaning(s). Furthermore, what an act means on the surface may be different from what it means at a deeper more symbolic level (Schwandt, 2003). To uncover that which structures the experience and which informs the actions of those being studied, one must grasp the intent of the action from the inside, described as “living their way into and through the lives of others” in order to foster authentic

and empathetic identification rather than spurious understanding (Denzin, 2001p. 138). In doing so, the researcher seeks to ensure the interpretations used to inform practice or policy reflect the point of view of those whom they are intended to serve (Stake, 2010).

An interpretivist view acknowledges the hermeneutic and cyclical process of interpretation and re-interpretation. In seeking to clarify and untangle the meanings produced by a set of experiences, each interpreter will assign different meaning to the same experience or described experience, depending on the context in which the meaning was originally created and the context within which the meaning is subsequently interpreted (Bryman, 2004; Patton, 2002; Willis, Jost, & Nilakanta, 2007). Rather than seeking to generate theory or find universal explanations, interpretivist focussed research seeks a richer and fuller local understanding of the phenomenon being studied in order to form situated knowledge (Stake, 2010). Knowledge of this nature is often termed phronesis, in that it is situated in a context and dependent on that context; it is also described as practical or tacit knowledge in contrast to abstract, universal knowledge. Such knowledge offers readers the opportunity to weigh up, judge, forge analogies, and assess findings for transferability of knowledge, principles or practice, depending on relevance to their own settings (Stake, 2010; G. Thomas, 2010).

Links to the proposed case study research project

The principles outlined above were considered useful for this study as the combination of the unique context and circumstances surrounding the introduction of the PHR along with individual HCPs', patients' and lay carer(s)' perspectives, approach, roles, knowledge and skills, and patients' individual health needs were all likely to have influenced how all parties collectively and individually used and interacted with the PHR. Furthermore, in accordance with the principles of constructionism, it is likely that all parties use of and interaction with the PHR occurred in a constant state of revision as its meaning was collectively and individually socially constructed and re-constructed in unique, complex and multi-layer ways.

Researcher Positioning

I conducted this research project with and amongst colleagues, adding the role of inside nurse researcher to my role as nurse leader and change agent (Löfman, Pelkonen, & Pietilä, 2004). To acknowledge the socially constructed nature of the world is to recognise that research is also a socially constructed activity from which socially constructed findings result. From both an interpretivist and constructivist perspective research is influenced by the pre-existing world

view and theories held by the researcher, hence complete objectivity and neutrality are impossible to achieve (Willis et al., 2007). In recognition of this, I sought to focus on conducting a more intense investigation through application of my insider position, rather than on bias elimination (Borbasi, Jackson, & Wilkes, 2005; Hand, 2003; Hobson, 2004). I was cognisant of Bonner and Tolhurst's (2002) caution that insider researchers may overlook or ignore subtle but vital information due to over-familiarity, loss of sensitivity, or prior assumptions and McEvoy's (2001) suggestion that insider researchers may feel constrained to question established mores or raise sensitive issues amongst colleagues. Therefore, I endeavoured to apply a process of reflexivity throughout all stages of the research (Carolan, 2003; D. Davies & Dodd, 2002; Dearnley, 2005). Denzin (2001) is supportive of researchers conducting inquiry within their own worlds of experience, rather than attempting to separate themselves from the worlds they study. Research conducted within this paradigm accepts and values personal data, provided that the researcher reflects upon and acknowledges their personal bias, values and positioning within the research setting (Willis et al., 2007). The reflexive strategies used to do so are discussed later in the chapter.

Research method and design

Putting forward the perspective that happenings are experienced, Stake (2010) urges qualitative researchers to explore how things happen and how things work. However, in highlighting that "important human actions are seldom simply caused and usually not caused in ways that can be discovered", he emphasises that the search should focus on influences, preconditions, and correspondences rather than simple cause and effect (Stake, 1995, p. 39). Furthermore, Stake (2010, p. 63) cautions against seeking simplicity or the best explanations, advocating instead that researchers pursue a collection of interpretations about a particular situation, "probing all assertions" until credible understanding of the experience is gained. As Stake's direction for CSR aligns with the theoretical principles outlined above his approach was selected as the primary guide for this project's research design.

This project is intended as a qualitative intrinsic case study inquiry; intrinsic in that the case itself (the use of the PHR within home based palliative care) was the primary focus of interest. Intrinsic CSR seeks to explore what this particular case is and does, along with what occurs within and around it, not to understand how the case is different from others, build theory or make generalisations, or come to understand some abstract construct or generic phenomenon. However, recognising that CSR tends not to fit tidily into one of three

categories (intrinsic, instrumental or collective), the study is also expected to offer some instrumental value, in that it may reveal information about broader issues and phenomena than the particularity of the case itself, such as continuity of care (Stake, 2005).

Developing a conceptual structure for case study research

The development and use of a research map is recommended, conceptually structured around key issues or themes in order to facilitate the CSR design and method and to avoid the risk of collecting unnecessary, repetitious, and overwhelming volumes of data (Abma, 2005; Stake, 1995, 2010). Within this approach issues are not information questions, but are “complex, situated, problematic relationships” that draw attention to problems associated with the case and how the case functions within and interacts with its context, both within situations of ‘stress’ and those considered more ‘usual’ (Stake, 2005, p. 448).

The selection of key issues is influenced by the focus of the inquiry, with intrinsic CSR seeking issues that will draw out the uniqueness of the particular case. However, for pragmatic reasons, selection will also be influenced by what can be learned within the opportunities of the study. Key issues fall into two categories: (i) etic issues brought in by the researcher, usually through reviewing literature relevant to the case, (ii) emic issues that emerge from inside the case, from those who belong to the case. To develop issues statements with which to shape the research design, Stake (2005) recommends starting with a topical concern, from which a foreshadowed problem is posed. From this foreshadowed problem, issue related questions are developed. However, he also cautions against pursuing too many issue related questions and instead recommends paring down the case’s parts to be studied and issues to be explored to just a few key aspects, thereby keeping the inquiry manageable. Topical information questions are also required within the research design. These differ from issues questions in that they direct data collection, whilst the issue questions “direct attention to the major concerns and perplexities to be resolved” and as such, focus interpretation of the gathered data (Stake, 1995, p. 28). However, he also cautions that selected issues may be found to not fit the case circumstances well and therefore, may need ‘repair’ as the research process evolves.

The conceptual structure of the study

The case

This project's case of inquiry was the use of the PHR for home based palliative care patients. Patients, lay carers, and the main HCP groups who interact with this group of patients were considered to be subunits of the case, and therefore, key areas for data collection.

Selected key issues and topical information questions

The following key issues and topical information questions (Table 1) were developed from the literature review outlined in the previous chapter; to inform and shape data collection and analysis and to shape the interview schedule and focus group discussion prompts.

Table 1 Key issues and topical information questions

KEY ISSUES QUESTIONS	TOPICAL INFORMATION QUESTIONS
<ol style="list-style-type: none">1. Did the PHR facilitate information sharing only, or did it also promote self-management, service-service and/or clinician-patient and family collaboration and co-ordination?2. Did the PHR have a mitigating effect on challenges and issues commonly associated with palliative care, and the involvement of multiple health services and providers?3. Did patients, their main lay carer(s) and their HCPs hold similar views regarding the function and benefits of the PHR, and did each party's approach to use align with this view?4. Did the PHR become more of a burden than an aid in circumstances where people appeared dis-inclined to use it?	<ol style="list-style-type: none">1. How do patients/lay carers and HCPs use the PHR and in what circumstances?2. What factors impact on and influence each party's use of the PHR?3. What position was the PHR given in patient/lay carer-HCP interactions and who established that position?4. What influence did the PHR have on patient/lay carer-HCP interactions and what factors contributed to this?5. What did it mean for patients, lay carers and HCPs to have and use a PHR within their care?6. What impact was the PHR considered to have on clinical information transfer, care co-ordination, quality of care, patient and lay carer empowerment, satisfaction and wellbeing?7. What factors were felt to influence the ability for the PHR to impact on these aspects?8. Did patients or lay carers experience any negative impacts from having a PHR?9. What are the perceived strengths, weaknesses, gaps and limitations of the PHR?

Selected method and approach for data collection

The following approach (see Table 1) for data collection was utilised to gather perspectives directly from those who had been provided with, or had used the PHR.

Table 2 Summary of participant groups and mode of data collection

PARTICIPANT GROUP	MODE OF DATA COLLECTION
Home based palliative care patients and their lay carers	One semi-structured interview per set of patient and lay carer(s)
Each main HCP group involved in palliative care	One focus group discussion per listed group
• District nurses • General practitioners and Practice nurses • Hospice HCP (preferably including a range of disciplines) • Hospital specialist cancer service HCPs (preferably including a range of disciplines)	

The interview method for data collection was chosen for its value to gain understanding of participants' experiences, perspectives, values, aspirations and world views through their stories, accounts and explanations. In addition, the method enables information to be gathered about things or processes that cannot be observed directly or effectively by other means, an aspect relevant for this project as observation of the PHR 'in use' was felt to be impractical and intrusive for palliative patients and families (Lindlof & Taylor, 2001).

The focus group method, in which the interviewer facilitates a discussion on the topic of interest amongst participants, was used for gathering data from the listed HCP groups. This method enables data to be gathered quickly from a large number of people in a short data collection time period. In addition, participants in the discussion can respond to and build upon other group members' responses. The comparisons, contrasts and critiques of the range of perspectives raised in the discussion provide insight into how people theorise their own world view and how they put their own ideas to work while the researcher can observe the processes of social interaction and group dynamics occurring during the discussion. Furthermore, the approach fosters democratic discussion, a factor of consideration given the potential power imbalance and conflict of interest associated with my role of PHR project lead (Kevern & Webb, 2001; Lindlof & Taylor, 2001; T. May, 2011; Minichiello, Aroni, & Hays, 2008). As outlined in the ethical considerations section below, the decision was made to use an

independent facilitator to conduct the discussion. The arranged facilitator had previously demonstrated skills in group coaching and facilitation.

Given that a fairly broad range of information was sought from HCPs (as per the issues and topical information questions listed above), a moderately focussed approach was chosen and promoted through the use of an interview schedule (Appendix 1) to shape the discussion. Recommendations such as starting with general and mainly unstructured questions (once the process of introductions, ground rules and consent processes are completed) to enable participants to settle into the discussion and then moving into more specific and probing questions were incorporated into the schedule (Stewart, Shamdasani, & Rook, 2007). To aid recruitment, arrangements were made to hold each focus group within participants' workplaces, during work hours but in a venue free from interruptions and surveillance from non-participating staff and the general practice focus group at a neutral location close to each participant's workplace (Bloor, Frankland, Thomas, & Robson, 2001).

To gather data from patients in a manner that promoted interviewee comfort, relaxation and confidentiality, and in an endeavour to promote minimal disruption, intrusion and fatigue, a short semi-structured interview approach was chosen, to be held at each patient's preferred location (Lindlof & Taylor, 2001). In semi-structured interviews the researcher enters into a dialogue with the interviewee, using open-ended questions and prompts in order to gain "an understanding of how they generate and deploy meaning in social life" (T. May, 2011, p. 135), rather than simply seek answers to pre-set questions (Denscombe, 2010; Minichiello et al., 2008). The method has good utility for enabling a pre-determined set interest points to be explored, whilst still enabling flexibility to respond to emic issues with additional questions (Casey, 2006; Holloway & Wheeler, 2010). Stroh (2000) and Rubin and Rubin's (2005) advice for ordering the flow of conversation was incorporated into the pre-developed semi-structured interview schedule (Appendix 2), in particular, opening questions (such as how long they had their PHR for) to set the scene and enable the interviews to re-connect with past experiences relevant to the topic, leading on to more in-depth and focussed questions (such as what did they particularly like about having a PHR).

Conceptual map of the case study research design and method

The conceptual elements and design of the study, including data collection from the identified case subunits are displayed in Figure two. The development and use of such a map provides visual structure, methodological support to the process of inquiry, and provides a framework

to guide the process of data collection, analysis and presentation of findings (Stake, 2005, 2010). To attend to holism, Stake (2005) recommends the conceptual map also identifies phenomena and contexts that sit outside the case but need considering for their influence on the case. The aim is to figuratively position the case in relation to these and to set out the issues and information questions framing the study. Contextual features and phenomena considered to be of relevance to the study (some discussed in Chapter two) are displayed.

Preparations for the study

Advice and feedback was sought from the region's Māori health unit regarding the content of the invitation to participate and the interview questions. Consultation with management staff from each listed HCP group workplace, seeking approval for participant recruitment within their organisation was undertaken during the project planning phase. With Hospice, this process also included agreeing the best approach for appropriate patient participant recruitment, and the role of the PCC team leader to support and assist with this. L. Woods and Roberts (2003, p. 42) advocate such an approach, noting the assistance of a 'gate-keeper' as valuable for "ensuring that patients and others in the organisation are not exposed to inappropriate or excessive demands generated by the research". Consultation also occurred with the Chairperson of the region's division of the NZ Nurses Organisation College of Practice Nurses and the Regional Convenor for the NZ Royal College of General Practitioners (GPs) seeking their support both for the proposed inquiry and to inform their professional networks of the proposed research. Ethics application was submitted to the Central Regional Ethics Committee and approval received in September 2007 (Appendix 3 and 4).

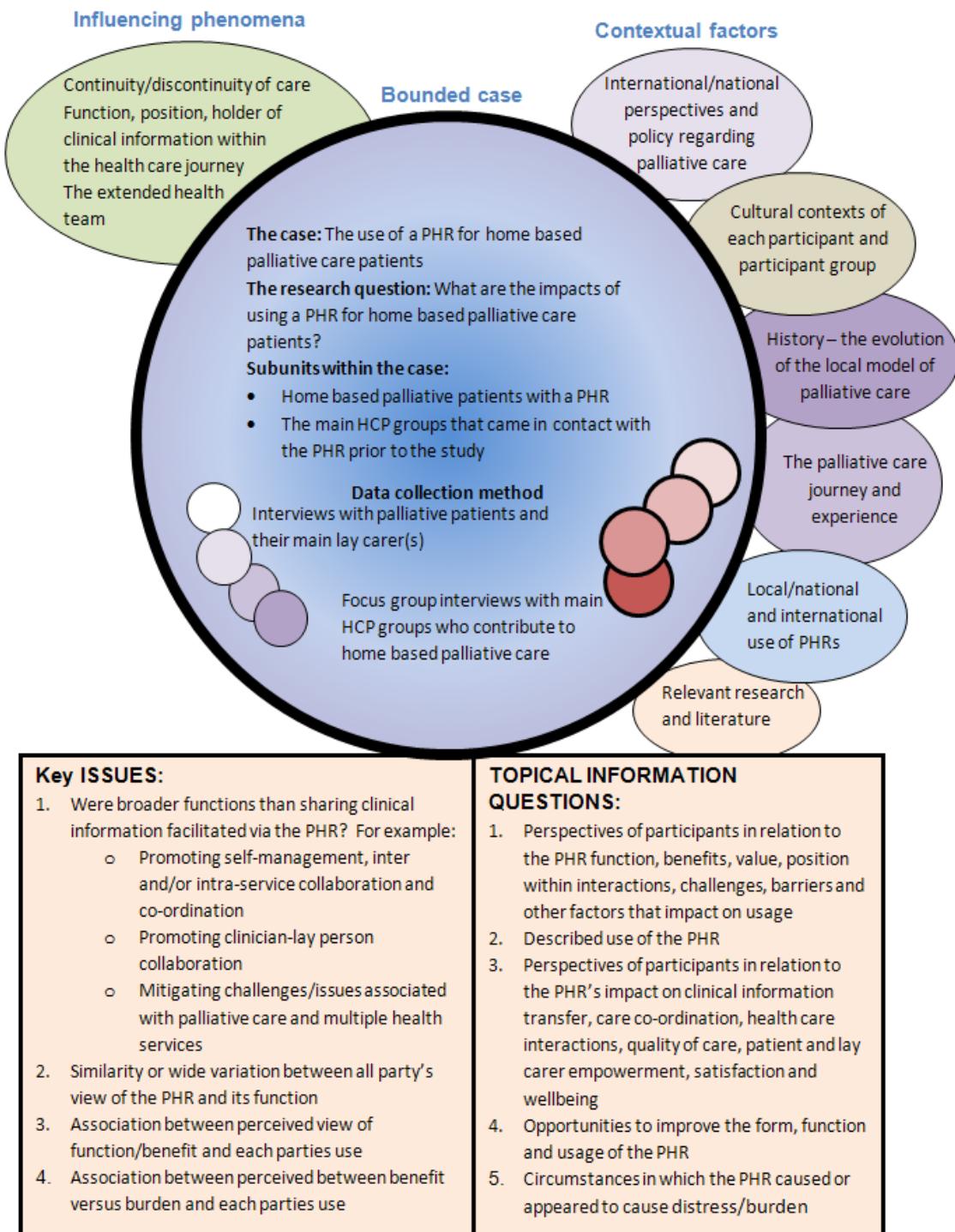
Participant recruitment

Recruitment and data collection commenced directly after receiving ethics approval and continued for a ten week period.

Health care professional participants

Health service staff directories were used to identify all potential HCP participants from each listed group. Each HCP was sent an information sheet (Appendix 5) to their place of work outlining details of the study and inviting their participation in a two hour focus group discussion to share their views and experiences with the PHR, provided they had used the PHR at least once (i.e. read its contents and or documented within the record). Table three shows the number of participants sought and the number of attendees.

Figure 2 Graphic of the inquiry's case study research design and method



Six to ten is considered the optimum number of participants for a focus group to ensure robust discussion and breadth of perspective (Mansell, Bennett, Northway, Mead, & Moseley, 2004; McLafferty, 2004). However, after receiving response forms from invited general practice teams, for pragmatic reasons the decision was made to hold only one general practice focus

group discussion, with the locally interested GPs and practice nurses. All five local potential general practice participants confirmed their attendance but due to workload issues that arose on the day, only three found it possible to attend. In all, twenty two medical and nurse HCPS attended one of four focus group discussions.

Table 3 Number of health care professional participants sought and that contributed data

HCP GROUP	NUMBER SOUGHT	RECEIVED EXPRESSIONS OF INTEREST TO PARTICIPATE	NUMBER WHO CONTRIBUTED DATA
District nurses		Sixteen district nurses	Eight district nurse participants (from rural, urban, evening and weekend district nursing)
General practitioners and practice nurses	Eight – ten participants from each listed group	<p>Twelve general practitioners</p> <ul style="list-style-type: none"> • 4 from the local urban area • 5 from rural areas • 3 had no contact with the PHR <p>Eight practice nurses</p> <ul style="list-style-type: none"> • 1 from the local urban area • 4 from rural areas • 4 had no contact with the PHR 	Three local general practitioner participants
Hospice clinical staff		Ten hospice clinicians	<p>Eight hospice HCP participants</p> <p>2 physicians</p> <p>6 nurses</p>
Hospital oncology services clinicians	Four – six participants (smaller team than hospice)	<p>Four oncology services clinicians</p> <ul style="list-style-type: none"> • 2 physicians • 2 nurses (1 unable to attend) 	<p>Three oncology services HCP participants</p> <p>2 physicians</p> <p>1 nurse</p>

Patient and their main lay carer(s) participants

Due to limited time and resources as sole researcher, the decision was made to seek views from only five patients and their lay carer(s). During the recruitment and data collection period, the PCC team leader considered which home based palliative patients receiving support from both district nurses and Hospice PCCs were appropriate to invite to participate in the study. Factors guiding this decision included the patient's and main lay carer(s)' current physical and emotional health status, ability to consider information and give informed consent, and their English language ability. The rationale for this process and criteria is outlined in more detail within the ethical aspects section of this chapter. Also, patients

needed to have had their PHR for at least four weeks. All five patients invited to participate accepted the offer, however, one was unable to participate due to health deterioration. Each patient elected to have their main lay carer(s) participate in the interview and for the interview to be conducted in their home.

Table 4 Number of lay participants sought and that contributed data

PATIENT AND LAY CARER PARTICIPANT GROUP	NUMBER SOUGHT	NUMBER WHO CONTRIBUTED DATA
Home based palliative care patients and their lay carers	5 patients and their main lay carer(s)	4 patients and their main lay carer(s)

Data collection and validation

Patient and lay carer semi-structured interviews

I conducted each lay participant interview, using the pre-developed schedule discussed above. Emic themes that emerged during each interview were also responded to, with additional questions posed at the time to seek clarification and understanding. Interviews were 45 minutes in duration and audio taped with permission. Additional details regarding the process followed are outlined in the ethical considerations section.

Health care professional focus group discussions

Each focus group discussion was facilitated by an independent facilitator (the exception being the general practice focus group which I conducted as the facilitator was unavailable for the arranged date). For all other discussions I remained at the back, listening for emic themes. Where these occurred, as previously arranged and prior to the conclusion of the discussion, I provided the facilitator with a short list of additional questions to explore. Each focus group discussion was audio taped with permission. The facilitator drew comments from all present, let discussion flow easily whilst remaining on topic, allowed useful pauses, recognised when to follow up with more probing questions and intervened where necessary to prevent dominant viewpoints or potentially damaging disclosure (Bloor et al., 2001; Stewart et al., 2007). The discussion in each focus group flowed in a lively and warm manner without need for the facilitator to actively work to ‘extract’ conversation, including the two focus group with less than six attendees, perhaps because attendees of each group had previously and regularly

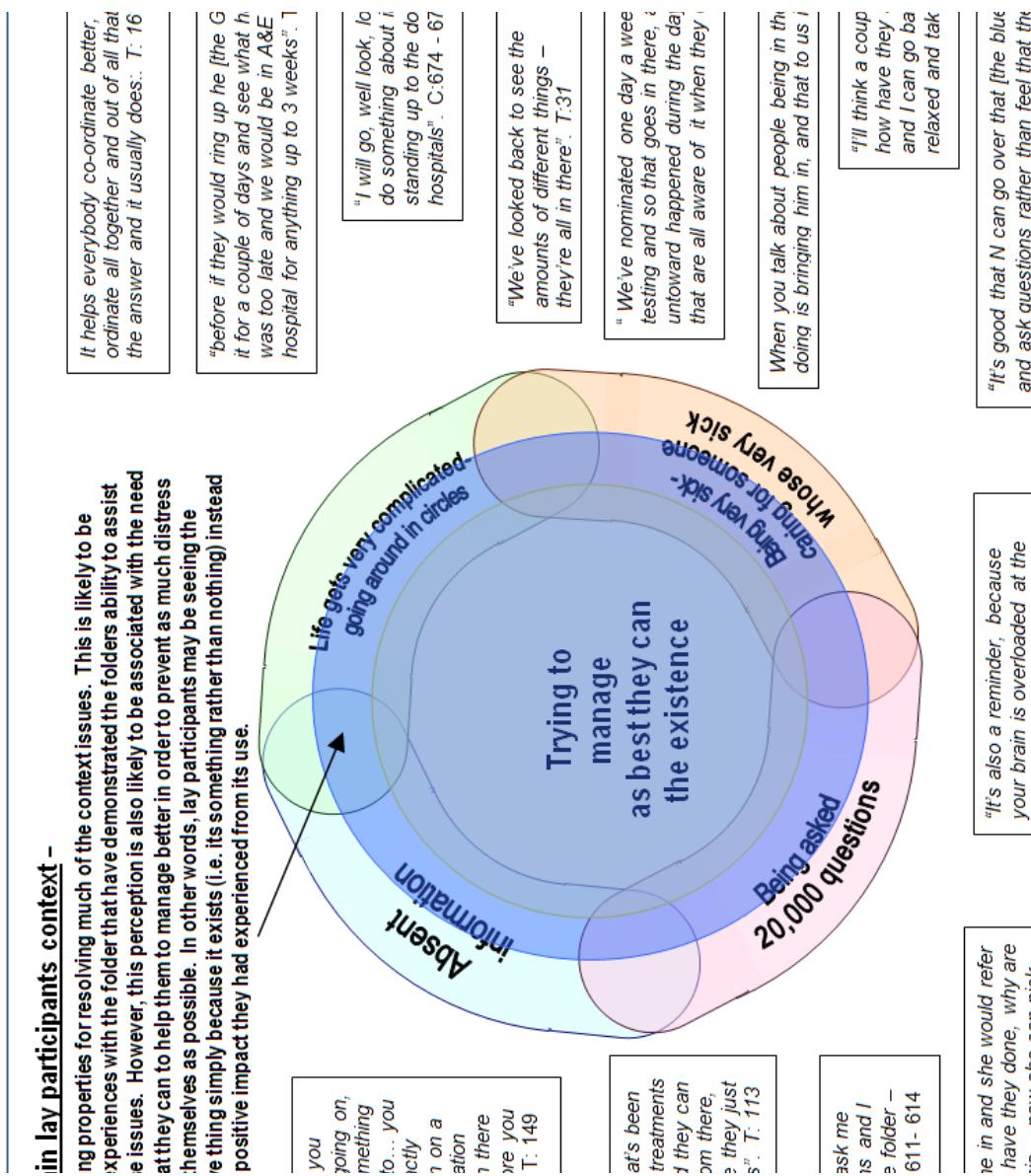
interacted and shared professional perspectives with other the group members (Howatson-Jones, 2007; Mansell et al., 2004; McLafferty, 2004). Robust but respectful reflections and critique of differing perspectives occurred in each discussion, including differing worldviews in relation to medicine and nursing.

Data analysis

Each interview and focus group audio was transcribed within 24 hours by a research assistant, after which I confirmed transcript content against the audio tape and assigned pseudonyms (Dearnley, 2005). Focus group pseudonyms were labelled to note the health discipline of the speaker so that the views, perspectives, and experiences of each discipline could remain visible. A summary of each transcript's main points was developed and forwarded to attendees who selected this option.

Data analysis followed the approach of Braun and Clarke (2006) and Stake's (1995), (2005) and (2010) directions for CSR. This approach included direct interpretation of individual instances and aggregation of instances to form "tentative issues relevant assertions", a process described as "looking for the emergence of meaning from the repetition of phenomena" and "in the single instance" (Stake, 1995, p. 76). The key issues and information questions noted in the conceptual map above provided the lens for systematic examination of each transcript, both for individual instances and patterns and themes. Emic issues pertinent to understanding the case and or impact of the context on the case were also searched for, within and across each transcript. Considered subunits of the broader intrinsic case study, each patient and lay carer interview transcript and each HCP focus group transcript were separately examined and relevant data assigned initial codes. Coded data from all four focus group transcripts was then collated to form one HCP participant data set and after further analysis was grouped into themes and sub themes associated with the perspectives and experiences of the four HCP groups. Each theme was then re-checked for 'fit' with each focus group transcript as well as across the whole collated HCP data set. The same approach was taken with the four interview transcripts, after which both data sets were further examined for linkages between, and themes across, both data sets. The use of models and diagrams was employed to visualise and assist with the thematic development process. The following is an example of one model developed in the early stage of theme formation.

Figure 3 Example of an early thematic analysis model



Rigor

Lincoln and Guba (1985) utilize the term trustworthiness in place of rigor and validity due to the latter term's incompatibility with qualitative research paradigms; advocating its assurance through credibility, transferability, dependability, and confirmability criteria (Denzin & Lincoln, 2000; Tobin & Begley, 2004). These elements were attended to within the study by engaging with a wide range of stakeholders, establishing a chain of evidence through audio taped interviews, field notes and a case study data base, and arranging for my supervisor to review anonymised transcripts to compare and test out emergent findings (Gibbert & Ruigrok, 2010; Holloway & Wheeler, 2010; Stake, 2010; Tuckett, 2005; Willis et al., 2007). In addition, all

participants were offered a summary of their interview/focus group discussion, with the option to check, comment and revise my interpretations. All lay participants selected this option, and all forwarded their summary back with comments added, accompanied by their signed permission to use their edited summary and interview transcripts in this study and publications arising from it. Only district nurse attendees requested a summary of their focus group discussion. This was provided within seven days and no additional comments were received back. The research plan was followed unless, for pragmatic reasons, it required adjustment. All adjustments were made in discussion with my research supervisor.

In qualitative research, proof of transferability rests with the reader. To aid this, the researcher endeavours to produce a sufficiently thick description of the research process with findings that are credible and coherent. The aim is to enable the reader to assess transferability through vicarious experience of the case and by applying their own tacit and experiential knowledge to compare its descriptions with their own particular setting (Stake, 2010; Stevenson, 2004; G. Thomas, 2010; Willis et al., 2007).

Ethical considerations

Ethical considerations for this study focused on three issues; patient vulnerability, risk of exploitation, and challenges for informed consent (Addington-Hall, 2002; Casarett & Karlawish, 2000; Stevens et al., 2003) and were attended to as follows:

Patient and lay carer participant recruitment and data collection

Arrangements were made for the PCC team leader to identify which particular patients and families could be invited to participate. Factors considered were whether: (i) their condition was currently stable, (ii) they were cognitively able to consider and give informed consent, (iii) they currently appeared to be overwhelmed by other concerns, agendas, or preoccupations, or experiencing distress, discomfort, or anxiety due to their health state (such as symptoms shortness of breath, fatigue, pain, nausea, vomiting) or existential concerns, (iv) they were considered to be in the 'end of life' phase of their disease process (Agrawal, 2003; Chouliara, Kearney, Worth, & Stott, 2004; Steinke, 2004).

Due to the potential for palliative patients' health and decision making capacity to rapidly change, 'process consent' was utilised. In this approach the researcher checks at regular intervals throughout the data collection process whether the patient still wishes to, and is able to participate (Addington-Hall, 2002; Harris & Dyson, 2001). First, the PCC team leader briefly

discussed the project with each identified patient and lay carer participant. Those who expressed interested were offered a short letter which explained the study (Appendix 6) and invited them (and their main lay carer(s) if they wished) to participate in a single interview discussion of no more than 45 minutes should they wish to discuss their experiences and views of their PHR. A stamped envelope addressed to me and response form, which reiterated that returning the form did not place them under any obligation to participate but merely indicated they were willing for me to contact them to discuss the study further, was also included. Potential participants only received one letter of invitation. Further details with regards to voluntary participation, confidentiality and the right to withdraw from the study at any point outlined in the letter can be viewed in Appendix six.

Prior to contacting those who returned a response form, suitability for contact was reconfirmed with the PCC team leader, after which I made a phone call to introduce myself, answer any questions, reiterate the voluntary nature of participating and ascertain if they wished to participate. Interview time and location was arranged according to their preference. On the day of, but prior to the interview, participants were phoned to re-ascertain consent and suitability to visit. All participants received the interview questions in advance to consider and prepare to decline any they did not wish to answer. Although the process of reviewing participant suitability with the PCC team leader did prevent complete anonymity for lay participants, it proved to be an important process. On several occasions, by the time I received the mailed response, their circumstances had changed, prompting the advice to not contact.

At the start of each interview, drawing on my palliative nursing skills, I first assessed for signs of distress, anxiety, discomfort due to health symptoms or existential concerns and continued to do so throughout the interview (Chapple, 2006). Written consent was obtained (Appendix 7) prior to commencing the interview and participants were offered a summary of their interview to review, comment on, and choose whether they wished to release it for use in the study. I visited again within two days of the interview (after first checking suitability to visit with the PCC team leader) to provide their interview summary, remind them of their right to choose not to release it or their interview transcripts for use in the study and explain the process for mailing back their signed consent should they wish to do so (Appendix 8).

Health care professional participant recruitment and data collection

Ethical considerations associated with HCP recruitment and data collection also existed within the study, particularly with regards to my roles as PHR project lead, and as nurse leader within

one of the participating organisations. These factors risked both a conflict of interest and power imbalance between researcher and some participants.

Several authors highlight potential risks for staff participating in research regarding their own workplaces and practices, particularly where the researcher holds a leadership position within that organisation. The measures implemented in this project to avoid inadvertent coercion or intimidation included the use of an external facilitator and an invitation to staff to attend a brief presentation of the proposed research where it was explained that although all staff would receive a letter of invite, the project was voluntary and that decision to not participate would not result in censure or a challenge to reconsider (Hilton, 2006; Kevern & Webb, 2001; O'Brien, 2001). The service improvement focus and the welcoming and respecting of all viewpoints were also outlined, along with a brief explanation of the planned focus group approach including external facilitation, debrief options, and ground rules such as respect towards all speakers, non-disclosure of attendees or their views expressed, no interruptions, and the right to leave the discussion at any point. Potential participants received one letter of invitation only.

Prior to commencing, focus group attendees were reminded of their right to withdraw from the discussion at any point, their obligation to hold all views expressed by participating members in confidence, and the other ground rules. Signed consent and non-disclosure agreement (appendix 9) were then obtained from all present, along with their wishes regarding a summary of the discussion to comment on (appendix 10). As noted earlier, the facilitator employed a range of strategies to prevent dominant control of the discussion, dismissal of participant views by other members, and potentially damaging disclosure.

Confidentiality

Confidentiality requirements and agreements, including patients' preferences regarding their families future access to their interview audio, were attended to according to the invitation sheet, signed consent process, focus group facilitator and transcriber confidentiality agreements. All consent, audio and transcript data is stored in a locked cabinet/password protected electronic archive, for destruction five years after study completion. Participants were advised prior to consent that the region's unique model of palliative care may enable readers to identify the study's location. Lay participants were also informed of the PCC team leader's involvement in recruitment and data collection.

Reflexivity

Reflexivity renders visible within the research findings the researchers philosophy and values, the lens with which the researcher views the phenomena under investigation and the manner in which this lens impacts on data collection and analysis (Carolan, 2003; D. Davies & Dodd, 2002). Reflexivity also encompasses the process by which one places oneself under the same critical analysis and scrutiny as the research itself. In doing so the researcher engages in explicit, self-aware analysis in a conscious attempt to take account of and acknowledge their own positioning and involvement in the study. Their own standpoint, values, preconceptions and assumptions regarding the phenomena being explored are acknowledged along with the nature and processes of their interactions with participants, in an attempt to understand the effect of such factors of the data and its interpretation (Holloway & Wheeler, 2010).

To attend to this advice, a range of strategies were employed including surfacing and recording all my preconceptions, prejudices, viewpoints, past experiences and assumptions in an attempt to suspend them prior to entering the field. These strategies included paying close attention to the manner in which the research questions were framed and interviews were structured, the use of a journal in which pre, during and post data collection action was reflected on and critique of the extent of use of self and researcher voice within the data collection activities (Dearnley, 2005; Dowling, 2006; Nunkoosing, 2005; Rountree & Laing, 1996; Tolich & Davidson, 1999). Reflexivity within this inquiry required acknowledgement of my role as project lead to establish the use of the PHR, and consequently my support for its use within home based palliative care. However, as a researcher I also recognised the need for an open mind when investigating the impact of use, particularly in light of literature that highlights mixed outcomes resulting from its use for patients, carers and HCPs.

Conclusion

In summary, the primary focus of this research project was to investigate the use a PHR within this region's home based palliative care setting in order to gain greater understanding about its use, features, challenges and impact from those who have and use it. Complexities and challenges associated with conducting research within the palliative care arena have been presented as the rationale for selecting a CSR approach for this project, and the key features of this approach described along with the theoretical framework underpinning this study. Stake's (1995), (2005) and (2010) CSR approach has been utilised for the project, including the use of a conceptual map incorporating key issues and information questions to guide data collection

and analysis. Ethical factors considered relevant to this study include patient vulnerability, risk of exploitation, and challenges for informed consent. An outline of steps taken during recruitment and data collection to attend to such factors has been discussed, along with steps to promote rigour and reflexivity. The following chapter presents findings which emerged from the four patient and lay carer interviews.

Chapter Five - Patient and lay carer findings

Introduction

This chapter presents findings which emerged from across the four interview transcripts, painting a picture of four patients and their lay carers' views and experiences in relation to three themes: using the PHR, their perspectives of their PHR, factors influencing engagement with their PHR. These themes and related subthemes are demonstrated in Figure 5.

Theme One: Using the patient held record

Participant's use of their patient held record

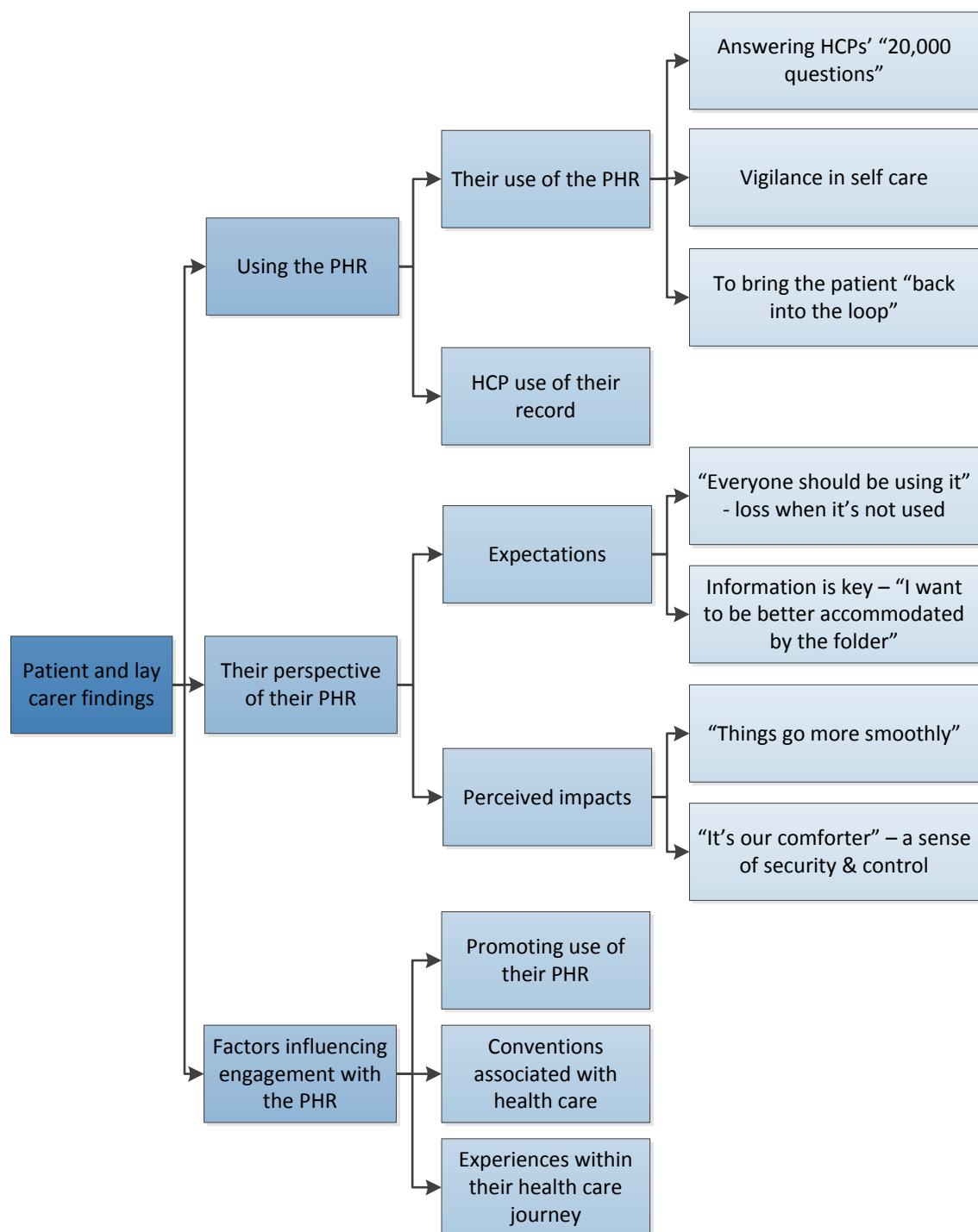
The length of time the PHR had been in place for each of the patients ranged from one to six months. In three of the four circumstances explored, both the patient and their lay carer indicated using their PHR to a significant extent. The fourth patient and lay carer's comments suggest they had not interacted to any great extent with their PHR, other than to make it available and visible for their home visiting HCPs and to occasionally read the contents. Factors that may have influenced this are discussed later in this chapter.

In the first three subcases, the patient/lay carer's use of their PHR appeared to be centred around three main purposes: (i) to assist with answering their HCPs questions, (ii) to assist with vigilance in self-care, both to keep track of and to inform their HCPs of routine and non-routine health events and clinical information, and (iii) to bring the patient "back into the loop".

To assist with answering health care professionals' "20,000 questions"

Participants in each interview reflected on the experience of being questioned over and over again by multiple HCPs, often regarding the same topic. In addition to the repetitious nature of this, other concerns were raised, such as the challenge of remembering information when one's memory is affected by disease processes and medication or by the stress, fatigue and changes to life patterns associated with providing carer support twenty four

Figure 4 Patient and lay carer participant themes and subthemes



hours a day seven days a week. Participants' concerns centred on the risks associated with relying on their memory when providing HCPs with information which would then influence care delivery, particularly if they were having difficulties with remembering key dates and other clinically important information.

When you are looking after some body, it sort of rolls on - one day just seems like the next and you have no concept of time – like if it's a week ago or a fortnight ago. But when someone comes in and asks when was that catheter put in – I've got no idea you know - I can't remember what took place two days ago. (C/29)

Across all four interviews the PHR was noted to be a useful aide-memoire, offering patients and their lay carers the opportunity to use it instead of relying on their own memory, thereby mitigating the risk of giving their HCPs inaccurate information.

It's also a reminder, because your brain is overloaded at the time and you don't remember, but it's in the book. I mean you might think something happened last week but it wasn't it was two weeks ago, but you put it in there at the time so you know. (WR/131)

Some participants also expressed the concern that as they were "observing things from a lay man's point of view" they may not recognise the clinical relevance in what they were hearing or observing, and therefore not pass important information on to their HCPs (C/405). These concerns appeared centred around fear of having a negative impact on their HCPs' decisions, and hence on the care provided.

What it is asking me to do is make a judgement based on my observations, or my interpretation, and I don't have the skills and qualifications to make those judgements. I don't know what to look for. (C/394)

As such, participants appeared to prefer that clinical information relevant to their care be transferred directly from one HCP to another through the use of their PHR, rather than with them being the verbal conduit for information exchange. However, when their HCP elected to question them rather than read their PHR, participants used their PHR as a "handy reference" from which to obtain the correct clinical information being sought.

And the doctors said "Oh, when did that change?" and I will say, "well the district nurse has written it in the folder, so could you have a look at what she has put in the folder. (C/38)

When they do ask me 20,000 questions I can relate to the folder – it's brilliant. (C/613)

To assist with vigilance in self care

A heightened sense of vigilance for symptoms and or circumstances that could cause suffering and distress for the patient was also apparent in much of participants' conversation, particularly the lay carers. A significant feature of this vigilance role was ensuring that key dates, interventions, and elements of treatments were kept track of and attended to in order to ensure that events were occurring as they should. Participants explained how their PHR assisted them with this process, viewing it as a diary in which all care and interventions were recorded to enable both themselves and their HCPs to have access to the most complete clinical picture possible so that they too might keep track and attend to key information in a timely manner.

It's imperative that you do know when you were last in there, when you had your last blood transfusion, when you were last in the hospice and things like this and it's a simple matter, you can get somebody to write it in the book for you. (Wr/67)

It's a handy reference book - you can look back and find out what you want to know. Like what the last person has done, if something is not working, if they tell you that one works - or won't work, changes to medications. (T/20)

Vigilance for reducing suffering appears to have been the motivation behind one lay carer's approach for writing in their PHR in order to update and assist the wider health team with their management of the patient. For example, writing the blood glucose levels and amount of analgesia taken in their PHR, but also noting non routine aspects of information as well, such as "if there is anything untoward that has happened during the day so they are all aware of it when they come" (Wr/15).

However, two of the other lay carers explained that prior to receiving their PHR they had used a notebook to jot down key information and questions and that even after receiving their PHR they had continued to use a notebook for that purpose. Factors influencing this decision are addressed in more detail further in this chapter.

To bring the patient "back into the loop"

The issues caused by reduced consciousness associated with deteriorating health, particularly the impact this has on one's ability to remain aware, informed and involved, was also raised by some participants. For example, one participant spoke of the risk for HCPs and even the lay

carer(s) to “take over and be quite dominant about how it is going to go and pretty much take [people with reduced cognition] out of the loop – so that they become the object rather than the patient”(C/588).

Again, the PHR was seen as a useful tool for mitigating this risk, provided the patient still had the ability to read, even if just occasionally and for short periods of time. One lay carer described how her partner used his PHR to re-orientate and remind himself about what had been occurring for him, the value being that he could do this at a time, pace and frequency that suited him.

Quite often N is disorientated depending on things have affected him ... so he will actually get the blue book and sit and read it and ask me what is meant by different things in it. I think that when you are very sick, there are certain things that you cling to, and your health is of prime importance to you – so things that can stimulate what is primarily important to you in their life are important. It's good that N can go over that and ask questions about what's in it, rather than feel that there is a lot said or done behind his back that he is not aware of. And that's giving him the element of control that he actually needs. You know it would be all too easy for us to discuss his health and leave him out. But that [the PHR] does give you a sense of what is going on doesn't it N? – Rather than us railroading you. (C/328)

Being able to have a look at what's happening when it suits me, or I am feeling up to it would be the main benefit. I go back and back to it. (C/450)

Health care professionals use of their (the patient's) patient held record

Across all interviews participants indicated their PHR was primarily used by their home visiting HCPs such as the district nurses, PCCs and other community nurses involved in their care such as nurses employed by the local Primary Health Organisation (PHO). Examples of how different home visiting services used their PHR fell into three categories: (i) communicating, planning and co-ordinating care between services, (ii) communicating requests and recommendations for the patient's treatment to the next HCP, and (iii) obtaining information needed for their care visit.

If the PHO nurse checks something or is not happy with something she writes it in there, and if she suggests something she will write it in the book, and when the district nurses come in they get it out and read it and then they write what they did. (T/49)

Before they just asked questions - if the District Nurse had the information, the PHO nurse would come in and she would refer to us – “what have they done, why are they doing this”? Whereas now she picks the folder up and read it instead. (T/109)

However, it was also reflected that whilst most of their home visiting HCPs had written in their PHR, many had still elected to question the patient and lay carer rather than read what others had written in their PHR.

There are some that do [read it at the beginning of the visit] but they would be one out of four. Most of them would ask me what has been going on. (WR/266)

In contrast, participants had formed the view that most HCPs at their non-home based health care encounters were unaware of, or dis-interested in using their PHR. In particular, it was highlighted that most doctors appeared uninterested, reluctant and disinclined to read or write in their PHR when they offered it to them, leading one participant to reflect that their PHR, “seems to be more for nursing” (C/34).

Why is it only the district nurses who are using it with such fervour? (Wr/403)

I have carried it up through radiology, oncology and nuclear medicine but they are not interested in it - they go – oh we don't really need that you know. (C/18)

Theme two: Participants’ perspectives regarding their patient held record

Expectations

“Everyone should be using it” – lost information and opportunities when it’s not used

Lack of engagement by HCPs with their PHR was of concern to participants, particularly given the effort that they and others were putting into its transportation and use. Indeed a significant portion of each participant’s conversation centred on this topic. When HCPs elected not to read their PHR participants were frustrated, particularly as they then found themselves

being asked “20,000 questions” even though the HCP could have obtained the required information from their PHR.

It’s a little disappointing from the point of view that people [in those departments] will ask me how long ago did such and such happen and I kind of think - well it’s in the book. (C/18)

However, it appears that HCPs electing not to write in their PHR caused the greatest concerns and strongest emotions.

Well I sort of feel let down because if they are not contributing to it – why are we doing it? It sort of brings a stigma of loss to it – it’s dulling the effect. (C/314)

Two common threads appear to run through participants’ comments, the first being a sense of loss. For example, there was the lost opportunity for their next HCP to be better informed about their care and treatment, lost information that could aid the patient and lay carer in their vigilance and self-care efforts, and the lost opportunity to read over and remind themselves of their own health care journey in the future. Furthermore, the comments below indicate that this loss was not lightly felt.

It is such a wonderful idea why isn’t everybody playing the game? I would like them to write in it, even if they just write that he had a scan, he had radiation, because you know for N [the patient] to go [up to the hospital] – it is a huge displacement in his day and his life, it might take 1% of my energy but it will take 100% of his energy. And the next day there is something gone wrong - if they had written in there he had a scan - that can explain [to the next HCP seeing him] why his energy levels are down because he has had a huge day. (C/294)

Then it’s a continuation, the nurses know they’ve been, know what they thought or done – it’s all written there for them as well... I think it’s important that if you are going to have a sharing of information then the sharing of information should be universal and that nobody should be missed out. (Wr/49)

The second common thread running through participants’ comments on this topic was a sense of entreaty for HCPs to use their PHR so that they could have the most current and complete set of clinical information about their condition and care as possible.

It just derails the whole system, and the whole thing falls to pieces. So the onus is on you as a professional to check the book to see what is happening and so forth – you can't just say - oh I didn't see it. If you don't look at it, somebody's life depends on it. It's imperative that people understand the seriousness of it all - it's not just something that passes by. (Wr/527)

Participants also provided examples of where they felt their health care had been negatively impacted through HCPs electing not to read or write in their PHR. One participant described how on admission to hospital her partner had been given a dose of medication based on old documentation rather than the current dose noted in his PHR, causing him to have reduced consciousness for a few days until the effect wore off.

Information is key - “I want to be better accommodated by the folder”

Health care experiences described by participants as “making their life so complicated”, “going around in circles”, or “fighting a losing battle” were raised within each interview as well as examples of feeling overwhelmed, out of their depth and worried about how to prevent pain and suffering (Wr/143), (Wr/455), (W/203).

When N was diagnosed as terminal, it came to the stage that we didn't know who we contacted for what was going on. Was it the GP, was it the hospice, was it the district nurse – we didn't know. And if we contacted one we were told we should have contacted the other, if we contacted this one we were told we should have contacted that one – and in the end we were going around in circles – and we just said – “look we have got to know, we can't carry on like this – we are totally confused. (Wr/143)

Don't forget that this is our first time round and probably our last... All I'm saying is that I found the procedures and what have you just abysmal. We didn't know where to go and when we did go it was the wrong place. It was distressing. (Wr/202)

Well to start with I didn't know he would need blood transfusions – I didn't have a clue – I just rang the hospice one day and said “he hasn't got up for so many days and he looks awful and he has no energy” – so they came and said “he needs a transfusion” – but we hadn't known he could have something like that. But the next time I noticed him get like that I rang the hospice and they said to me “you should have rung your GP”. But the GP didn't have the right form to order it –the hospice had that form and

they couldn't fax it, they had to bring it down – there was so much confusion – we were never clearly told who we go to for the next times this happens. By this stage we are in a state of confusion and upset – we need to have things clearly laid out for us and the blue folder is a good option for that. (Wr/171)

The central issue to these experiences appeared to be that participants felt they had lacked information and knowledge, the consequences of which appeared to be threefold: (i) the perception that they themselves had not responded to circumstances, or managed a situation as well or as quickly as they could have, (ii) the perception of experiencing difficulties rallying the help they needed from the right service promptly and easily, and (iii) uncertainty and lack of awareness about what to look out for and what to expect for the different stages of their palliative care journey. Reflecting on these experiences, participants expressed the desire to have “been better accommodated” by their PHR to address issues such as these, and therefore, be better equipped to navigate through their health journey (Wr/509). In particular, participants suggested that receiving their PHR at time of diagnosis would have been useful, and for it to have included personalised details about their particular condition and its management, particular symptoms to watch out for and how to respond to them, available services and how to contact them.

Once you are in the hands of the medical profession you have all different doors that you go to, you've got your GP, hospice, your specialist, your blood people, the lab. Who do we go to for what? But if it's all in there, explained – and with the phone numbers written up – we can look up and see - that would be really valuable. (Wr/191)

When we were first registered with this disease - that was the time that we should have got the blue folder and with all the information in there. Every cancer is different so there should be a guideline for the cancer you have ... what treatments are given, and what things you might need and should expect to occur – something like that in here along with the phone numbers – that would be excellent – because I didn't know he was going to need transfusions – nobody told us – and if that was all said then – ok – you would look out for the symptoms. (Wr/226)

I am not aware of what the cocktail of drugs – or when they change it – is actually going to do to him – and therefore what I perceive to be scary – the medical fraternity obviously perceive to be absolutely normal. And there have been too many times to

count when I've thought he's almost on his final axis – and then the nurse will come and say – “no he's not dying yet” – and I'm like – what are you talking about – look at him - but she's right. (C/276)

In describing how “complicated” his life had become “as a result of having a terminal illness”, one participant explained that he wanted his PHR to be a compendium or “filo fax” that would assist him to manage the complicated nature of his life better (Wr/452). This participant also made the comment that “a filo fax has a personal owner otherwise it doesn't work”, which suggests that he believed the primary purpose of the PHR was to meet the needs of the owner, and be set up accordingly. His recommendation was for the most important information, dates and results pertinent to his condition and its management to be documented on a summary page or table at the front of his PHR as this would make it easier for him and his family to easily look up and contribute to that information, and for them and their HCPs to be vigilant and keep track of key information. This participant also highlighted the importance of making sure that what was written in their PHR was understandable to lay people, suggesting the view that HCPs should write in it with the patient and family in mind, rather than for the HCP using professional language and jargon.

The idea of a summary chart or table was also raised by another participant, not only because it would help her to look up information and answer questions more easily, but also because it would act as an educational tool communicating what information was relevant, thereby assisting with her care and vigilance over her partner’s health.

To make it easier for me I want to look on a chart showing me things that I should be looking for – like when he has a bowel motion, what colour his urine is – all those sorts of questions that the nurses and doctors ask you – and there must be a host of other questions and information that people want to know – but because I'm not medically qualified I don't know – so if there was a chart that would tell me what to look for and then I can write it in there... like a reference chart – and things you can even add in yourselves like change of drugs and it's just like an open chart where I wouldn't have to write a lot of things. (C/154)

Perceived impacts

“Things go more smoothly”

Despite the experiences described above, participants believed their PHR had improved some aspects of their care delivery, with one participant reflecting that because of their PHR “everything goes more smoothly” (T/171). Overall, comments regarding this topic conveyed the perspective that having access to the same information and plans had assisted their HCPs to be well informed and to deliver their care in a more consistent, collaborative and co-ordinated manner.

At least they all know what they are doing. What one's done and the other has to do. They can come in and say - ok what's been done - and you can give them the blue folder and they can read all the notes pertaining to whatever they want to have a look at. They know what's been done, what treatment's been given and they can work straight from there. (T/104)

It helps everybody coordinate better, they can coordinate all together and out of all that should come the answer and generally it does. (T/156)

Some lay participants also suggested that their HCPs' choice to work collaboratively through their PHR had led to more effective clinical management of their condition.

Our GP wasn't very good at prescribing antibiotics for urinary infections from the catheter – he would brush over what our concerns were. And now they just say antibiotics needed in there [their PHR] and he will give them, whereas before he would leave it too late and we would end up in A and E. (T/160)

“It's our comforter” - a sense of reassurance, security, involvement and control

Although participants described inadequacies with regards to how their PHR was used, overall, three of the patients and lay carers appeared to have formed a strong attachment to their PHR, describing it as something of great value to them.

I'd hate you to take it away – it's like our cuddly rug, it's our comforter. (C/590)

The value of the PHR for these participants is likely to have been shaped by their positive experiences using it to answer their HCPs' questions, and feeling more involved and informed.

However, the depth and extent of value described by some was of surprise given their feelings about some HCPs not using it, and that the PHR did not fully accommodate their needs. It is also possible that this level of value may have been shaped by the hope and desire to not experience the challenges encountered previously in their palliative journey, and if so, may have been more associated with the aspirations these participants held for their PHR, rather than their experienced reality with it.

An additional explanation for the level of value expressed by some is apparent in the comments below. Having access to their own health care information appears to have assisted these participants to feel more informed and therefore equipped to manage, promoting a sense of security, reassurance and feeling more in control, rather than feeling “in the dark” or “in the deep end all the time”.

I need to know what to do and what's happening with him, and if I can help in any way. I can always look at this and see – and I can write in it. I don't like being in the dark. Hate it... From my point of view [the patient speaking now], she is more invigorated and encouraged because she actually understands what is going on.
(Wr/331)

At least now you know what's going on – you've got something to refer to. When we didn't have our own notes – you had nothing and were at the deep end all the time.
(T/149)

The opportunity to read their or their partner's own health information, whenever they wished or needed and at a time convenient to them also appear to have added to that sense of control and reassurance.

I can go back when I am relaxed and take it in.... and read about what they have thought, how they have seen things today – even though it's usually the same as what I thought and saw. (Wr/23)

I check it sometimes - just see what they have written if I see them writing a lot. (W/9)

Furthermore, having access to, and learning more about the content of their own clinical record, appears to have prompted a sense of awareness and confidence for some patients/lay carers, assisting them to speak up and speak out about what they wanted.

Now I will go, well look, look, look at that and do something about it. You can see me standing up to the doctors and the hospitals. (C/674)

The extent to which their PHR was both used and considered to have mitigated issues associated with having a terminal illness and receiving input from multiple HCPs and or services appears to have influenced participants' views as to who gained the most value from it. This in turn appears to have shaped participants' views as to whose purpose it should primarily be considered and shaped for. Two of the four interview participants expressed the firm view that their PHR was primarily for aiding them, with a secondary role of assisting their HCPs in the delivery of their care. These participants described using their PHR extensively.

The benefits we get from it far outweigh the burden or the benefits the medical side gets from it. I think it is the benefit to you in particular 'hon' [referring to the patient] - especially the benefit you get from reading it - would that be correct? (lay carer speaking to the patient). Yes that would be the main benefit (patients reply). (C444)

In contrast the other two interview participants indicated less extensive use of their PHR and appeared to view their PHR primarily as a tool to aid their HCPs, describing it as "more for the others who write in it" (W/132).

Theme three: Factors influencing engagement with their patient held record

Promoting use of their patient held record

Except for one of the subcases explored, each patient's main lay carer appeared to have taken the lead role in promoting HCP use of their PHR. Their approach included ensuring the PHR was available and visible for visiting HCP to use and offering it to those who did not first ask for it. Three also described prompting their home visiting HCPs to write in the folder if it appeared that they had forgotten to do so, or were unaware to do so. The lay carers also described taking their PHR to HCP clinic appointments and to hospice or hospital when the need for admission arose. However, each lay carer also mentioned that sometimes they forgot to take it to their GP appointments.

Regardless of how proactive each lay participant was regarding use of their PHR, their methods for promoting its use at non-home based HCP encounters appear to have been more passive than the methods they employed in their own homes, particularly in relation to medical

appointments. For example, all lay participants described how they would physically offer the folder to their doctor, and then watch to see if they used it. If the doctor did not write in it, they did not remind them, despite describing how “disappointed” they were when this occurred. This approach may have been influenced by hierarchical structures and conventions that when endorsed, promoted or reflected by either the patient or HCP can foster a power imbalance. The only example provided of vigorously attempting to ensure their PHR was written in at one non-home based appointment offers credence to this suggestion. For example, whilst being disappointed and frustrated to see the GP not write in their PHR, this participant did not appear to verbally prompt the GP to alter that decision. In contrast, she was comfortable to approach the practice nurse more firmly, place the PHR in front of her and direct her to write in it.

Participants in three of the four interviews appeared to place high value on their PHR being as complete and current as possible, and also appeared to have been quite proactive in trying to achieve this. However, comments also suggest that the district nurses played both a covert and overt role in communicating this expectation to patients and carers, and it is likely that this had influenced participants’ approach and attention for promoting use of their PHR.

Conventions associated with health care delivery

While participants from each interview had read the contents of their PHR, two had not chosen to write in their PHR and perceptions relating to conventions associated with clinical documentation appear to be the main contributing factor. Three participants expressed the view that their clinical record was the domain of the HCPs to write in; however, a closer look at one participant’s comments suggests discomfort with having others read and critique her writing. Although this particular participant discussed how useful she felt it would be if her observations and information were written into their PHR for their HCPs to view and use, she had not yet overcome her inhibitions to do so.

I should write in it.... But when you write something – you are open to scrutiny once you have put anything on paper. And I think it is that, not so much the folder - it's probably my own inhibitions. I am happy to put it in my book - ...and she's [the district nurse] reading my book anyway [and writing what she reads into the PHR] so what's the difference? (C/138)

This participant went on to suggest that the PHR be changed to include a summary table or chart where she could contribute key information, either by ticking set prompt boxes or writing one or two key words in a table, suggesting that a more structured and less narrative style of writing in the PHR was something she would feel comfortable to do. Perhaps the more structured and guided approach of writing one or two words or figures in a chart felt more attainable, making it easier to contribute useful data without concern that it would not look credible or appropriate to HCPs reading it.

In the meantime, as shown in the comment above, the participant had elected to show her own separate notebook of information to the district nurse each time she visited. It appears that the degree of trust which had developed between her and the district nurses enabled her to feel comfortable to show her notes to the district nurse, who then wrote a summary of that into the PHR. This solved her dilemma of wanting to ensure her PHR held the most complete set of clinical information possible, without experiencing the intimidation of writing in it herself. It is also possible that she felt that as "the expert", the district nurse was the best person to decide what information was relevant and therefore should go in the folder (C/283).

The suggestion that unfamiliarity with writing in health records, particularly with the style and language that HCPs tend to use, could constrain lay people from writing in their folder was reinforced by another participant's comments.

I had no problems [writing in the PHR] because I have been there and done that before, But Mr Normal man and wife out on the street would probably be too scared to write in it. They would need to be educated by the first person to give it to them that it doesn't matter how you write in there, what you write is fine, just write how you feel or see something at the time, but write it in, it will be necessary. It could be a bit intimidating for the normal man and woman, because they wouldn't know, and they maybe too scared to look at it. They may think - oh that's private we can't look at that - but in fact they can look at it as it is part of them. (Wr/358)

Having previously working in the health care sector, it appears that this participant's past experience of reading and writing in clinical notes may have influenced the extent and manner with which she had interacted with the PHR. The final sentence in the comment above is interesting as it appears to suggest that patients and their families may feel they should not be looking at their own clinical information because they would consider it the property and

domain of their HCPs. Although legislation about patients' rights to their own health information has been in place for many years in NZ, it would appear that historical perspectives regarding this remain. The following comment reinforces this issue.

I think it should have been in homes years ago. I mean everything was hush hush – patients didn't know – the nurses went in and did their cares and went back to their rooms and wrote up the notes and it was only them that saw them, so the patients and their carers didn't know what was going on. (Wr/324)

If it is adopted I would like to see it for everybody, because during your life you have very little access to your own medical records, when you go and ask for them they sort of quote the 15 psalms of the privacy law. (C/491)

A further perspective raised by participants and one that is likely to have influenced engagement with their PHR was the belief that HCP recommendations or requests were more likely to be acted on when communicated HCP-HCP (either by their PHR, or by other traditional means of communication). This view appears to have developed from experiences of verbally passing on one HCPs requests or recommendations to another and finding that they were not given sufficient credibility or attention. In contrast to these experiences, participants noted that "they [HCPs] respond to what they've read from other HCPs [in the PHR] more than anything" (T/116).

Experiences within their health care journey

Experiences that can be grouped under the heading of discontinuity of care had occurred during each participant's palliative care journey. While these experiences appear to have motivated some participants to use their PHR in a manner focussed on preventing or reducing the experience or impact of discontinuity, comments from one reflect the opposite. The experience of discontinuity appears to have left this participant discouraged and unmotivated to "fight" any more, with comments conveying a sense of failure, both on the health sector's part, and on his/her² part to make a difference for the patient.

In addition, this participant's comments carried a strong sense of frustration and anger over their current circumstances, with the emotions expressed appearing to be centred around grief over loss of the expected life, anger over the perception that the health sector had let

² I have used both genders to reinforce anonymity for this participant

them down by failing to bring the necessary help and relief, and feeling overwhelmed by the experience of looking after his/her partner, with an associated sense of failure.

The books alright – I just get tired of people coming in and covering the same ground, repeating the same answers, and then they go away - yeah yeah – and nothing bloody happens. It's repetition, it's annoying trying to fight for things, and yes we'll get this and we should be able to get that, and all of a sudden – no you can't have it – it's just idle talk – they don't get very far, they are just fighting a losing battle. I'm sick and tired of it. Because I'm here 24 hours a day trying to get through it – I try and do everything for N, dress N, make sure N can get into bed, remind N to take the pills, ask what N wants for tea, do the washing, ironing then cleaning up. I haven't had a game of bowls for ages. I just got tired – absolutely tired of it. We never got any before; I can't see it coming now. It's a total waste of my time, covering the same ground – just getting nowhere. It's bloody hard, and I don't do the right things sometimes. (W/179)

Whilst this participant was providing a great deal of 'hands on help' to his/her partner, from the general sense of the interview it appeared that he/she had stepped back, both from being involved in the planning and navigation of the partner's care journey, and from interacting with the PHR. However, I do not believe this, or the comments above reflect lack of care or concern for his/her partner; to the contrary, I get a sense of caring deeply but feeling hopeless and powerless to prevent the progress and effects of the disease, and the loss of their expected present and future. Over all, there was also a general sense of loss of faith in the health sector, and loss of hope in the likelihood of anything changing for the better, and this appears to have brought him/her to the end of resilience. It is possible that this participant also transferred this stance of pointlessness to the PHR, fostering his/her lack of engagement with it. It is suggested that the degree to which participants interacted with their PHR also appeared to be associated with their perceived sense of efficacy; in other words, whether they believed their efforts could have a positive difference in their or their partner's journey of care.

Conclusion

Lay participants indicated their PHR was useful for helping them to answer their HCPs' questions, assisting with self-care and vigilance, and to stay involved and informed. Their descriptions reveal that their PHR was mainly used by home visiting clinicians, primarily for communicating, planning and co-ordinating between services, noting key information for the

next clinician's attention, and obtaining information needed for their visit from it. In contrast, lay participants' experiences with HCPs use of their PHR at non-home based health encounters had prompted the view that these HCPs were unaware of or disinterested in their PHR.

Lack of engagement with their PHR was of key concern to most lay participants, and was described as "loss". In keeping with this, a number highlighted their wish and indeed expectations that their HCPs use and write in their PHR. In addition, other features that would enable them to be better accommodated by their PHR were raised, including more patient-focussed and individualised self-care and decision support information and tools. Despite limited use by some HCPs, lay participants believed their PHR had promoted collaborative, consistent and co-ordinated care, in addition to providing them with a sense of reassurance, security, involvement and control.

The descriptions provided suggest a connection between the lay participants' own level of use of their PHR and the manner in which they promoted its use with their HCPs. Whether they viewed their PHR as either the domain of the HCP or primarily for themselves also appear to have influenced their own engagement with it. Prior experiences within their own health care journey also appear to have acted as either motivation to use their PHR to prevent the experience or impact of discontinuity or left the lay participant discouraged and unmotivated to 'fight' for help any more. The following chapter presents HCP participant findings.

Chapter Six - Health care professional participant findings

Introduction

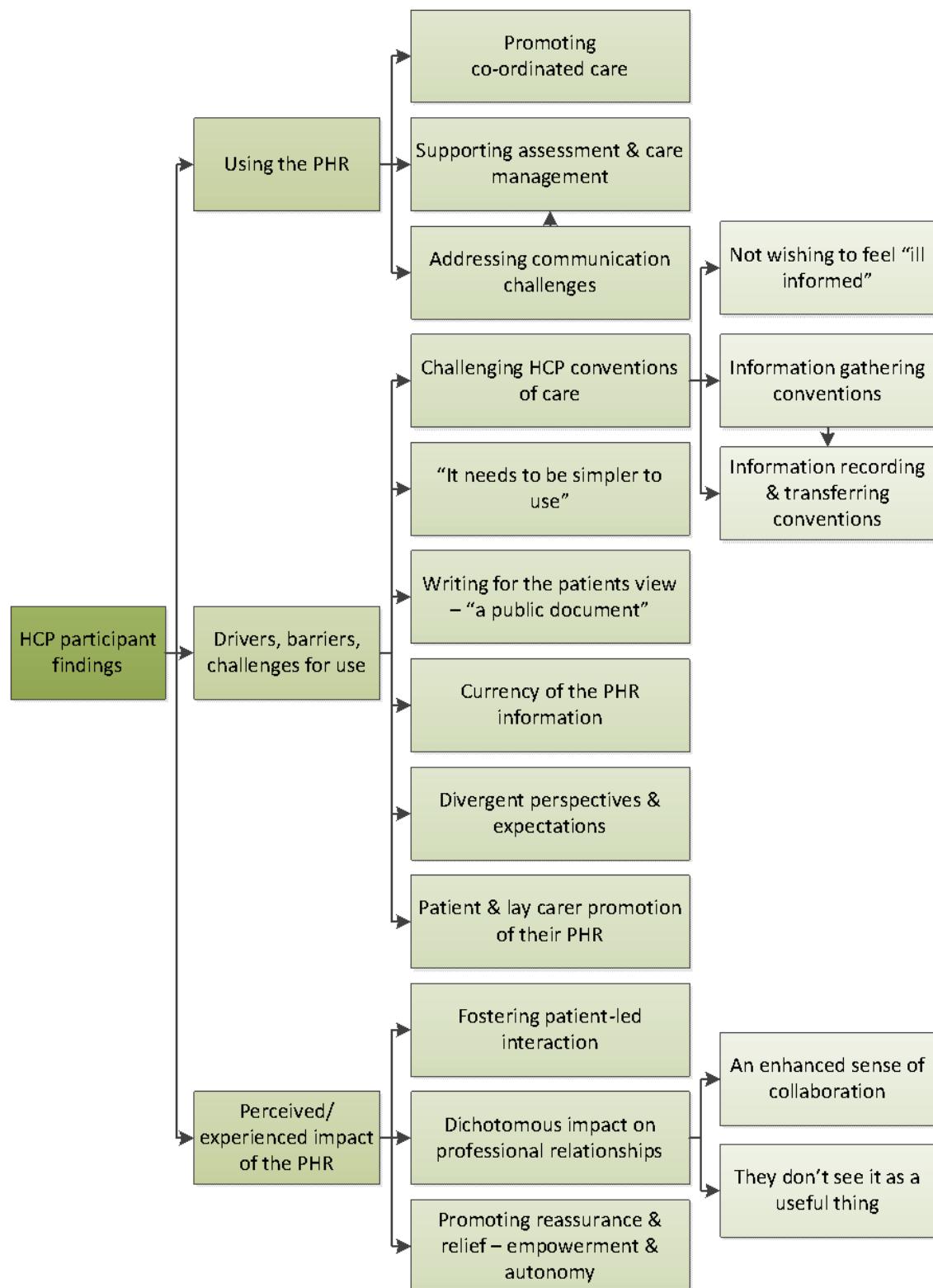
This chapter presents findings which emerged from across the four focus group discussion transcripts, painting a picture of 15 nurses and seven physicians' use and views in relation to three themes, using the PHR, drivers, barriers and challenges for use, and perceived/experienced impact of the PHR. These themes and related subthemes are demonstrated in Figure 6.

Theme one: Using the patient held record

District nurses appeared to have interacted with the PHR more frequently than the other HCP group participants. This had been expected considering the 'hands on' nursing care role the DNS in this region provides for many palliative patients, and that this service had also elected to use the PHR as their primary patient clinical record. Also as expected, the hospice focus group PCC participants described extensive involvement with the PHR as they primarily visit patients in their home where the PHR was located. Hospice physicians involved in home, clinic and hospice inpatient based service provision described a much lesser degree of interaction, as did hospice nursing staff involved solely with the inpatient aspects of palliative care.

General Practitioner participants indicated minimal contact with the PHR, with each having seen only one or two patients with the PHR. This may be associated with practising in a large urban setting with numerous GPs and each GP having only a small number of palliative patients each year. In addition, most of those patients lived in a rest home so they did not have district nurses involved in their palliative care, and therefore did not have a PHR. Each member of the hospital based specialist cancer service focus group described several examples of contact with the PHR, both in their outpatient clinics and within the hospital inpatient setting. The physician participants in the hospice, specialist cancer services, and GP focus groups all indicated that the PHR was rarely brought by patients to their clinic appointments, and if it was brought it was rarely offered unless asked for by the HCP. Three subthemes relating to how, and for what purpose participants used the PHR emerged from the combined focus group discussion data and are presented below.

Figure 5 Health care professional participant themes and subthemes



Promoting co-ordinated care

Participants in each focus group described using the PHR in a range of ways that appeared to be focussed on promoting well informed, co-ordinated and non-duplicative care delivery between and across the patient's wider health care team. For example, several district nurse, PCC and GP participants explained how they wrote questions, suggestions, or prompts in the PHR that they wished the PCC, GP or any other HCP seeing the patient next to be aware of, or to follow up. Using the PHR as a time saving method of communication between HCPs and services, thereby avoiding the need for phone conversations, was the common feature of these approaches. In line with this, several participants highlighted that efficient care co-ordination by the PHR was further improved when other HCPs took the same approach to communicate key messages to them.

For me it saves time. I can see if what I've said or what I've thought about has been followed up and I don't have to keep on ringing people to find that out. It's a good communication tool. (District Nurse Focus Group (DNFG)/249)

In keeping with the goal of working in a more efficient, interconnected and co-ordinated fashion, the PCCs and district nurses also described using the PHR in a manner that reduced some care activity duplication. For example, they documented particular activities in the PHR when completed thereby ensuring they didn't get repeated. A second example was locating shared documents such as the nursing care plan in the PHR to avoid the need for both services to develop and store separate documents. One PCC reflected that she was "always thankful when I get there and find the district nurses have already done the care plan which saves me a lot of time and I no longer have to make another one for our clinical record" (Hospice FG Nurse Community/797). The opportunity to use the PHR to reduce strain and intrusion on the patient and family through reduced duplication was also highlighted, particularly with regards to conducting sensitive and potentially distressing conversations. The following example was offered by one PCC as evidence of this and of the sense of partnership associated with two HCPs collaborating via the record.

This lady was dying, and she was dying ever so slowly and the district nurses had been in that morning and had one of those deep and meaningful conversations. She had talked with the family and had documented this really clearly in the care plan – lots of sensitive stuff but written beautifully and you could see from it that she had actually had that conversation. And I walked in there and I was about to have the same

conversation. So the patient had already been through this and expended all this energy in having this conversation and she could see I was ready to launch into another one, and she just said – could you read what the district nurse has written, and I read it and we were on the same planet straight away, so I knew exactly where she was and she didn't have to explain it to me at all. And I felt really good about it because the district nurse before me had done good work and documented it really appropriately, and the blue folder [PHR] was a medium of being able to pass that information on quite clearly. (Hospice Focus Group Nurse Community (HFGNC)/379)

Another point of value raised by a range of participants was the opportunity to ascertain from the PHR which other services and HCPs were involved in the patient's care, in particular "who had been in before me", making it easier to know who to contact if follow up by phone or letter was required (HFGNC/42). The PCC participants placed particular emphasis on this aspect, and it is possible that having easy access to this information may have made their role of co-ordination, liaison and oversight a little more straightforward. Overall the PCCs appeared to hold the view that by acting as a tool for the patient's wider health team to "all be on the same page", the PHR supported "continuity of care, not just good quality care" (HFGNC/825).

In terms of communication it's excellent, and I think once it's even more effectively across the wider team it could be a really great tool. (HFGNC/42)

Supporting assessment and care management

Clinicians from each focus group commented on the value of having access to a more complete set of clinical information in the PHR than traditionally available at their patient encounters. One GP described checking what other HCPs had documented in the PHR regarding the patient's current symptoms and treatment plan along with the documented effectiveness of that approach without the need to phone another HCP to obtain the necessary information. This information was then used to prepare the next aspect of the patient's management plan. Another GP described the value of being able to outline their recommended treatment in the PHR and to then receive feedback through it about the outcomes of that treatment from the nurses and in turn use that information for the next phase of planning.

Very useful to get a flavour of the interactions of the previous few days, especially with troubleshooting the symptoms that people get. (GP Focus Group (GPFG/79)

Palliative care co-ordinator participants also spoke highly of being able to read the clinical assessments, diagnostic findings, and care delivery documentation from the other HCPs involved in the patient's care, explaining how these assisted them to "get a feel for what is happening" (HFGNC/228). They also commented that the "day to day care, hands on stuff and their [district nurses] impressions" written in the PHR provided "a wealth of information that is very valuable for the PCC" (HFGNC/303). It is very likely that this wider range of information assisted the PCC in their role of oversight of the patient's care which may account for the depth of regard expressed by PCCs in their comments below.

I rely heavily on the blue folder because it's such a great source of information. I am actually quite relieved when I see it there, because it's another piece in the jigsaw for making up the information you need to know in the patient care....I think I couldn't live without it. (HFGNC/64)

Hospice inpatient service participants also described using the PHR to obtain a more complete clinical picture, particularly in relation to what had occurred for the patient prior to admission to the inpatient unit. Access to background information of this nature was considered useful as it "gave clues as to whatever they [the patient and their lay carer(s) are talking about, where their situation was going, and adds to my assessment" (HFG nurse inpatient (NI)/256). It was also found to be useful for supporting a consistent approach between unit and home based teams for managing particular health needs and nursing interventions such as, "seeking clarification about wound management, certain dating, catheter insertion" (HFGNI/28).

The manner in which the PHR aided in the delivery of after-hours district nursing support was also emphasised, particularly for "patients who are not known to us" and where "it's an acute situation" (DNFG/164). Prior to the introduction of the PHR, patient's district nursing clinical records were stored in the district nursing base closest to where the patient lived and therefore were not available for the after-hours district nurse (who operated out of the main centre) to view prior to visiting the patient, or to write in after visiting the patient. This was considered to have impacted on the ability of both the after-hours and day district nurses to be well informed about that patient's particular health care needs and circumstances, with the key concern being that the nurse may not have sufficient information to provide the most appropriate clinical response. In contrast, with the PHR available in the home, district nurse participants described the value of being able to quickly and more fully apprise themselves of the patient's current health care needs and circumstances.

Addressing communication challenges

Participants raised the challenge of providing co-ordinated, consistent and quality palliative care to patients and families where a number of different services and HCPs in each focus group. The traditional approach for each service to have separate clinical records was described as adding to this challenge, in particular, for ensuring the patient's whole health team had timely access to the current clinical picture and plan.

It's not very clever of us this far on in the computer revolution that we can't know exactly what the patient is on in general practice, and what is happening in the house; it's a bit sad, an indictment really and this record is an attempt to pull some of that stuff together, and so if we make a key management change, then it needs to be known across the sector, not just in one point. We are all guilty of doing it [clinical documentation] in our own silo. (Cancer Services Focus Group (CSFG) Doctor (D)/97)

The existence of traditional methods of information transfer between hospital and community services currently employed across the health sector was acknowledged, such as 'patient letters' dictated by the physician after the patient's appointment with them, or hospital/hospice inpatient service discharge notes. However, participants from the GP and cancer service focus groups indicated that information transferred by these methods was not always available when needed, both in relation to information arriving to them, and information they sent out to other members of the team. Also of concern was that these traditional modes of inter-service communication did not often include input from the broader health team (such as nursing).

Participants reflected on the difficulties and inefficiencies associated with key information about the patient's management not being available to them at point of care. In particular that this often meant using up valuable time chasing the information they required, described by one participant as "doing the Sherlock Holmes bit all the time" (HFG/781). It was highlighted in each of focus group that lack of time or opportunity to obtain the required information from elsewhere often meant relying on the patient/lay carer to provide them with key clinical information such as seeking information from patients about what other HCPs involved in their care had said, done, or recommended. Concerns that this approach relied on the capability of the patient/lay carer(s) to take note of, and remember the relevant clinical details and that it often placed a burden on them to 'tell their stories over and over again' were expressed. A number of participants also gave examples of where they felt that not having the most up to

date clinical information at point of care had risked the patient not receiving the most appropriate management.

Within the context of the above communication challenges, the opportunity provided by the PHR to bring clinically relevant information from a range of health services together into one document held by the patient was found to be useful. All teams, regardless of their care setting, could be informed of key information in a timelier manner than that provided by other traditional approaches and without needing to rely on the patient/lay carer(s). For example, hospital based HCPs explained how they used the PHR to communicate their plans and recommendations “out to the community” as well as finding out about “the community side of care”, particularly in circumstances where it may have been difficult to obtain that information from the patient (CSFG Nurse (N)/147).

Knowing about the community side of their care is very useful. I have access to the hospital notes very easily so I know what is happening in the hospital, but I don't necessarily know what is happening in the community. (CSFGN/147)

I think I would have had difficulty finding out his medication because often patients don't remember medication, don't remember changes made [to their treatment plan]. I also wouldn't necessarily have known much about what was happening in regards to the Hospice, because again, he wasn't particularly clear himself, but it was very clearly documented in there [the PHR]. (CSFGD/62)

Theme two: Drivers, barriers, challenges for use

Challenging health care professionals' conventions of care

Not wishing to feel or appear “ill-informed”

The desire to have sufficient and current clinical information available at the point of care was a theme throughout all focus group discussions. However, a particular emphasis on “feeling ill-informed” was raised during the district nurses’ discussion, particularly in relation to the value versus inconvenience of placing their main clinical patient file in the home rather than the district nursing base. Discussion regarding this appeared to fall into two categories of opinion. The first category encompassed views was that placing the main file with the patient helped the nurse to not feel ill-informed because when they arrived at the home they could also read documentation written by clinicians other than the district nurses visiting the patient.

With the blue folder I feel a bit more confident about going there as well, I don't feel I am going in quite so blind. (DNFG/705)

These perspectives associated with the value of feeling may have arisen from experiences providing after-hours district nursing triage and assistance to home based palliative patients, a role that often requires responding to quite acute, unpredictable and challenging situations, and generally without having other district nursing colleagues to assist. However, the opinion of other district nurses who also provided after-hours district nurse support fell into the second category, which encompassed views of feeling ill-informed because the full district nursing file was no longer available to read prior to visiting the patient.

When we get call outs ... we only have our brief summary base notes and these are not always at the base we are working from. The full record is at the home and so I can't clearly identify all the issues at base about what's going on until I get to the home and that can be a problem because the family confront you the minute you get in the door and you are not fully informed and I don't like that feeling. I like to know exactly what's going on, and then I have to ask them for the notes and I have to quickly read them, but it's not always such a good look sending someone in who doesn't necessarily know exactly what's going on. (DNFG/1003)

From comments made it appears that the district nurse 'base file', containing a brief summary of the patient's care needs, 'between district nurse shift' messages regarding the patient and documentation of any 'non-face to face' care provided (such as phone call advice to the patient/lay carer), adequately met the needs of some district nurses (provided it was kept up to date) whilst for others, placing the main file with the patient had caused some challenges.

The double handling [of having the two files] is a bit of a nuisance, but it's actually handy. I like to know before I go in there on a day to day basis. It doesn't help the patient's impression of you if you go in and you don't know. (DNFG/720)

No matter which camp participants' opinions fell into, the experience of feeling ill-informed appeared to engender strong feelings for these nurses. Several appeared to equate uninformed with feeling inadequate, or not being professionally equipped to respond to the situation. These perspectives also suggested a concern about conveying the impression of not

being professionally capable to the patient and/or their family, thus causing them to lose confidence in the nurse's ability. Interestingly, it sparked a conversation in the focus group where other colleagues challenged the expectation to have all the answers all the time, with one suggesting that the change in placement of the main file could be managed with a change in both perspective and the manner in which one approached the situation.

Speaker 1: Well then why don't we? - Why are we so precious about not admitting that we don't know everything about them?

Speaker 2: It's just that I don't want them, when I walk in the door, not to have confidence in us, so you want to be professional and them to feel like they can have faith in you.

Speaker 1: It's just how you go about it. It's just another thing you have to be highly aware of as you are going in - that they don't feel threatened at all, that you're not highly capable of working out what their issues are. (DNFG/1021)

Information gathering conventions

Comments from physicians throughout the focus groups reflected a preference for objective data, i.e. data that was presented as measurable facts, or observable for themselves. This particular group of participants spoke of viewing subjective data with caution as it had been shaped by the perceptions and interpretations of someone other than themselves. In addition, there appeared to be a hierarchical order to the degree of confidence that the medical practitioner participants placed on information provided to them by others, which in turn appears to have shaped their views and use of the PHR. For example, several GPs described information provided to them by patients as "very biased because it is naturally what they are feeling" (GPFG/87). In contrast, information provided by nurses was described as objective. Their comments suggested a preference for making treatment decisions on the basis of information provided by, or at least verified by, a HCP. Accordingly, GP participants described using the PHR as a means for verification, appearing to consider its contents objective and, therefore, dependable.

Where doctors get information from is fundamentally from the patient or their family and sometimes that is very biased because it is naturally what they are feeling. So to have the blue folder which gives us something objective, where the nurses have been

able to say, patient losing power in their limbs... so it's very useful from the point of view of providing an objective assessment given by one of the nursesso it does act as a very objective way to assess how the patient is doing, naturally [their feelings] will be incorporated , so she [the patient] might say that she is feeling the pain, the nurse might say oedema, and I might say weakness, and that's the combination that is really the important thing. (GPGF/87)

However, whilst most physicians commented that the PHR was useful for obtaining objective information to supplement subjective perspectives and possible memory gaps of patients'/lay carers', many also emphasised a preference to gather their own information from the patient prior to seeking information from the PHR. Again, this appeared to be associated with the concern that their assessment findings would be "biased" or "influenced" by what they read, potentially leading them in the wrong direction (HFG/632).

One thing that I feared is that it could take the place of your own assessment and it could influence your assessment because you go there, you read first and you can either stop at that information that is given and take it further from there or it could condition you even towards making a diagnosis, making an assessment, taking a decision and judgement about what is happening which could influence your management and from that point of view I would not want that. I would read it maybe later on if I need more information. (HFGD/146)

These physicians did not appear to be suggesting that the contents of the PHR were so biased, subjective, or distorted by the writer's perceptions to not be useful. Rather, most explained that after they had gathered their own information and formed their own impressions they may seek confirmation from the PHR. This approach, highlighted as stemming from their training, appears to be a strong precept within the practice of medicine, with one participant explaining that as doctors it is "what you are called to do with your own skills, your own assessment, your own knowledge, your own experience. You are in there and ask the questions of the patient" (HFGD/160).

The differences between how doctors and nurses gather and use information became a significant feature of the hospice focus group discussion and I noted during the discussion the level of interest it generated for the nurses present. At the end of the focus group, several nurses commented that they had gained a greater understanding as to why their medical

colleagues were not using the PHR as envisaged and encouraged by their PCC colleagues and reflected on the contrast between their own approach and that described above. In particular, they commented that they both recognised and welcomed the different standpoints from which each HCP noted, interpreted and then conveyed information via the PHR, preferring to consider and take these into account rather than view them with caution.

Recognition and consideration of other colleagues' perceptions also featured in the district nursing focus group discussion. Differences in perceptions were described as inevitable due to differences in HCPs and the rapid changes that can occur for palliative patients and their circumstances, with one district nurse explaining that "it can be a matter of a different time of day can't it? I mean someone might be very anxious at this time of the day and then when we go in the evening they might be quite calmed and thinking about things quite differently" (DNFG/453).

Expanding on this topic, a number of nurses in both the hospice and district nursing focus groups indicated that, where possible, they would avoid questioning the patient and or their family by using information from the PHR, considering this to be more optimal for the patient.

Because they [the patient] don't have to tell the story over and over and over again, the nurse has a read and then it evolves from there. (HFGNC/137)

I had one family who wrote in it ... and what they wrote was quite relevant to the patient and it's been quite good to actually read what they have written rather than have to go in and question them, so that's quite useful as well. (DNFG/70)

Some nurses did indicate a preference to initially gather information through observation and conversation, rather than look at previous entries in the PHR to gain a sense of what had been occurring. However, in general, it appears that medical participants tended to look at the PHR more towards the end of their patient interaction, after a conversation with the patient and as they were preparing to write their consult note. In contrast, nurse participants generally indicated that they obtained and read it earlier within their patient interaction, most often shortly after greeting and engaging with the patient.

Information recording and transfer conventions

Differences between how doctors and nurses write in the clinical file was also a significant feature of the hospice focus group discussion, in particular the view that nurses wrote lengthy

notes, more like a narrative, or ‘story’, whilst doctors tended towards briefer notes that focussed on specific ‘facts’. These different documentation styles were noted by both medical and nurse participants. Comments suggest the physicians recognised the value their nursing colleagues placed on the “stories” written in the notes, particularly for the opportunity to gain greater understanding of the patient’s particular circumstances and preferences for care. However, these medical participants appeared to prefer not to read through them in order to be apprised of the key messages and plan.

But I feel this [PHR] should be for communicating factual stuff and information about what is done. I don’t think we should go beyond that. I mean again stories are there to be heard, once you are in there you hear stories and you would want to relay them in a way and that is one way [by writing them in the PHR] that you are actually relaying them. But ultimately I would probably feel - I have a very good example - I had an intense very meaningful conversation about dying with Mrs X and there – full stop. Rather than talk about the whole lot and write it down in a way which then becomes a story.... I would want to look into the folder for the facts. But as I open the few folders that I have opened I get put off I have to say that because it is long, there is too much story. (HFG/654)

Nurses like stories, nurses like to hear the journey and I’m not saying that doctors don’t, but with different hats on I guess. As well as liking to hear the journey, we tend to write stories as well, so the blue folder gives us an opportunity to have that. (HFGND/366)

I would quite like to see some kind of page where it just says changes made... something that you just hone in on, instead of having to read through the whole story. (HFG/338)

It appears their nurse colleagues were aware that their style of documentation was problematic for their medical team members and some efforts to adjust their style had already occurred. However, adjustment was also reflected to be difficult as “it’s about changing a nurse’s process of writing and that’s not always achievable” (HFGNC/508). Perhaps this lack of resolution was the driver behind the solution offered by one medical participant, which was to add a separate section into the PHR for medical staff to document in. Whilst this idea was challenged by others present as “separating” information, and therefore not in the keeping

with the aim of bringing patient information from all HCPs' together, it was defended as a means for directing and simplifying the process for doctors.

I just find like in rest homes they actually have a medical page in most of them and I actually find that really beneficial because I know, I find that page and see when they last saw them and what their stuff was and I am a lot clearer and it's what I'm looking for rather than their general day to day stuff. (HFG/768)

Hospice physicians were not the only participants to highlight a preference for not reading through lengthy nursing documentation. The GPs also reflected that some nursing notes did not appear relevant to them, and hence they would prefer to read a summary of key points written for their attention in a separate section of the blue folder. In essence, their preference was for other HCPs contributing to the PHR to select out of their clinical findings and care documentation only the key points that would be of interest to the GP in their management of the patient, and note these on a summary page.

With just a very small amount [of data] - perhaps a graph and table of some sort in which a summary word is added. (GPFG/238)

As mentioned earlier, discussion regarding other, more traditional, methods for recording and transferring information between HCPs and services occurred in several focus groups, primarily raised by the medical participants. Whilst concerns were raised by the hospital specialist cancer service and GP participants about the rate with which these methods transferred information between services and the breadth of multi-disciplinary information in their content in the some focus groups, this was not the case for the hospice focus group discussion. Physicians' comments in this focus group appeared to indicate a preference for their service's traditional approaches, and less of a preference for using the PHR. These approaches included; 'patient letters' dictated at the conclusion of the patients medical review, the hospice's electronic patient information system which all members of the hospice multidisciplinary team could view and contribute to, and the face to face and phone conversations between all members of the co-located hospice multi-disciplinary team.

One reason for the preference to continue to dictate letters rather than writing in the PHR is that the former process is quick and convenient, requiring less time than writing a note. This possibility is supported by a suggestion offered at the hospital specialist cancer service focus

group as to why medical practitioners were not so keen to write in the PHR. Interestingly, the physician who raised this point went on to suggest that it was time for this pattern to change.

Recognition of it [the PHR] is one thing, and recognition by doctors that we can write in notes, should write in notes, we dictate a lot and we get into patterns of behaviour and some of that pattern as a consultant is you don't write in the patient file because the junior staff do that, we don't write outpatients because you dictate, so that pattern is quite difficult to break sometimes. (CSFGD/38)

It is also possible that the desire to avoid duplication may have shaped the apparent reluctance of physicians to use the PHR. One hospice doctor explained that "before I go into an outpatient [clinic appointment] if I haven't managed to speak to the PCC I would read up on VIP" [the hospice's electronic patient management system] (HFGD/676), suggesting that they felt fully appraised of the key issues and hence did not consider it necessary to also read the PHR. In addition, if the physician considered the primary purpose of the PHR was to share information with other HCPs but had already elected to dictate a 'patient letter' to other members of the health care team, writing in the PHR may have been considered unnecessary. Other factors that may have contributed to some HCPs being reluctant to write in the PHR are discussed in the topics below.

"It needs to be simpler to use"

In addition to the challenge of searching through lengthy nursing documentation for the key points of interest, challenges with the way information was laid out in the PHR was highlighted in the GP, hospital specialist cancer service and hospice focus group discussions, in particular, the need to go to several places in the folder in order to glean useful information. It was suggested that doctors, and indeed any HCPs less familiar with the PHR, could find this confusing, frustrating and time consuming, which may discourage use. Furthermore, having to go "flick, flick, flicking" through all the pages and sections of "quite a thick folder that doesn't come to me prior to the visit" during a time limited clinic appointment was highlighted as impractical (HFG/617), hence the suggestion to simplify it "if you want more people to use it" (HFG/737).

Another issue raised by some participants was that they "never know where to write" or what they are expected to write, suggesting that clearer education be provided to potential users of

the PHR to inform them of its purpose along with where and what and when to document in it (HFG/757).

By comparison if you go into a rest home, the nurse who shows you round or whatever will generally say to you, please write in the doctor's notes in which case one generally does what the nurse says. (HFGD/331)

Perhaps on the very front of the folder there could be a piece of paper that says what this folder is, and that directs people's actions with it. Like if I [as a patient] go to Dr M and put this in front of him and it clearly says please write the outcome of visits. Being more direct and in your face so that they know what is expected of them. (HFGN/517)

Overall, it was felt that layout and style of documentation issues were adding time and some inconvenience to the patient consultation, and were therefore, likely to be impacting on HCP decisions as to whether or not they would use the PHR.

Writing for the patient's view - "a public document" - the risk of giving patient's their notes

The complexities and challenges associated with writing clinical documentation that would be viewed by the patient and or their family was a common theme across each focus group. A number of participants spoke of the need to be cautious about what and how information was documented in the PHR. These concerns appeared to be centred on the sensitive or confidential nature of what they were writing and the impact it might have on the patient and or their family when they read it. Concerns that what was written could be misinterpreted or, interpreted in such a way that it annoyed or distressed the patient/family were also raised.

Sometimes it's very awkward to write in what you see because there might be family dynamics that might not be appropriate to write... you have to be very careful with your wording, knowing they are going to read it, not to inflame the situation, ...you may word it a little differently than what we may communicate to ourselves knowing that its only for our ears and eyes. (DNFG/420)

Unfortunately what you write in it is limited so I would write facts, like dosages, suggestions, but certainly other stuff I would be very careful. (HFGD/218)

Within this topic, perspectives tended to fall into two groups, however, there did not appear to be a pattern of grouping across the disciplines. The first common group of perspectives focussed on a reluctance to document sensitive information in the PHR.

Yesterday I had a new patient ... and he is actually unfortunately in a very poor prognostic group and we had a discussion over the pros and cons of treatment. I did outline the prognosis but I thought to write quite starkly what the prognosis was in the blue folder was potentially not helpful to him to keep reading that information so I didn't write that down. I just simply said [in the PHR] we had a discussion about treatment options and he was going to make a decision – maybe that was wrong but I thought at the time that was better....I just felt with the consultation it wasn't necessarily something I was happy to do. (CSFGD/193)

The second general group of perspectives acknowledged that documenting particular information in the PHR required care, but also spoke of the need to overcome this challenge.

One of the reasons I went into cancer in the first place, it was seeing doctors in particular lying to patients about what they had i.e. cancer and what the outlook was - and the fantasy of cancer is far worse than the reality to patients, so we underestimate our patients and families in terms of what they are able to cope with and the stuff they want to hear from us. So I think we need to take, or get rid of some more of, our paternalism and obviously confront it and hear what they want to say. (CSFGD/295)

Several approaches were described for dealing with the dilemma of sensitive or confidential information. These included: describing their perspectives and perceptions to the patient and family and gaining clarification of their agreement and understanding prior to documenting in their PHR, utilising a different style of language when documenting in the PHR, or communicating the sensitive information via an alternative mode than the PHR.

It has led me into having further conversations face to face which I think is good ... if I have got a feeling that things are deteriorating I will write that but it will be after discussions with the family and I will say that I am writing that in the notes and that's my perception – how do they feel about what I'm writing? (HFGNC/282)

We have chosen not to put that [initial nursing assessment] in the home folder ... because it has a lot of personal stuffbecause there are some private things that the patient said that they don't want the family to know and they have stated that.

We will share it [the assessment] with the District Nurses ... but to have it in an open forum [the PHR], I still feel a bit dodgy about that. (HFGNC/597)

As both perspectives tended to occur in each focus group, some critique of the varying viewpoints occurred between colleagues. One participant commented to another that in choosing not to write information considered sensitive in the folder, the HCP had limited the information available to for the next HCP's interaction with the patient.

Somebody else might need to know what the prognosis is and how are they going to find out if that type of information isn't written in it? (CSFGD/ 193)

Interestingly, one participant raised the point that having the document at home "was a risk" – although not going on to clarify what that risk was. Picking up on the point another participant agreed that there was the possibility that the information could be "acquired, photocopied and obtained through that process", however, in asking patients to be "involved in it, it's a managed risk we are taking" (HFG/480). It was of surprise to hear this concern, if the point was indeed in relation to patients copying their own notes, as patients are entitled to copies of their clinical records anyway. However, it is possible that this participant was referring to the risk that other people may acquire or view the information without the patient's consent.

Currency of the information in the patient held record

Whilst participants in each focus group offered many examples of writing and gaining benefit from others' documentation in the PHR, concerns were raised as to the completeness of its contents. Overall, the general reflection was that "there's a huge variety, in that some [HCPs] will always use and ask for it and others don't" (DNFG/237). This appeared to be a source of significant frustration and disappointment for members of the district nursing focus group and the majority of their comments related to this topic, their key points being that if the PHR information was incomplete or not up to date, the opportunity to use the PHR to achieve particular goals was compromised. Some hospice focus group members also signalled frustration when this occurred, but with much less emphasis than the district nurses.

We all send notes with our patients over there and they come back blank - with no addition in it at all even though they have gone to radiotherapy, oncology - you have no information coming back with those folders. (HFGD/524)

Whilst incomplete information in some PHRs did not appear to deter district nurse participants from using them, comments from other focus group participants suggest that concerns regarding this may have been a barrier to use for some HCPs. The key concern appeared to be that not having the most up to date clinical information available to them at point of patient contact could result in not providing the most appropriate clinical management. Interestingly, gaps were felt to be due to other HCPs not contributing to the folder, rather than any omission in contribution from the respondents present. Furthermore, gaps in content were most commonly ascribed to the GP.

We also have to remember that it is not complete, because the GPs don't write in it, we don't write in it, so it is not complete, there are gaps in it... the completeness needs to come from everybody. (HFGD/187)

Members of the hospital specialist cancer service focus group highlighted that using the PHR with confidence requires a sense of reassurance that it does indeed contain the most current clinical picture. The view was expressed that all services involved in palliative care should become more aware of, and "collaborate" by writing in the PHR to ensure this (CSFGD/239).

Divergent perspectives and expectations of the value and function of the patient held record

Different views regarding the function, value and overall purpose of the PHR transpired in all four focus groups. These in turn appear to have shaped how, and the extent to which, each HCP used and expected others to use it. District nurses appeared to hold the highest expectations of their own and others' use of the PHR. These expectations centred on three goals: (i) promoting a partnership approach to community based care between services by using the PHR to facilitate collaborative planning, care delivery and liaison, (ii) using it to extend the level of up-to-date clinical information available at point of care, and (iii) using it to optimise care co-ordination, thereby assisting patients and families to experience continuity and quality of care.

The cancer service focus group appeared to view the PHR function as primarily for bringing clinically relevant information from both the hospital and community sectors together into one

document, so that both “sides” could be aware and informed in a more timely manner than traditional information transfer approaches provided, thereby supporting clinical decisions and management at each patient interaction regardless of the setting (CSFGN/147).

In general, GP participants appeared to view the PHR as primarily for them to “get information from”, to “keep updated”, and less about them “giving information into”, unless they felt “writing a little note was going to be helpful to the overall scheme of things” such as communicating their recommended treatment plan to the nurses and request for particular feedback to them via the folder (GPFG/23, 55).

The hospice focus group discussion showed the most variation with regards to group members’ views of the PHR’s value and purpose. In the main, it appears that hospice physician and inpatient nurse participants found it to be less ‘vital’, and more ‘for interest’, other than in circumstances where specific dates and key facts were sought. In contrast the PCCs appeared to have significantly incorporated the use of the folder into their practice, using it as a tool to assist them to provide palliative care co-ordination on behalf of the wider hospice service. Given the investment in the PCC role, it is suggested that the other hospice team members present did not find it so necessary to interact with the PHR in relation to care co-ordination as the PCC appears to perform that role for patients on behalf of the wider hospice team as demonstrated in the comment below.

I tend to get primed with the information via the PCC before I go. (HFGD/23)

Probably we have already got the patient journey as to why the journey is occurring from conversations with the PCC who is already organising their admission. (HFGNI/27)

However, within the context of this, both the hospice physician and inpatient nurse participants appeared to recognise that the PHR assisted the PCC provide overall palliative care co-ordination to patients on behalf of the hospice.

I think the major stakeholders in this would be the patients, families, the district nurses and the PCCs, as it looks like it’s helping them deliver good quality care and provide better continuity of care and support. (HFGD/820)

Participants’ examples for illustrating the function and purpose of the PHR were, for the most part, associated with the processes of multi-service care delivery, and appeared to be centred on making things easier for the HCP. Whilst the opportunity for the PHR to improve the

experience of care for patients and their lay carer(s) was identified by a number of participants, the examples provided also primarily related to HCP processes. Therefore, the PHR appears to have been viewed primarily as a tool to assist HCPs, rather than patients and lay carers. Interestingly, when asked specifically about their views as to whether the PHR was primarily for patients or HCPs, the comments offered indicated uncertainty regarding this. This is also likely to have influenced how HCPs did or did not interact with the PHR.

You have to decide what the document is for. (GPFG/224)

I think that's where the purpose that needs to be clarified and is it both? If it's both how do we plan to use it as both? If it is one or the other then we need to focus it accordingly. I personally believe it's both. (CSFGD/293)

Patient and lay carer promotion of the patient held record

In commenting on how to ensure HCPs were aware of or remembered to use the PHR, participants in both the district nursing and hospice focus group identified that the key lay with patients/their lay carer(s). In particular, it was stated that promoting its use relied on patients/their lay carers taking the PHR to appointments and having it available at home visits, presenting it to the HCP and asking them to write in it. Thus a significant level of expectation for ensuring its success was laid by these two groups on the patient/lay carer(s).

If you've got someone who is prepared to poke it in front of everybody's noses as they walk in the door and not as they walk out the door then it gets used a lot more. (DNFG/204)

It also depends if the patient and family have come on board utilising the Blue Folder – if they don't take it to the GP then they don't know. (HFGNC/323)

The district nurses in particular described how when first giving patients' their PHR, they explain its purpose, ask if they wish to have one, show them how it is used, and then invite them to support its use by making it available at all their HCP interactions, both at home and elsewhere.

To begin with, we kept having to prompt them about it, but now as I present the folder [to the patient] I say "every time someone comes in give this to them so they can see what's going on and also so they can write in it and tell everybody else" and that seems to work better now. (DNFG/216)

From HCPs' descriptions of how patients introduced their PHR into the health encounter it would appear that many had taken this expectation on board quite vigorously.

The majority of the time it is there, either it's sitting out where I can see it or family at the house quite often come up and say to you "well you know there's the blue folder".
(DNFG/212)

I mean that Blue Folder gets thrown at you as you walk in the door. (HFGNC/232)

Several HCPs highlighted that the manner in which the patient/lay carer brought it to their attention did indeed convey an expectation for them to use their PHR and subsequently influenced their actions towards it.

If the patient gives that then I will obviously look at it because I can see there is an expectation and I don't want them to feel that some as precious to them isn't valued so I will. (HFGD/632)

I had an experience recently where they were extremely significant for the wife, extremely, and she was very anxious that I should write in them, it obviously meant an awful lot to her. (DNFG/543)

The manner in which patients/lay carer(s) were described to present their PHR to the HCP may have been due to the level of value it held for them, but could equally have been due to the level of expectation placed on them to do so. However, another possibility is that patients/lay carer(s) may have felt awkward, uncomfortable or uncertain about introducing their PHR and asking the HCP to use it, therefore taking the approach of getting it over and done with as quickly as possible - in a sense like handing over a 'hot potato'. Alternatively, patients/lay carer(s) may have developed the approaches described above in response to past experiences in which their HCPs put aside and did not use their blue folder or forgot to use it. Regardless of the reason, there is a sense from these comments that introducing it altered the traditional order, flow and processes these HCPs employed when interacting with patients, a topic discussed further in theme three – fostering patient led interaction.

In addition to involving patients/lay carer(s) through promoting the use of their PHR, both the district nurses and PCCs highlighted that they also encouraged patients/lay carer(s) to write in their folders. This focus for this appeared to be on promoting greater involvement in their own health care, an expectation that is now part of the culture of contemporary health care as

reflected in one participant's comment regarding "the patient delegated roles that are so important" (CSFGD/239).

I have had families writing it, but just general things, I have been encouraging them to put their questions in there that they think of until the next visit. (DNFG/85)

I have said if you need to write something in this then certainly go and do - and when I've asked them to let us know how much elixir is he having and things like that [so that we can keep track of the patient's pain management requirements], I'd certainly ask them to do that [write that information in the blue folder] so we can keep it all in one place, all in one compact unit. (HFGNC/402)

However, both the district nurse and hospice participants also highlighted that not every patients/layer carer engaged with their PHR in such an active manner, reflecting that some did not demonstrate much interest in, or connection with it.

But some people have not even thought about it and you have to ask every time, have you still got the blue folder and you feel that's a bit of an intrusion. (DNFG/571)

Theme three: Perceived / experienced impact of the patient held record

Fostering patient led interaction

The presence of the PHR appeared to change the process, flow, and conventions for the way that HCPs traditionally interacted with their patients. For example, participants from both the hospital specialist cancer team and the hospice focus group commented that patients/their lay carer(s) often presented their PHR to them right at the start of their interaction.

I mean that blue folder gets thrown at you as you walk in the door. (HFGNC/232)

Whilst the term "thrown" was used to describe the process, I wonder if it was more that the way it was introduced 'threw' the HCP off and disrupted their usual process for getting their interaction with the patient underway. From the comment below it would suggest that the culture of how some HCPs interact with their patients has been changed by the PHR.

A lot of families will present the blue folder to you at the door and it becomes part of the culture of the health professional's visit – out comes the blue folder or the first thing they will say is the blue folder is on the desk. (HFGNC/126)

Traditionally, a HCP establishes a therapeutic rapport with the patient, particularly when meeting them for the first time, by introducing themselves and then easing into the conversation with some therapeutically focussed questions and statements. The description provided below suggests that the manner in which the PHR was presented, and the conveyed expectation to look through it, made it difficult for this HCP to conduct the patient interaction according to traditional methods. Experiences such as this may have prompted some HCPs to prefer to put the PHR aside until more towards the end of the consultation.

Yesterday I had a patient, and he was a new patient to me, and the first thing that he did was as soon as he came through the door was sort of throw this folder at me and it broke up the whole introduction. And he wanted me to look at the folder and read through the folder and it was very difficult then to try and put the folder to one side, (although it was extremely helpful), right at the beginning of the consultation to have this sort thing put in front of me and - here read this first - before I could actually meet the patient and talk things through with the patient, talk out why he is here ... it made that a little bit more difficult. (CSFGD/49)

As mentioned earlier in this chapter, some participants indicated that they now took time to reflect back to the patient/lay carer(s) their (the HCP's) impressions of the patient's condition and circumstances in order to clarify and confirm their approval to write that in the PHR. Furthermore, a number of participants also reflected that writing notes in front of the patient had also "changed the consultation slightly", as shown in the comments below (CSFGD/218).

At the end of the consultation there is a period of time where you are writing [in their PHR] and the patient is just sitting, so that is not always a good thing. (CSFGD/218)

Sometimes you spend a long time with the patients and then you are writing the notes up with the patient and often feeling that you want to not intrude on them anymore because you are there a long time, and they may be imminently dying. (DNFG/322)

The comments above appear to convey some sense of awkwardness associated with the altered consultation, and a concern of conveying disrespect, or intruding on patients and their families by staying longer in the house. However, not all participants felt the patient interaction was altered in a negative fashion. In the comment below a district nurse participant suggests she spends less time "explaining what is happening" to other family members present, because rather than asking her, they read the information in the folder.

Because they want to know the information and they've actually got it there - and that's helpful because quite often they want you to explain it for them, and you are actually trying to address the patient and you're spending all this time trying to explain what's happening – they want you to explain it to their daughter or son or whatever. I find I get less of that because they've got it all there in a good sized bible. (DNFG/761)

Dichotomous impact on professional relationships

The PHR appears to have impacted on inter and intra-service professional relationships. Findings suggest that for the district nurses in particular there was a dichotomous nature to this impact. As shown below, the introduction and use of the PHR appears to have enhanced professional relationships but also fostered the potential for disrupted relationships between district nurses and other wider health care team members; the direction of this impact appeared to be related to the manner in which other HCPs engaged with the PHR.

An enhanced sense of collaboration

The value and goal of a collaborative and co-ordinated team approach to palliative care was a repeating theme within Hospice focus group participants. This group appeared highly focussed on operating in a manner that contributed to this approach and also on demonstrating this culture to their patients and families. While it is not suggested that other HCPs did not share a similar goal, the embedded nature of this culture and the interdisciplinary team approach to care may have prompted hospice medical participants to interact with the PHR a degree more than other medical practitioners appeared to, despite also indicating its layout and style of contents didn't fit with their preference.

The experience of working together to achieve the goals of the PHR project, in particular using the record to promote co-ordination, liaison, partnership care and reduced duplication appears to have strengthened the relationship between the district nursing and hospice services. The PCCs reflected that the PHR had encouraged them to communicate more with the district nurses and to involve them more in both the planning and delivery aspects care. This development was also noted by district nursing participants, who explained that the delivery of palliative care between the two services felt "more shared now than what it used to be" (DNFG/697). As demonstrated in the comment below, it appears that working together provided both services with a positive experience and fostered a sense of value for the different contributions that each provided.

I personally think that it has encouraged us, encouraged open communication with the District Nurses and I mean that's verbally and written... I think we are more encouraged to ring them and involve them if we change the care plan, so it's not just that they have to go into the home and look at the care plan, it's that you've thought – I've written that care plan and I should advise you that I have done that and things have changed, so I think it has encouraged me specifically to remain in contact with the person who is going in there next or potentially going in there next. (HFGNC/86)

The potential for disrupted relationships – “they don’t see it as a useful thing”

The district nurses appeared to hold high expectations of the PHR, however, many of their comments also reflected a high level of frustration and disappointment that these had not been realised when other HCPs did not read, use, or write in them.

There is that expectation [that other HCPs read, use and write in the PHR] but that doesn't necessarily mean it occurs.... I can count on my hand the number of times the [name of another HCP] has written in it, and I actually have asked a couple of times ... but I know the preference is to ring me up by the phone and sometimes it's really awkward because you feel that you're the only person using it....and it is really quite a disappointment because to get that information or feedback you have got to seek answers from those people and then of course the folder is at the patient's home and you have to use your base notes and then of course there is duplication of information and it's really quite annoying. (DNFG/48)

Well they might understand what I am doing but I don't necessarily understand what they are doing because they don't inform me [via the PHR] until I ask them. Sometimes they come and I don't know, and sometimes they come and don't write in it. (DNFG/770)

The level of these expectations and the emotions associated with their non-realisation can be understood in the context of the DNS's involvement in the project. Implementing change tends to require additional time and effort, and can cause inconvenience to those involved, particularly during the adjustment phase, so it is understandable that any service undergoing a change process would want to see a positive outcome for their effort. Conversation in this group touched on the time and effort the service had put into establishing the PHR and reflected that some inconvenience had arisen as a result, such as adjusting to the challenge of

no longer being able to read the patient's clinical record prior to arriving at the patient's house. The time, effort and inconvenience these participants had undergone for this project is likely to have fuelled the depth of emotions associated with their view that other HCPs did not appear to have made similar effort and adjusted their practice to use the folder.

I don't think it has been properly utilised the way it should be and so to me it's just creating more work for me. (DNFG/1065)

Several district nurses also explained how whenever other HCPs elected not to write in the PHR, the end result was more inconvenience and effort for them, including having to spend time chasing up the information from their visit by telephone; this appears to have added to their sense of frustration over unmet expectations.

The patient tells me "oh they have had a visit" and I look in the folder and it has not been written there, and you don't know what has been said other than what the family can tell you, and that's not always the information you need to know and you don't get a fax and then you have to go and search out that information, on the phone usually. (DNFG/240)

The comments below suggest that lack of engagement was interpreted as lack of value for their district nursing contribution. Conversely, the sense of appreciation described when other HCPs took the time to write in the folder provides insight as to the sense of value, both for the PHR and the principle of working in partnership, that this action conveyed to these participants.

I'd like to see it be a true partnership, rather than some people putting in and some not; wherever they [the patient] go and whoever they are seen by - fill it in. That's the aim isn't it? It's supposed to be a team thing. (DNFG/340)

I asked [the GP] to write in the notes, and I had to leave and he never did and he didn't take any notice of what I had said in the notes. I think the level of awareness is there but they don't see it as a useful thing. (DNFG/640)

Recently one of the hospice doctors went out to see one of my palliative patients, and they wrote a very comprehensive report in the folder, and I felt really good about it and felt included and informed. (DNFG/262)

Promoting reassurance and relief - fostering a greater sense of empowerment and autonomy for the patient/lay carer

Based on their interpretation of interactions with, and comments from, patients/lay carer(s), HCPs from three of the four focus groups reflected that a number of patients and lay carer(s) appeared to experience a sense of relief and reassurance as a result of having a PHR. It was suggested that this was due to both holding their own clinical file, and observing their health care team collaborating and attempting to co-ordinate their care through the use of it.

There are some families who are very enthusiastic about it because it's like a bible of information and they love the fact that everybody writes in it and they feel that everybody is working together, knows what the others are doing - so it's kind of comprehensive. I had a patient's family member say to me the other day how wonderful she thought it was and how it helped her a lot because she had all this information there together from all the disciplines. (DNFG/194)

A lot of people come to our service feeling that some of their care has been given in an uncoordinated way. They have come via quite a number of departments, consultants, GPs possibly. There is a sense that the patient can actually visualise that people are coordinating and talking with each other and whatnot through the folder. (HFGNC/109)

It was suggested that patients were reassured by knowing that the information about their condition and management was in one place and available for their whole health team to use; hence they felt they were less likely to experience problems because their HCP did not have the information they required to assist them. Furthermore, it was also suggested that patients and lay carer(s) were relieved by the knowledge that they should not need to "tell their story over and over again" (HFG/135). Instead, their HCPs and, if they wished, their family members could read it in their folder, making it easier for everyone to be kept up to date without the responsibility for this resting with them. Indeed they could have this level of security because they themselves were holding their information.

Some people will have six or seven different people come in every day and if they have to say that story over and over and over again, I think you can almost see a relief, there's the Blue Folder, help yourself sort of thing. (HFG/135)

I think some patients find it useful for sharing it with other visiting relatives, sharing the information – they've got it all there. (DNFG/757)

It was also suggested that giving patients their clinical notes had fostered “a greater sense of empowerment and autonomy”, based on the opportunity to pick and choose if and when they wished to read it (CSFG/154). A number of participants indicated that whilst palliative patients/their lay carer used to keep a notebook/diary in which they would jot down information about their condition, questions to ask, what their HCPs said to them, health appointments and other key points, they had noticed that since giving patients their PHR not as many people appeared to do this. The suggestion was made that as they could use their PHR for this, they didn't find it necessary to use a notebook for “keeping track because now they can see that the track is being kept” (DNFG/556). However, it would also appear that participants were taken by surprise with the extent to which some patients /lay carer(s) interacted with their folders, sought reassurance from, and developed a sense of connection to their PHR.

When the patient died the wife wanted a copy, as a diary of the last things that had occurred for her husband and what had occurred and how he died and how peaceful it was. (DNFG/537)

Putting a photograph of themselves in the front slot to make it a bit more personal. I had one family who then got all the photo albums out because they couldn't decide which was going to be the best photo to put in ... and they actually took great delight in finding the perfect picture and that was a bit unexpected. (DNFG/589)

Conclusion

Health provider participants described using the PHR to promote co-ordinated care, support assessment and care management and to address communication challenges. The need for all to use and contribute to the PHR contents to ensure current and therefore reliable information was highlighted by a number of HCPs. However, many HCPs also indicated that factors had constrained or prevented their own use and some recommended altering the layout and contents of the PHR to make it easier for them to use. Home visiting clinicians interacted most frequently with the PHR, particularly nursing staff. Introduction and use of the PHR appears to have challenged, and been challenged by, a number of conventions. These include HCP routines and processes for conducting patient encounters and for gathering, recording

and transferring information, along with the different approaches that physicians and nurse employ for these activities. Other challenges associated with PHR use included HCPs reticence to appear ‘ill-informed’ and ‘writing for the patient’s view’, both of which appear to be associated with concerns for the patient’s/lay carer’s emotional wellbeing, and the quality of their patient-provider therapeutic relationship.

All HCP participants expressed support for the concept of the PHR in general terms although differing views regarding its level of value, function and overall purpose were apparent and appear to have shaped the nature of each HCP’s engagement with the PHR. Medical participants appeared to view the PHR primarily as a tool to “keep updated” by, and less for “giving information” to. In contrast, nurses viewed it as a tool for sharing information back and forwards. Whilst set up and use of the PHR appears to have promoted lay person-provider and provider-provider collaboration in some circumstances, evidence suggests it has also brought the potential for disrupted relationships, frustrations and disappointments, particularly for those most connected to and invested in its use. Despite the challenges and barriers outlined by many HCPs, many also noted that the PHR appeared to promote reassurance and relief for patients, both through holding their own health information and seeing their wider health team collaborating together through the PHR. HCPs also reflected on the manner in which the PHR promoted patient autonomy and assisted patients and carers to be more informed, aware, and involved in their own care. Some expressed surprise at the extent to which some patients/lay carers had connected with their PHR and its contents.

Chapter Seven - Discussion and recommendations

Introduction

Commencing with an outline of the study's limitations, this chapter then discusses the linkages between the two participant group findings (group one being the combined HCP findings, group two being the combined patient and lay carer findings), particularly those associated with influences on the use and perceived function of the PHR and perceived impacts arising from its use. These linkages are presented in relation to relevant literature and a number of recommendations are proposed. The chapter concludes with a summary of the research inquiry and key findings.

Limitations of the findings

The following limitations should be noted when considering the study's findings. There were a small number of participant perspectives obtained, particularly those speaking from lay person or GP perspective. In addition, the practice nurse perspective was absent. Rather than extending a general invite to participate to all home based palliative patients during the study period, a more focussed process for identifying and inviting lay participants was used. Whilst this was considered ethically necessary, it could not be considered that the four lay participants' perspectives represent the views and experiences of this wider patient group. To promote holistic inquiry, CSR tends to incorporate multiple means for data collection, such as document analysis and observation. However, for reasons outlined in Chapter three, this CSR sought participant perspectives only. While a wide range of views were collected, multiple data sources were not used, which could be considered to have limited the findings. Merging the range of HCP perspectives into one data set could also be considered a weakness in that it has limited the opportunity to present and discuss the variations between disciplines in more detail. It also needs to be acknowledged that my insider research position is likely to have influenced all stages of this study despite highlighting it through study design and reflexivity.

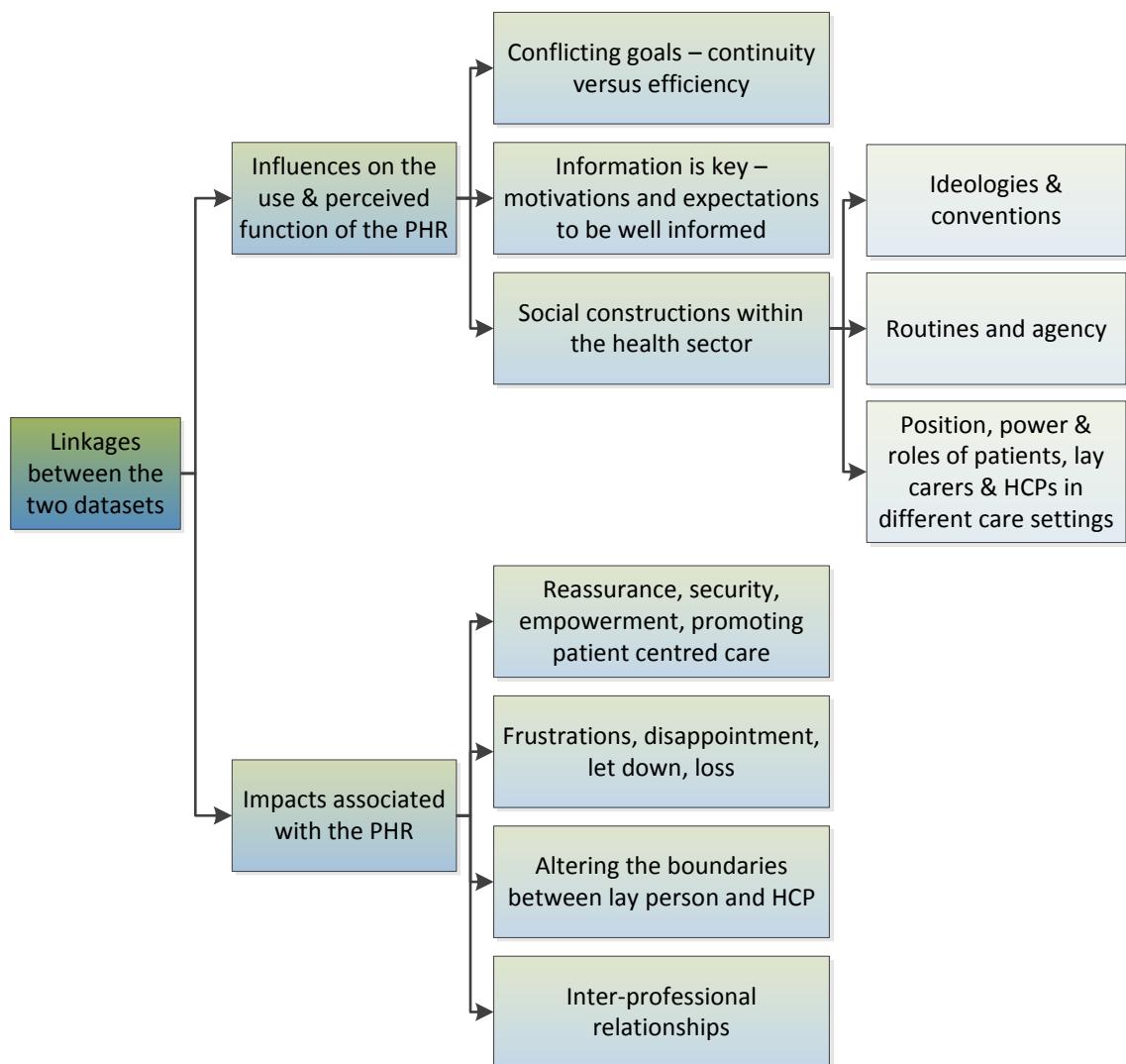
This study is positioned within a theoretical framework that argues an unlimited number of constructions regarding the same reality can simultaneously exist, all of which need to be taken into account. The aim, therefore, is not to make generalisations, but instead to seek a range of perspectives to gain a fuller and richer understanding of the use and impact of the

PHR within this study's local context, along with factors that appeared to influence this. As such, it provides readers with an opportunity to weigh up and judge whether the findings have instrumental utility to other contexts or contribute to reflective and practical knowledge.

Linkages between the two data sets

Cross analysis and comparison of the two main data sets (the combined lay participant data set and combined HCP participant data set) revealed a number of links, grouped into two main themes shown below. The following discussion provides an overview of the subthemes within these that emerged from across both data sets.

Figure 6 Combined health care professional, patient, and lay carer themes



Influences on the use and perceived function of the patient held record

Conflicting goals: Continuity versus efficiency – and for whom?

Whilst this CSR project was not intended for an inquiry into continuity of care, descriptions that reflect either the pursuit, or experience of continuity/discontinuity can be recognised in both the HCP and patient/lay carer data sets. These findings are of little surprise given the main aim behind introducing the PHR and the contemporary focus placed on continuity by health services and consumers. Whilst participants across both data sets appeared to be focussed on the broad goal of continuity of care, findings suggest HCP participants' use of the PHR was influenced by different motivations from those reflected by patient and lay carer participants.

Use of the PHR by patient and lay carers tended to centre on improving their experience of care, in particular, using its contents to assist them to manage as best as possible and to reduce the risk of suffering and distress. Other PHR studies report a similar focus of use by patients and lay carers, mostly commonly as an aide memoire, obtaining information and guidance, keeping abreast, recording and monitoring progress, as a chronological record and a communication aid (Drury et al., 1996; Finlay & Wyatt, 1999; Greenfield & Jones, 2007; S. Johnson & Mayor, 2002; Lecouturier et al., 2002; Sharp et al., 2004; van Wersch et al., 1997; Williams et al., 2001). In contrast, use of the PHR by HCPs in this study tended to be centred on improving processes of care, but with a particular focus on gaining efficiencies and reducing inconvenience, and primarily in the direction of gain for the HCP and sector. Similar approaches were reported in several other PHR studies (S. Johnson & Mayor, 2002; Lecouturier et al., 2002; Sharp et al., 2004; van Wersch et al., 1997; Williams et al., 2001).

Health professionals appeared to view the PHR primarily to assist with their role, rather than primarily to assist patients and lay carers. Other HCPs indicated that some PHR features were so inconvenient they were a deterrent to its use. Findings suggest HCPs were less likely to use the PHR in circumstances where they did not believe they required assistance from it, or considered it time consuming/inconvenient, unless the patient/lay carer was able to bring sufficient influence to bear on them to do so. Hence, most lay participants' wishes for HCPs to use their PHR in order to improve their experience of care appeared to be in conflict with HCPs' desire for efficiency and convenience. This tension is reflected in lay participants' comments that many clinicians, particularly doctors and hospital based clinicians appeared disinterested or reluctant to use their PHR, the challenges they experienced trying to promote

its use with HCPs, and the frustrations and disappointments they experienced when it was not used in accordance with their wishes and views of its function. Similar findings are reported by patients and lay carers in most of the PHR studies reviewed for this thesis and concerns regarding efficiency appear to have contributed to low HCP use in these studies also (Gysels et al., 2006).

Despite viewing the PHR as primarily for their aid, HCPs appear to have placed the onus for promoting its use primarily on patients/lay carers, thereby making them responsible for promoting change in traditional HCP routines and practices. While most carers appeared to have not only accepted this responsibility but also vigorously promoted use, several expressed the view that HCPs also had a professional onus to proactively engage with their PHR. The driver behind this perspective can be found in examples by lay participants of un-coordinated, dis-organised, delayed, inadequate, absent and fragmented care delivery, along with the described impact of these. Sadly, a large body of palliative care literature reports similar experiences (Funk et al., 2009; Gilbert, Ussher, Perz, Hobbs, & Kirsten, 2010; Lundstrom, Johnsen, Ross, Petersen, & Groenvold, 2011; McIlpatrick, 2007; Perreault, Fothergill-Bourbonnais, & Fiset, 2004) .

Continuity requires excellent information transfer between HCP and services, effective communication and a therapeutic relationship between clinicians, patients and family, along with flexible care that adjusts to the patient's/family's needs (Freeman et al., 2001; Haggerty et al., 2001). Continuity of care is defined as the experience of a co-ordinated and smooth progression of care from the patient's point of view. Therefore, whilst organising and improving processes to "deliver care in a continuous, seamless fashion" is important for promoting continuity (Harrison, 2009, p. 51), enhancing care processes is most meaningful if performed with the patient's experience of continuity in mind rather than convenience and efficiency for the health sector (Freeman et al., 2001; Hardy, Hudson, Keen, Young, & Robinson, 2006; King et al., 2009). However, in viewing the PHR as a means for improving care processes, HCP participants' perspectives of what promotes continuity appear to have incorporated an emphasis on efficiency. Freeman et al. (2001, p. 10) also note this emphasis by HCPs in their scoping exercise, commenting that continuity appears to be "a proxy for a variety of values, beliefs and assumptions held by numerous stakeholders" including the value of convenience. These values differed between the various stakeholders and at times appeared to be in conflict with each other, leading to trade-offs, or prioritisation of one value over another.

Attention to efficiency is a contemporary feature of the health sector, included within most quality of care definitions and programmes (Health Quality & Safety Commission, 2012; Institute of Medicine, 2001; World Health Organisation, 2006). It is suggested however, that tension exists between promoting care that is both efficient and patient centred. Furthermore, questions can be raised as to whether the direction of some efficiency focussed activities promote patient centred quality care or instead solely promote fiscal savings (Nugus & Braithwaite, 2010). Whilst it is not suggested in this report that a focus on efficiency is inappropriate, it is suggested that a drive for efficiency may have shaped the HCP participants in this study views of the PHR and its primary function, influencing both the nature and extent of their use of it, and the position it was given in health encounters.

Two common themes associated with continuity emerged from across the four lay participant interviews: (i) the view that systems should be in place to ensure that all providers they come in contact with were already informed and therefore prepared to meet their needs in a prompt and effective way, and (ii) a sense of frustration and let down when their health care experiences didn't measure up to this expectation. Health care professional participants reflected awareness and empathy for such experiences of discontinuity, along with a desire to prevent them from occurring. However, this recognition and philosophy of care did not appear to have altered the direction of their emphasis on efficiency. Resource constraints coupled with the rising number of people requiring health care services may have acted as a powerful constraint to change, fostering an approach to efficiency that privileges the needs of the health sector over the focus on patient centred efficiency in care delivery.

Studies which have focussed on continuity of care from a lay person's perspective have shown that patients and lay carers believe that they too have a part, and indeed expect to take a key role in promoting continuity of care for themselves, possibly in recognition that not to do so risks adverse outcomes (Freeman et al., 2007; Nair et al., 2005). For example, a number of studies exploring continuity where care extends across a number of inter-professional and inter-organisational boundaries reported patients experiencing gaps and chaos in their care, highlighting that transition in care points can put continuity under strain. Within these studies, information transfer from HCPs to patients featured strongly in patient's accounts of their experiences with, and priorities for continuity of care; some described how they wished to promote their own continuity of care by taking responsibility for the transfer of information - either verbally, or by holding their own care records (Freeman et al., 2007).

There are significant challenges for achieving continuity in a sector that includes “increasing specialisation, differentiation and fragmentation between different organisations” (Helleso & Lorenzen, 2005, p. 807). Inter-organisation continuity is influenced not only by how information is exchanged, but also the manner in which each member of the team is involved, including the patient and family’s ability to participate in decisions and receive and contribute information (Agarwal & Crooks, 2008; Helleso & Lorenzen, 2005). In light of this, it is argued that HCPs’ views of lay people need to shift from that of relatively passive recipients of care to that of active partners in which the HCP seeks to collaborate with them in order to achieve continuity, recognizing that patients and carers have different perspectives on, experiences of, and priorities for continuity from professionals (Freeman et al., 2007; Parker et al., 2010). This does not mean that the views and experiences of HCPs are not to be valued, but rather that HCP perspectives should not be privileged above those held by lay people (Parker et al., 2010). Emerging from these findings is an understanding that continuity is not “a process that, with proper organisation and co-ordination of services and systems can be delivered ‘to’ patients”. Instead, it is an experience to be “co-constructed through the interactions between patients, carers/families, and professionals” with positive achievement being dependent on the strength of those connections and relationships (Parker et al., 2010, pp. 29-35).

In summary lay participants’ motivation to use the PHR appeared to be centred on improving their experience of care. In contrast, HCP participant use tended to focus on promoting efficiency and reducing inconvenience for health professionals and the health sector. Health care professionals appeared reluctant and less likely to use the PHR if they felt its contents were not required, or would be time consuming or inconvenient to use, which echoes findings reported in a number of other PHR studies. It is suggested that the contemporary focus on quality of care, a broad concept which includes an emphasis on efficiency and productivity has shaped HCPs’ perspectives and use of the PHR, whilst evidence that palliative patients and their lay carers continue to experience discontinuity has acted as a key motivator behind their use and promotion of their PHR. As such, the goal of efficiency gains appears to be in conflict with patient and lay carer’s wishes and views regarding the function and use of their PHR. Emerging models for continuity indicate that the concept is not something HCPs deliver ‘to’ patients but instead needs to be co-created with patients. Rather than privileging one group’s needs over the other, it is advocated that patients’, lay carers’ and HCPs’ views and experiences are assessed and incorporated, and that services take a co-design approach to both care delivery and the provision of health information.

Information is key - motivations and expectations to be well informed

Breaks in continuity occur “when information and knowledge about past care, or about the patient, cannot be brought to bear on current care or when security about future care is jeopardised by inadequate resources or conflicting care plans” (Freeman et al., 2007, p. 51). Relational and management continuity are considered vital for preventing this, with informational continuity providing the foundation on which these are built (Saultz, 2003). In keeping with this, access to sufficient information at point of care or time of need to support decision making was raised as a key requirement by most participants in both data sets and appears to have provided strong motivation for PHR use, particularly for patients, lay carers and the community based nurses most frequently involved in their palliative care journey.

The motivation of home visiting nurses to use the PHR may have been driven by previous experiences associated with palliative care. Nurses caring for the dying at home regularly face encounters with suffering, some of which are brought about through poor co-ordination arising from lack or delayed information sharing between services. Facing and responding to these circumstances, often on their own, can arouse strong feelings for the nurse (Brazil, Kassalainen, Ploeg, & Marshall, 2010; Wallerstedt & Andershed, 2007) and such experiences tend to foster a high sense of responsibility and motivation to prevent or minimise such encounters by promoting conditions to enable “a good death” (Dunne, Sullivan, & Kernohan, 2005, p. 376). General Practitioners also highlight the challenge of after-hours house calls to palliative patients unknown to them, where there is no information from their usual team to inform after-hours point of care decisions, suggesting this leads to unnecessary hospital admission, duplication of therapy, tests or medication, or delays in care (De Bock et al., 2011; Hincapie, Warholak, Murcko, Slack, & Malone, 2011).

The desire of patients and lay carers to be well informed is understandable when considering the context of having a terminal illness. Such a diagnosis is life changing, with the patient and generally their closest support people facing a completely new existence, one that is not of their choosing, and often not of their control. Furthermore, the realisation that their experiences within this new existence will be, to a large degree, dependent on understanding and remembering a great deal of new information, and on mastering many new skills appears to bring a sense of great responsibility, particularly for the lay carer. This sense of responsibility is often accompanied by a high degree of anxiety, related to concern that if they do not manage the situation adequately, they (or the one being cared for) may experience

preventable suffering (Andershed, 2006; Bee, Barnes, & Luker, 2009; Funk et al., 2010; Linderholm & Friedrichsen, 2010). This study adds to the evidence that feeling uncertain, out of one's depth and unfamiliar with health practices, language, and how to access and navigate health services compounds patients and lay carer anxiety. Lay participants' comments also confirm that hunting out advice and assistance are particularly stressful and tiring aspects of the palliative journey, efforts made more difficult by lack of timely information (Clemmer, Ward-Griffin, & Forbes, 2008; Epner, Ravi, & Baile, 2011; Funk et al., 2009; Innes & Payne, 2009; McIlpatrick, 2007; Neergaard et al., 2008; Ramfelt & Lützén, 2005).

In addition to the role information plays in shaping the nature, efficiency and quality of care, the findings suggest that access to adequate information also promotes a sense of reassurance, confidence, control, efficacy and security for all involved in the care journey, including the patient and lay carer. District nurses and PCCs spoke of the relief of knowing a fuller picture of information would be available for them in the home than traditionally was the case. Lay participants also highlighted the comfort and security they received from having access to their own clinical record, not only for enabling them to more aware of and involved in their own care, but also as a means of facilitating vigilance, optimum management, and continuity for themselves. In contrast, they described experiencing a strong sense of loss when information was not recorded in their PHR, which may account for the robust manner in which patients and lay carers promoted its use. Studies commissioned in the United Kingdom and in Canada also found lay people felt they had a significant role to play in generating continuity for themselves in partnership with their providers, with many expressing a clear desire to 'manage' rather than 'cope' with their condition (Parker et al., 2010). Being included in the flow of information, care planning and education were considered crucial to this. Indeed it appeared to be important to lay people that HCP-patient and information sharing occurred in addition to HCP-HCP information transfer (Freeman et al., 2007).

Similar outcomes associated with access to adequate and timely information are reported in palliative care literature (Docherty et al., 2008; Funk et al., 2010; Innes & Payne, 2009; Ramfelt & Lützén, 2005; Stajduhar et al., 2008). In these studies lay carers of home based patients spoke of the importance of feeling secure in their caregiving role, and how access to relevant and timely information (including that of prognosis) promoted this, enabling them to feel prepared for what they might encounter. Being involved in care and feeling able to effectively provide quality home care for their family member enhanced lay carers' sense of coping. Conversely, feeling unprepared and unable to assist due to lack of preparation, knowledge

and/or ability prompted feelings of frustration, fear, anxiety, stress, uncertainty, powerlessness and insufficiency. The relationship between feeling secure, having trust in their HCPs, being provided with access to information, and being treated with dignity, respect and esteem was also highlighted. Patients and lay carers felt HCPs should be more forthcoming with information about what to expect, with failure to do so reducing trust in their health care team (Funk et al., 2009; Innes & Payne, 2009). Echoes of all these perspectives can be found in the lay participant findings from this study.

Ensuring future care was not jeopardised by inadequate information also acted as a barrier to use for some HCPs, with concern about gaps in the PHR contents described as the main driver behind this. Such gaps fell into two categories. Firstly, HCPs forgetting, or electing not to write in the PHR and secondly, layout and design of the folder and contents not being configured to provide the information required, or not in a quick and easy enough manner. Similar concerns by HCPs about information gaps in the PHR are reported by Cornbleet et al. (2002) and Mathews and Byrne (2009). However, HCPs in another study found the PHR gave them access to more information than normally available, decreasing the provision of contradictory information as well as aiding their treatment decisions and planning (van Wersch et al., 1997).

The desire for the PHR to operate as a decision support tool and with a more user friendly format was common to both participant groups, although the requirements to achieve this differed between the two groups. In order to be “better accommodated” by their PHR, lay participants appeared to seek a hybrid style PHR, incorporating both their HCP’s clinical documentation, and lay person focussed and individualised education regarding their particular condition and its management. Suggested information included symptom identification and management and information about the services and resources available along with how and when to contact them. In other words, content specifically focussed on building their own knowledge, skills, and efficacy for vigilance and management of their condition. In contrast, to enhance the decision support function of the PHR, physician participants recommended the contents of the PHR be reduced and styled to become more of a summary of key clinical facts.

A large body of research confirms most palliative patients and lay carers want, need, and indeed expect to be well informed. In addition to general information about their disease, patients and lay carers need written information and educational material about the practical aspects of what to look out for, how to manage, who to seek help from and when (Bee et al.,

2009). Tools such as information packages and guides to support lay people decision making regarding their own health care have been found to be valuable (Charles & Gafni, 2010; Owens et al., 2009; A. Street & Horey, 2010). However, in addition to desiring information about their condition and how to manage it, this study confirms other studies' findings that many lay people also wish to have and hold 'their own' clinical information so that they can be more aware, involved, vigilant, proactive and supported to promote continuity for themselves, thereby enabling them to feel and be more in control of their own health care journey (Fisher et al., 2009; Forsyth et al., 2008; Freeman et al., 2007; Wibe et al., 2011). Such goals align with the ideology of patient centred care, an emerging model in which patients are co-partners with their health professionals.

Overall, the findings reflect a connection between the perception of being well informed and feeling well equipped to manage the current situation. In turn, feeling well equipped appears to promote a sense of confidence, efficacy, empowerment and control. These experiences and the impacts arising from them appear to have acted as powerful motivators for use of the PHR for some participants. Both lay and physician participants wished to be "better accommodated" by the PHR, recommending changes to the lay out and contents in order to strengthen its decision support and self-care elements. Overall the study confirms that most lay people prefer, and gain value from, access to their own clinical care record.

Social constructions associated with the health sector

Ideologies and conventions

Findings from both data sets indicate home visiting nurses engaged the most with the PHR, in contrast to physicians who had the least contact. It was also reflected across both data sets that most doctors were unaware of or disinterested in using the PHR. However, despite evidence of low utilisation by some, comments in all focus groups indicated that both medical and nurse participants supported the concept of a PHR to promote information sharing. Rather than support for the concept of information sharing being the main influence on each discipline's use (or lack) of the PHR, findings suggest that conventions and routines played a significant role, particularly those that direct and shape each discipline's practice, and that influence information access and disclosure to patients. Based on their systematic review of patient centred care, Haesler, Bauer and Nay (2007) argue a similar perspective.

For example, nurses' preference for reading and considering other colleagues' perspectives and clinical impressions in the PHR was in marked contrast to physicians' reticence and caution regarding this. Some doctors considered that nursing documentation was often too lengthy and much of little use to them. In contrast, nurse participant comments indicate value for the nursing narratives they document, aimed at enabling their colleagues to gain insight into the patient and lay carers' perspectives and experience. These factors were offered as reasons for why some physicians appeared reluctant to read and use the PHR, and why some had remained with their traditional approaches for information gathering rather than using the contents of the PHR. Solutions offered by medical participants to resolve these issues tended to centre on changing the style of PHR nursing documentation, and changing the layout and design of the PHR contents to make it easier to obtain the information they required from it.

These contrasts reflect differences within the ideologies, health care models, concepts and language of medicine and nursing, believed to be instilled during training and maintained within workplaces (Khokher, Bourgeault, & Sainsaulieu, 2009; Mannahan, 2010; R. Mitchell, Parker, Giles, & White, 2010). Traditionally, physician training occurs in a highly competitive setting with limited places, setting the scene for independent and autonomous functioning. Socialised to be the key decision makers about patient care, and to assume a role of leadership, physicians are empowered to decide the extent to which they will receive and consider input from other clinicians whilst nurses are trained to work as a team, to collectively work out problems and exchange information across shifts (S. Baxter & Brumfitt, 2008; Hall, 2005; Nugus & Braithwaite, 2010; Turner, 2010). The medical model of practice tends to be pathology orientated, seeking measurable and factual data in order to build biomedical case knowledge (Donnelly, 2005). In contrast, the holistic and phenomenological lens of nursing focusses on understanding and communicating the patient's 'lived experience' of illness and wellness, and it is argued that these differences in perspective affect each discipline's grasp of the wider clinical situation. For example, one study of nurse-physician collaboration reported that doctors tended to dismiss and devalue nurse assessment information that did not fit into the schema of biomedical knowledge (Stein-Parbury & Liaschenko, 2007). The effect was two-fold; collaboration between both parties was impaired, and lack of recognition and utilisation of nursing knowledge by physicians impacted on the safety and quality of care.

The socialising factors noted above influence all aspects of practice, including documentation. Furthermore, as echoed in this study, one discipline's approach to documentation is not always useful for other disciplines. Other studies reported similar findings, in that nurses found

medical documentation too symptom-orientated and missing valuable details, whilst doctors felt nurses provide a lot of irrelevant information, deeming their notes to be an ineffective means of communication at times (Heinzer, 2010; A. Street & Blackford, 2001). Such perspectives challenge nursing, particularly the cultural perspective of the narrative account in nursing; considered to reify the construction of nurse-as-carer and patient-as-person and therefore represent the nursing identity and convey their professional acts (C. May & Fleming, 1997). In attending to the ‘lived experience’, nurses seek to paint the “full picture of the patient” in order to aid the wider health team’s understanding (Heinzer, 2010, p. 56). However, nursing documentation can also be “defensive” as nurses seek to ensure evidence of thorough care, within and between team communication, and that specific orders are communicated for ethical, safety and legal purposes (Heinzer, 2010, p. 57).

Conventions associated with disclosure and patient access to their own health information were also raised in both data sets. The challenge of promoting patient centred care that is ethical and altruistic without reverting to historical practices of paternalism and control was demonstrated in the range of comments regarding this topic and reflects similar themes discussed in the literature, particularly those related to disclosing prognosis and progress (Frampton, Horowitz, & Stumpo, 2009; Gilhooly & McGhee, 1991; Innes & Payne, 2009; Michiels, Deschepper, Bilsen, Mortier, & Deliens, 2009; Siminoff, 2010). Providing patients with access to their own clinical information that was considered subjective or sensitive in nature was of particular concern for some HCPs. Concerns were expressed about misinterpretation, distress, loss of hope, damage to family relationships, or damage to the therapeutic relationship between the patient/lay carer and HCP. Risk of information being copied was also expressed, presumably based on a concern that this could be kept by the patient/family after their care had concluded, or transferred to others without HCP knowledge or consent. In keeping with findings reported by Morris and Thomas (2002) and S. Woods, Beaver and Luker (2000), lay participants in this study were critical of HCPs’ historical practice of not fully informing patients, and of limiting patients’ access to their own health records, using privacy laws as justification.

Society has traditionally afforded hierarchical status and power to the social construction of the HCP. Collectively held ideologies influence the position and role of HCPs and lay people, shape the nature of their interactions and appear to foster power imbalance between health professionals and their patients; power is located within control and gate keeping of three fundamental dimensions: (i) material resources, (ii) ‘human resources’, and (iii) knowledge,

decisions and information (Barrow, McKimm, & Gasquoine, 2011; Coulter, 2002; Grimen, 2009; R. Mitchell et al., 2010; Nugus & Braithwaite, 2010; Poland, Lehoux, Holmes, & Andrews, 2005; Wibe et al., 2011). Promotion of the health care record as the domain of the HCP, under the control and ownership of HCPs is one example of power enactment. Paternalism is now criticised for “fostering passivity, sapping self-confidence, undermining people’s ability to cope and promoting dependency” (Coulter, 2002, p. 107). Limiting patient access to personal health information limits their opportunities to gain knowledge, expertise, and confidence, both in health management, and the language used by HCPs. This access imbalance perpetuates the concept of HCP as ‘expert’ who knows best, reinforcing the power imbalance between HCPs and lay people (Larsson, Sahlsten, Segesten, & Plos, 2011; Macnaughton & Evans, 2004; S. Woods et al., 2000). Contemporary ethics direct clinicians away from paternalism and towards the goal of patients-as-partners in their own health, particularly through providing free and easy access to their own health records (Coulter, 2002). However, footprints of historical paternalism were also evident in the lay participant data set. For example, lack of confidence and knowledge with health care language, and the knowledge that HCPs would view what they (the patient/lay carer) wrote in their PHR were highlighted as barriers to writing in it unless a guide to aid what and how to write in it was provided.

Differing views regarding ownership of the clinical record also appear to have influenced opinions as to which group the PHR was primarily for: a) the patient and lay carer, or b) the HCPs providing their care. Most HCP participants appeared to view the PHR as primarily there to aid the wider health care team with delivery of patient care. In contrast, the perspectives of lay participants sat within two groups: (i) their PHR was primarily for their HCPs – a tool to aid information sharing between their HCPs, (ii) their PHR was as much for themselves - to be informed, involved and assisted to navigate and manage their own care - as it was to aid their health care team. These varying perspectives also appear to have influenced the nature and extent of each party’s interactions with it. As such, the perceived function and manner of use appears to have existed on a continuum, ranging from operating as a shared HCP clinical record located with, and transported by the patient/lay carer to that of a more hybrid style of clinical record. The record was hybrid in that it incorporated HCPs’ clinical documentation but also provided patients with health information and self-care support, and acted as a tool to promote patient and lay carer-as-partners in care delivery.

Lay participants who perceived that the PHR was for their own purposes appear to have sought a more patient- HCP partnership approach for their care, reflecting an emerging trend

arising from evolving ethical principles and health care ideology, increasing availability of online information, the consumer movement, evidence of positive outcomes ensuing from such an approach, and a move to achieve health savings by promoting self-care (Aita, McIlvain, Backer, McVea, & Crabtree, 2005; Bélanger, Rodríguez, & Groleau, 2011; Buetow, Jutel, & Hoare, 2009; Dieterich, 2007; M. Johnson, 2011; Keith, 2009). In contrast, other participants appeared content with a more traditional patient-HCP relationship. This contrast supports other findings that while many people do wish to participate more in their health care decisions, some prefer to take a more passive role, leading to the conclusion that the ‘patient role’ has become multifaceted (Bélanger et al., 2011; Brundage, Feldman-Stewart, & Tishelman, 2010; Wibe et al., 2011). However, Ramfelt and Lutzen’s (2005) argument that sharing information with patients and lay carers promotes and supports their identity, and thus their will and capacity to participate, offers further insight into factors which may have impacted on some lay participant’s limited engagement with their own PHR. The findings suggest the degree to which people wish, and elect, to participate in their care delivery and decisions is not only related to their physical, personal, and social characteristics and circumstances, but also the manner in which HCPs interact with them; this includes receiving encouragement and adequate and comprehensive information to support engagement (Aita et al., 2005; Dieterich, 2007; R. Street, Krupat, Bell, Kravitz, & Haidet, 2003).

Linking the findings from both data sets reveals some differences expressed by HCPs between the philosophy of use and the reality of their use of the PHR. For example, a number of HCPs described using the PHR to avoid patients having to repeat their ‘stories, however, patient/lay carers’ comments suggest most HCPs, particularly their doctors, had continued to question them rather than seek information from it. Described exceptions tended to be associated with ‘technical’ or ‘clinical’ information (such as those related to diagnosis or interventions currently in place), suggesting that most HCPs preferred to gather such information from HCPs (via the PHR) rather than from the patient/lay carer. This preference may have been shaped by the ideology of clinician as ‘expert’, and/or a positivist ideology which elevates ‘unbiased’ data, an argument supported by one physician in this study who described such information as more robust and less ‘biased’ (Aita et al., 2005; Dieterich, 2007; Keith, 2009; Larsson et al., 2011).

With regards to gathering the more qualitative or ‘non-technical’ information required, examples suggest HCPs continued their traditional approach of questioning the patient/lay carer rather than seeking such information from the PHR first. This approach contrasts with expressed preferences of lay participants that HCPs use their PHR to reduce repetitive

questioning. Although comments from across the HCP data set indicate awareness and empathy for this, this does not appear to have often prompted change in practice. Given the level of support for the PHR concept expressed by both nursing and medical participants, it seems likely that ideological factors and characteristics (as noted above) were not the only factors that contributed to limited or no use by some HCP participants; strongly embedded routines of practice for each discipline are also likely to have played a key role.

Routines and agency

Routines facilitate actions, specifying what a person will do, and in what order. They too are shaped and driven by ideology, attributes and artefacts associated with the person(s) performing them, and as such can become symbolic of the profession that performs them (van Raak, Paulus, Cuijpers, & te Velde, 2008; Zisberg, Young, Schepp, & Zysberg, 2007). Such artefacts include: written rules, professional standards, and more physical elements such as forms, electronic patient management systems, decision-support tools and means of communication, right through to elements that construct the general physical setting. The level of specificity of the artefact(s) and strength of ideology(s) structuring the routine will impact on how it is performed and the extent to which it varies or is stable. However, whilst practices are carried out against a background of ideology and artefacts, one's particular course of action will always, to some extent, be novel. Hence agency plays a significant part in the construction-reconstruction of routines (Pentland & Feldman, 2005).

Agency is influenced by two factors; power and reflexivity (van Raak et al., 2008). Individuals act in a context created by the actions of others (which moderates or amplifies individual agency); the extent to which individuals or groups can act or prompt others to act in novel ways determines the extent to which they can influence the future direction of the routine (Pentland & Feldman, 2005; van Raak et al., 2008). Creating co-operation between services and disciplines tends to require changes to existing routines of one or all parties. However, the stability of current routines associated with different members of interdisciplinary partnerships will influence whether new routines necessary to drive co-operation can develop; in other words, current routines and the settings with which they are associated may be divergent or convergent to change (van Raak et al., 2008). Divergent routines similar to the findings of this study are reported by Parker et al. (2010) in that professionals preferred communicating face to face or over the telephone, rather than electronically or through

alterative systems; this was considered to be more efficient and effective in ensuring continuity of care.

The above theory is significant for this study. Multiple people and disciplines performing the same routine (use of the PHR) make it very unlikely that a single understanding, goal, or practice will exist. The level of autonomy and authority afforded to physicians, in contrast to nurses, also influences the level of agency district nurses and PCCs (also nurses) had to shape the practice and routines of doctors, particularly those not from their own organisation. Another factor is that some disciplines are more embracing of routines than others. Many nursing tasks are quite procedure and routine driven, whilst medicine tends to view routines as erosion of discretion, judgement and autonomy (Grimen, 2009). There are differing organisational systems with electronic documentation options available for facility based health encounters in contrast to home based care (Featherstone & Keen, 2012). Furthermore, ‘siloeed’ practice settings and lack of face to face liaison limit opportunities for the various services to engage in collective reflexive discussions regarding use of the PHR.

The position, power and roles of patients, lay carers and clinicians within different care settings

The setting in which the patient-HCP interaction occurred also appears have influenced use of the PHR. Within their own home, patients/carers appeared to have reasonable success promoting PHR use, and in accordance with their wishes or needs. In contrast, despite robust efforts by lay people to encourage its use, findings from across both data sets suggest the use of their PHR in non-home based health encounters was primarily established by the HCP and according to the HCP’s preferences or needs. This finding suggests the party considered to be ‘in charge’ of the space tends to hold the authority and influence to establish the routines and practices that will occur there. This supports the argument that in patient-professional dynamics; “place matters - as a geographical location and lived experience, as demarcation of space, and as a site of meaning creation” (Bender, Clune, & Guruge, 2007, p. 21).

The concept of who is ‘in charge’ is one of power. Furthermore, power relations “take place” and are manifested concretely in time and space in all settings (Poland et al., 2005, p. 173). Different places or institutions do different kinds of work, have different values, operational codes, are structured by different underpinning philosophies and are controlled and influenced by different kinds of power. Power is “embedded in ways of thinking and doing things, in daily actions and interactions, as well as in institutional practices and broader policies” and is “most

pervasive and visible in institutions” where nearly all aspects of daily life are regulated for efficiency (Poland et al., 2005, p. 174). As such, hospitals are perceived as places and spaces owned by HCPs, structured for the efficiency of medical functions, and locations to which lay people ‘visit’; placing patients in a more passive position as being the guest involves acknowledging that the non-guest dominates the setting (Andrews, 2003; Spiers, 2002).

‘Home’ too, is a ‘place’ and ‘space’ in which power exists, incorporating concepts such as: familiarity, ownership, respect, social and physical security and privacy, physical and emotional sustenance, development, shelter and support, along with memories, events and experiences associated with that ‘home’ which create and maintain the self-identity of the inhabitants (Andrews & Shaw, 2008; Appelin, Brobäck, & Berterö, 2005; Gilmour, 2006; Lindahl, Lidén, & Lindblad, 2011). Even if it is a site of less positive experiences, ‘home’ tends to be viewed as a private and personal domain (Bender et al., 2007). Imbued with these concepts, the relationships, opportunities and activities that occur within the home are influenced by agency and by personal and power relationships (Andrews, 2003; Peter, 2002). In contrast to facility based care, home based patients gain a degree of gatekeeper power, having the option of allowing the health provider to enter their home.

Hospital based patients have reported feeling inferior to their HCPs, treated as objects, helpless in the face of hospital routines, as well as experiencing paternalistic forms of help such as domination and secretiveness, clinicians who appear indifferent to their feelings and other structural barriers to participation (Gilbert et al., 2010; Larsson et al., 2011; Sainio, Eriksson, & Lauri, 2001). Peters and Sellick (2006) noted that home based palliative patients described a higher degree of control over their illness and treatment, and confidence in dealing with the effects of their illness than hospital based patients reported, possibly due to the less regimented nature of home based care. Within general practice facilities, the physical and longitudinal spaces between the clinician and patient is suggested to hinder face to face communication and connectedness (Buetow, 2009). In contrast, McGarry (2003) describes how being a guest in the patient’s home permeates all aspects of district nurses’ practice, including negotiating access to various parts of the home, conversing with the patient and family, negotiating and delivering care. These approaches are purposefully selected to acknowledge patients’ jurisdiction over their home and activities within it and to “create spaces that engender a more egalitarian partnership”, providing patients with more control than experienced in the hospital setting (Bender et al., 2007, p. 27).

Findings from this study support the argument that the dynamics of the home care setting enable patients and lay carers to exert greater influence on the health care routines and practices they wish to occur in their home, as opposed to those at their non-home based health encounters. However, the fact that it was nurses who most regularly and frequently visited the participants at home offers another possible explanation for their confidence in promoting its use in their home. Research suggests that the degree of status and power afforded to HCPs varies according to subgroup (for example, doctors, nurse) (Andrews & Shaw, 2008; Lofmark & Hammarstrom, 2005; Nugus & Braithwaite, 2010; Peter, 2002; Whitehead, 2007). Liaschenko (1997, p. 52) that “as a society we have been schooled to see the work of medicine rather than the work of others as most significant in patient care”, suggesting a link between care work (generally provided by nurses) being female gendered and considered of lower social status than that of doctors. As such, the degree of power imbalance between the lay person and HCP may have been influenced by the subgroup that HCP occupies. One lay carer participant example of insisting that the practice nurse wrote in their PHR but not feeling comfortable to challenge their GP to do the same offers evidence in support of this.

However, participants' level of confidence to direct and establish PHR use in their home may also have been influenced by relational continuity. Home based palliative care patients tend to be visited by the same group of HCPs and on a regular and increasingly frequent basis. Such continuity is likely to foster familiarity and trust, both with the health provider and the routines and practices associated with care. This argument is supported by one lay carer's explanation that based on familiarity with the district nurse she felt comfortable to show her the separate book in which she recorded her partner's health information, even though she felt too uncomfortable to write in their PHR because her writing would be visible to others. Palliative participants in other studies have also stressed the importance of positive personal chemistry and relationships with their HCPs, making it easier to take part in their own care and to feel empowered, involved and enabled to manage (Andershed, 2006; Epner et al., 2011; Funk et al., 2009; Linderholm & Friedrichsen, 2010).

The nature and role of the home visiting clinician's therapeutic relationships with lay participants also appears to have shaped the use of the PHR in the home. Palliative care tends to be focussed on supporting and assisting the patient to remain at home for as long as they prefer and all involved can sufficiently manage, a key aspect being to facilitate patient and lay carer involvement and confidence in the management of their condition (Appelin et al., 2005; B. Johnston & Smith, 2006; Pastrana et al., 2008; Peters & Sellick, 2006). Within this context,

the home visiting nurses spoke of discussing the contents of their PHR with patients and lay carers and making plans with them accordingly. At times this included planning together what to write, indicating that the PHR became quite central to their interactions. Such experiences may have positively reinforced and promoted patients/lay carers' own level of engagement with their PHR, and their confidence and desire to promote its use to other home visiting HCPs; it may also have further reduced the power imbalance between themselves and their home visiting HCPs, which in turn appears to have fostered a sense of awareness and confidence to speak up about what they wanted.

In contrast, non-home based health encounters appeared more divergent to promoting PHR use. In addition to structural constraints such as set and limited appointment times and the position of the lay person 'guest' visiting a setting where the HCP is 'in charge', patient and lay carers' interactions with clinic/hospital based providers tend to be more infrequent, with less likelihood of seeing the same HCP each time. Furthermore, such appointments tend to be more focussed on occasional review of the disease process (primarily to provide treatment or advice to the primary care team) rather than engaging the patient/lay carer in the assessment, planning and delivery of their own care. It is also possible that the nature of each HCP's role within their health team impacts on the extent to which their team uses the PHR, particularly for hospice clinicians where the PCC role had been implemented specifically for promoting care co-ordination within and across services involved in the patient's palliative care. In combination, these factors appear to have situated the PHR more on the periphery of patient's non-home based encounters with their HCPs.

In summary, despite indications of support for the concept and value of a PHR, particular ideologies, conventions and routines appear to have acted as powerful barriers to change. Differences between rhetoric and practice were apparent, indicating that desire does not always translate to change. However, the position of the patient and lay carer within the home care setting combined with the philosophy and approach to palliative care appeared more conducive to promoting PHR use than non-home based health care. Evidence suggests a growing number of patients seek greater participation in their health care delivery and decision making. Changes to HCP education and training combined with redesign of health provider routines and clinical documentation systems to promote patient centred care, participation and communication are required in order to shift to partnership models of care.

Impacts associated with the patient held record

Reassurance, security, empowerment, promoting patient centred care

As highlighted in the ‘information is key’ section, the PHR appears to have provided lay participants with a sense of relief, reassurance and security, a view expressed across both data sets, albeit for different reasons. Health professional participants felt that the visual demonstration of collaboration, the experience of co-ordinated care and reduced repetitive questioning through the use of the PHR had promoted these impacts. However, whilst these outcomes were highlighted and appreciated by lay participants, findings confirm that access to their own health information was the primary factor that promoted reassurance and security. Awareness that access to their own health information appeared to empower patients, enabling them to choose if and when they wanted to read what health providers had written about their care and condition, was touched upon by HCP participants. However, the lay participant findings provide a much fuller picture as to the manner and extent to which access to one’s own health information promoted empowerment. In particular, access of this nature appeared to promote a sense of security and feeling more in control, both through feeling more equipped to manage and participate in their own health care and by reducing some of the uncertainty or sense of ‘feeling in the dark’ about their circumstances. This supports Thiede’s (2005, p. 1454) argument that “individuals can only become autonomous within the health system if they perceive themselves as having a clear concept of their own health. Information impacts on the perception of health itself and on access to health services”.

Frustration, disappointment, ‘let down’ and loss

Not all impacts associated with the PHR that emerged from both data sets were positive. Gaps in information due to some HCPs not writing in the PHR brought significant disappointment and frustration for some participants, particularly for district nurses, patients and lay carers. Such circumstances prompted a sense of loss for some lay participants, in particular, the lost opportunity to feel informed and involved, and the loss of information which might impact on future care. Comments from across both data sets suggests that particular HCPs’ lack of use was taken as an indication of their lack of interest in or value for the PHR, its contents, or that it assisted the patient and the wider health team. These experiences have relevance for the level of satisfaction with care of patient and lay participants, particularly in light of growing evidence that “patients often are more satisfied with care and even experience greater health outcomes when they are more actively involved in health encounters and when their

physicians are more informative, supportive and take into account the patients perspectives” (R. Street et al., 2003, p. 609).

Altering the boundaries between health professional and lay person

The PHR was implemented for its potential to promote knowledge sharing, partnership and collaboration across a diversity of boundaries including those between secondary and primary care, disciplines, HCPs and lay people. As such, the PHR can be described as a boundary crossing artefact (or boundary object), designed to build bridges and to facilitate interaction between these worlds and world views (Akkerman & Bakker, 2011; Oswick & Robertson, 2009). Boundary crossing involves “negotiating and combining ingredients from different contexts”, in doing so it “opens up third spaces that allow negotiation of meaning and hybridity”, the production of something new – be it a new practice, routine, culture, or style of dialogue (Akkerman & Bakker, 2011, p. 135). Over all, findings from across both data sets suggest the presence of the PHR did alter the traditional style and manner of some HCP and patient/lay carer interactions, most markedly those occurring in the home setting. Within the home care setting the PHR appears to have “softened the edges” and “loosened the threads” of traditional conventions associated with clinical documentation and roles enabling new ones to develop (Kislov, Harvey, & Walshe, 2011, p. 5).

Boundary crossing is a process in which previous lines of demarcation between practices and boundaries become uncertain or destabilised. This can promote feelings of threat, or tension for some involved. For example, tensions can occur if the newly negotiated practices do not harmoniously co-exist with other practices, where power relationships between stakeholders are asymmetrical and goals are potentially divergent or contested, or where the boundary objects do not fully or rightfully capture meanings and perspectives that meet all stakeholders' perspectives (Oswick & Robertson, 2009). Both positive and less positive perspectives regarding the boundary changing properties of the PHR were reflected within both data sets. For example, whilst most patient/lay carer participants appeared to value the manner in which their PHR assisted them to be more involved and exercise more control regarding the delivery of their care, the perceived experience of having the offer of their PHR for use rebuffed appeared to be less positive. Whilst a number of HCP participants reflected positively about how the PHR had led them to question the patient/lay carer less and to discuss more with them what they were writing in their notes, some were less positive about the manner in

which the PHR interrupted and changed their usual processes for commencing, conducting and concluding their patient interactions.

Inter-professional relationships

The experience of communicating back and forth between different providers through the PHR appears to have promoted a sense of collaboration for some HCP participants, and to have strengthened some inter-service relationships, particularly those between the district nursing and hospice services. However, as an artefact introduced into the broader context of palliative care, the PHR also appears to have created the potential for less positive inter-professional relationships, particularly between district nurses and other HCPs and disciplines. As with lay participants, perceived lack of use by some appears to have been taken by HCP participants to imply disinterest in collaborating. Furthermore, some district nurse participants appear to have extended this interpretation to signify lack of value for their nursing contribution. Similar perspectives are noted in Stein-Parbury and Liaschenko's (2007) study of collaboration between disciplines and are described by Mitchell, Parker, and Giles (2011, p. 1326) as a threat to professional identity, arising from the "diminution of a professional's experience, values or occupational role" albeit perceived or actual.

The literature highlights both the great potential for inter-professional partnerships to capitalise on their different knowledge and strengths, but also the potential for such partnerships to generate a range of negative affective responses, arising from the very nature of the teams diversity (Chan & Nichols, 2011; Propp et al., 2010; San Martín-Rodríguez, Beaulieu, D'Amour, & Ferrada-Videla, 2005; Walshe et al., 2007). Mutual trust and respect of the professional skills and attributes of individuals within their own disciplines, along with effective communication skills are essential underpinnings of positive inter-professional relationships. However, promoting this requires time, space and interest for clinicians to meet and negotiate a shared vision, a common language, and a plan to address structural and procedural obstacles to co-operation (Hall, 2005; Travaglia, Nugus, Greenfield, Westbrook, & Braithwaite, 2011). Access to such opportunities is a particular challenge for the inter-professional community based palliative care sector (Walshe et al., 2007).

Summary of the research and recommendations

There is firm evidence that use of a PHR within home based palliative care can bring a positive impact for patients, their lay carers, HCPs and services involved in their care, particularly through its use to promote information sharing, care co-ordination, and collaboration between service providers and to promote a more patient-provider partnership approach to care. There is also evidence that the PHR can assist with mitigating some affects associated with having a terminal illness, through the provision of information and decision support aids. However, a significant portion of these impacts appear to be highly associated with HCPs level of engagement with its use, reflecting findings noted in many other PHR studies. This study adds further understanding to these, highlighting that some well embedded aspects of the health sector currently act as barriers to broader and more extensive use of the PHR, particularly those associated with the drive for efficiency, and those associated with the boundaries of conventions, routines, and care settings. Not only do these factors appear to be limiting the positive potential of the PHR, they appear to have a level of negative impact at times on those who come in contact with the PHR.

HCP participants tended to view the PHR primarily as a tool to assist with their delivery of care ‘to’ patients; hence if it was not felt to provide assistance, they were less likely to use it. In contrast, some lay participants viewed the PHR as being as much or more for their benefit as that of their HCPs, and sought to partner ‘with’ HCPs in their use of it. Others held a more traditional view, considering it the domain of the HCP, engaging with it in a more passive manner. Regardless of their level of engagement with their PHR, all four patients and lay carers confirmed that it was more of an aid than a burden to them, and again, the extent of the aid appeared strongly connected to their HCPs level engagement with it.

It has been highlighted that PHRs alone will not be able to solve the challenges and effects of fragmented health environments and that changing the well-established culture and practices of these environments “will take a more powerful intervention than a PHR” (Ayana et al., 2001, p. 6). Furthermore, fulfilling the promise of positive outcomes through use of a PHR “will require more than just information access; it will also entail using PHRs as transformational agents that can enable self-management by patients and improve patient-physician collaborations” (Reti et al., 2009, p. 14). Cornbleet et al. (2002, p. 211) suggest that “success is more likely if the PHR becomes part of the clinical culture”. Taking this advice on board, the following improvement issues, opportunities and recommendations are offered.

1. That use of a paper based PHR for people with life-limiting conditions continues in this region. Presently, many in this patient group would not be very familiar with mobile electronic information storage/transfer devices such as 'flash sticks'. While an electronic shared clinical care record may be more likely to suit some health professionals and services, transferring the PHR to an electronic medium would, I believe, privilege health provider convenience over providing patients with easy access to their own health information.
2. That the PHR be given to the patient at time of diagnosis with a life limiting disease, or promptly after through a follow up home based visit.
3. That the DNS consider using the PHR as a summary of their care and key points to share with other services involved, rather than the repository for their full and main district nursing clinical record. Careful consideration would be needed to ensure the valuable 'lived experience' nursing perspectives are not lost from the information shared with other services through the medium of the PHR.
4. That all key stake holders who interact with the PHR have an opportunity to contribute to a redesign and re-launch of the PHR. It is recommended that the services and groups involved in this include: palliative patients and lay carers, clinicians from the hospice, district nursing and hospital cancer services, general practitioners, practice nurses, and other community nurses and services who provide support and care to patients with palliative care needs.
5. At a minimum the redesign of the PHR includes:
 - a) Patient focussed education and self- care decision support aids in a range of media (written, DVD, internet resources) and a process by which these are updated and added to the PHR according to individual presenting needs.
 - b) Concise and clear instructions regarding the overall aim of the PHR, purpose and mode of use for each section, plus other key instructions to provide guidance to all coming in contact with the PHR.
 - c) Agreed language, communication and documentation tools and strategies to promote information sharing and uptake between services and between disciplines.

6. That the above key stakeholder group collectively reviews and seeks to address identified intra and inter-service routines, conventions, practices and processes currently acting as barriers to HCPs writing in, reading and using the contents of the PHR, and that patients and lay carers are involved in this process.
7. That regularly feedback is sought from patients, lay carers and HCPs with regards to the PHR, how and if it is meeting their needs, their experiences with and preferences for engagement with it.
8. That opportunity is sought for regular education forum/workshops with all key stakeholders to promote understanding, awareness and engagement of the PHR and its use. Regular patient and lay carer feedback regarding use of their PHR should be provided to these forums.

Conclusion

This CSR inquiry of the PHR within home based palliative care has revealed conflicting goals for its use and purpose. Most HCPs who engaged with the PHR appeared to do so in the pursuit of efficiency, and primarily in the direction of gain for the HCP and sector. For some HCPs, use of the PHR was not considered congruent with efficiency and this discouraged their use of it. In contrast, most lay participants viewed their PHR as a tool to assist with self-care and improve their chances for continuity. Where contributed to and used productively by HCPs, the PHR provided some patients and lay carers with the agency to promote and co-construct a more patient centred and empowering journey of care with their HCPs. Conversely, evidence suggests that non-engagement with the PHR by HCPs contributed to inconvenience and discontinuity along with frustration and disappointment, particularly for those most connected to, and invested in its. Each HCP advocated sharing information to promote quality palliative care and most acknowledged the value of the PHR for this. Nevertheless, as this inquiry has shown, particular ideologies, routines and rituals currently operating within the health sector and various health disciplines have the power to constrain/restrain partnership and innovation. There is however, evidence that the position of the patient and family within their own home offers a degree of counteraction of power and agency. Some lay people had used this position to influence and co-construct the use and function of their PHR with their home visiting clinicians. In conclusion, the following comments from the four patients and their lay carers who participated in this study are offered as the final thoughts for this report.

“I just get tired of people covering the same ground, repeating the same answers”.

“I’d hate you to take it away – it’s like our comforter”.

“Your brain is over loaded and you don’t remember – but it’s in the book”.

“At least they all know what they are doing - things go more smoothly – it helps everyone coordinate better”.

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Appendices

Appendix 1 Focus group interview schedule

Focus Group Interview Schedule

Introduction

- ⇒ Explain purpose of today's focus group
- ⇒ Provide opportunity for questions
- ⇒ Explain focus group ground rules and confidentiality requirements for all participants.
- ⇒ Ensure consent forms are completed

Opening

- ⇒ Please tell us your name; where you work, and approximately how many times you have used "The Blue Folder".

Transition

- ⇒ What do you generally use the 'Blue Folder' for?
- ⇒ In what circumstances would you choose not to use the 'Blue Folder'?
- ⇒ At patient visits, who usually makes the first move about using the 'Blue Folder'

Key Questions

- ⇒ The 'Blue Folder' was introduced so that information important for a patient's care could be easily shared between people and services. What is your opinion about whether the 'Blue Folder' has helped this to happen?
- ⇒ The 'Blue Folder' was also introduced so that patients care could be well co-ordinated. What is your opinion about whether the 'Blue Folder' has helped this to happen?
- ⇒ What is your opinion about whether the 'Blue Folder' has improved patient care in any other ways than already discussed?
- ⇒ How has the 'Blue Folder' changed the way you interact and communicate with your patients who are receiving home based palliative care?
- ⇒ What unexpected things have occurred for patients, health professionals and services as a result of using the 'Blue Folder'?
- ⇒ What would you change about the 'Blue Folder' system (use, format, process)
- ⇒ What do you particularly like about the 'Blue Folder' system (use, format, process).
- ⇒ What obstacles seem to be affecting the use of the 'Blue Folder' – can these be overcome?

Ending Questions

- ⇒ Are there any other issues about the 'Blue Folder' that you would like to raise?
- ⇒ Do you think the use of the 'Blue Folder' should continue?

Conclusion

- ⇒ Do participants wish to see a summary of themes from this focus group discussion to comment on?
- ⇒ Thank you for time
- ⇒ Remind options for follow up support as required

Appendix 2 Semi-structured interview schedule

Patient and main family carer interview schedule

Introduction

- ⇒ Introduction and thanks for meeting today.
- ⇒ Provide further explanation as required, answer any questions
- ⇒ Ascertain if patient wishes to proceed to interview - today or another day?
- ⇒ If today, ensure consent forms are completed.

Opening

- ⇒ How long have you had your 'Blue Folder' for?
- ⇒ Who usually takes responsibility for looking after your 'Blue Folder'?

Transition

- ⇒ Can you tell me how you use your 'Blue Folder'?
- ⇒ Can you tell me who else tends to use your 'Blue Folder'?
- ⇒ Who usually makes the first move about using your 'Blue Folder'?

Key Questions

- ⇒ What is your opinion about whether your 'Blue Folder' helps information that is important for your care to be shared between people?
- ⇒ What is your opinion about whether your 'Blue Folder' helps your care to be well co-ordinated?
- ⇒ What is your opinion about whether your 'Blue Folder' affects your quality of care?
- ⇒ Can you tell about whether you find it a burden or a worry to have a 'Blue Folder', or whether you find it upsetting in any way?
- ⇒ What do you particularly like about having a 'Blue Folder'?
- ⇒ What do you particularly dislike about having a 'Blue Folder'?

Ending Questions

- ⇒ Would you suggest any changes to the style of the 'Blue Folder'?
- ⇒ Would you suggest any changes to the way its used by people?
- ⇒ Would you recommend that our services keep using a 'Blue Folder' for patients?

Conclusion

- ⇒ Do participants want to see a summary of the themes from their interview to comment on?
- ⇒ Do participants want a copy of the audio recording of their interview?
- ⇒ Participants wishes if family request copy of audio recording at any stage in the future?

Appendix 3 Initial letter from Regional Ethics Committee



Central Regional Ethics Committee

Ministry of Health
Level 2, 1-3 The Terrace
PO Box 5013
Wellington
Phone (04) 496 2405
Fax (04) 496 2191

22 August 2007

Denise White

Dear Denise

CEN/07/08/058 - A case study of the use of a patient held record for home based palliative care
Denise White

Thank you for the above application which was considered by **Central Regional** Ethics Committee at its meeting on 14 August 2007.

The study was approved subject to the following conditions.

1. Page 12, D7 data to be stored for 10 years. (Amend also in information sheet).
2. **Information Sheet (OSEC 2.2, 30)**
 - Should include a footer with version number and date.
 - Invitation statement should be amended to read "You are invited to help us find out how the 'Blue Folder' is working for everyone involved in home based palliative care".
 - Page 1 para 2, 1st sentence amend to read "I would like to learn more about the **effects** of"
 - Recruitment and Involvement, para 2, last sentence, amend as follows: "You may also wish to invite your family carer, support person, nominated spokesperson, or a member of the Maori Health Unit **to participate etc.....**"
3. **Consent Form (OSEC 2.2)**
 - Should include a footer with version number and date.

Your response will be checked by the Administrator and a letter of approval forwarded if all the above points have been satisfactorily addressed.

If you have any queries, please contact me.

Yours sincerely

Claire Yendoll
Central Ethics Committee Administrator
Email: claire_yendoll@moh.govt.nz

Appendix 4 Follow-up letter from Regional Ethics Committee



Central Regional Ethics Committee

Ministry of Health
Level 2, 1-3 The Terrace
PO Box 5013
Wellington
Phone (04) 496 2405
Fax (04) 496 2191

5 September 2007

Denise White

Dear Denise

CEN/07/08/058 - A case study of the use of a patient held record for home based palliative care
Denise White

The above study has been given ethical approval by the **Central Regional Ethics Committee**.

Approved Documents

Information sheet for Patients, version 1, dated July 2007
Information sheet for General Practitioners and Practice Nurses, version 1, dated July 2007
Information sheet for Cancer Services Health Care Staff, version 1, dated July 2007.
Information sheet for Hospice Health Care Staff, version 1, dated July 2007
Information sheet for District Nurses, version 1, dated July 2007
Patient Participant Consent Form, version 1, dated June 2007
Health Care Professional Focus Group Participant Consent Form, version 1, dated June 2007

Accreditation

The Committee involved in the approval of this study is accredited by the Health Research Council and is constituted and operates in accordance with the Operational Standard for Ethics Committees, April 2006.

Progress Reports

The study is approved until **September 2009**. The Committee will review the approved application annually and notify the Principal Investigator if it withdraws approval. It is the Principal Investigator's responsibility to forward a progress report covering all sites prior to ethical review of the project in **September 2008**. The report form is available on <http://www.newhealth.govt.nz/ethicscommittees>. Please note that failure to provide a progress report may result in the withdrawal of ethical approval. A final report is also required at the conclusion of the study.

Amendments

It is also a condition of approval that the Committee is advised of any adverse events, if the study does not commence, or the study is altered in any way, including all documentation eg advertisements, letters to prospective participants.

Please quote the above ethics committee reference number in all correspondence.

1

It should be noted that Ethics Committee approval does not imply any resource commitment or administrative facilitation by any healthcare provider within whose facility the research is to be carried out. Where applicable, authority for this must be obtained separately from the appropriate manager within the organisation.

Yours sincerely -



Claire Yendoll
Central Ethics Committee Administrator
Email: claire_yendoll@moh.govt.nz

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Appendix 5 Health care professional letter of invitation and response form



Massey University

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Reviewing the use of a Patient Held Record within home based palliative care

Information Sheet for General Practitioners and Practice Nurses

You are invited to help us find out how the 'Blue Folder' is working
for everyone involved in home based palliative care

Introduction

My name is Denise White. I am studying towards my Masters of Philosophy at Massey University, and am also employed as

In 2005, along with the district nurses and Hospice Palliative Care Co-ordinators (PCCs), I introduced a Patient Held Record, commonly called the 'Blue Folder'. This record is used for people receiving support from the district nurses and Hospice PCCs with an aim to improving their continuity of care. It contains information relevant to the patient's home based palliative care, and is available for patients and all who are involved in their care to use. Although health professionals other than district nurses are under no obligation to use the 'Blue Folder', many chose to do so.

I would like to learn more about the impacts that the 'Blue Folder' has on home based palliative care, and find out whether any changes need to be made to it, or how it is used. To do this, I plan to seek feedback from each group of health professionals who regularly come in contact with the record. I also hope to speak with several patients about their experiences and views of their 'Blue Folder'. This research is supported by Hospice and

Invitation

If you have used a 'Blue Folder' at least once, and in any way, you are invited to take part in one focus group discussion with approximately five to nine other general practitioners and practice nurses. This will be held at [REDACTED] Hospice one evening in September or October 2007, and will be no longer than one and a half hours. Light refreshments will be provided.

What does participating in the focus group discussion involve ?

Focus group members will be asked to describe how they use the 'Blue Folder', and give their opinion about:

- What impacts the ‘Blue Folder’ has on patients and their care, the sharing of information relevant to their care, and the co-ordination of their care.
 - Whether there are any service improvement issues/service delivery gaps regarding any aspect of the ‘Blue Folder’.

This discussion will be audio taped to aid data collection. I will not lead the focus group discussion but will attend to take notes to aid data collection.

Risks and benefits

There are no direct benefits for you in taking part, however, you may enjoy the opportunity to share your experiences and ideas in order to help us improve the continuity of care for our shared patients.

Reviewing the use of a Patient Held Record within home based palliative care: General practitioners and practice nurses information letter; Version one: July 2007

Participation in this study is completely voluntary, and your decision will not affect your employment in any way. Even if you agree to participate in the study, you are may withdraw from the study until the focus group begins, without having to give a reason. Once the focus group discussion begins your comments will become part of the wider discussion, therefore, it would not be possible for your contribution to the study to be withdrawn. However, you may ask that a particular comment made by yourself during the discussion is not used. You would need to contact me within seven days after the focus group to arrange this.

As the discussion will only focus on use of the 'Blue Folder', and as general practice teams are under no obligation to use this folder, it is unlikely that any information disclosed will negatively reflect on any participant's professional standing or competency. You may choose not to answer any questions. If you have any queries or concerns about your rights as a participant in this study you are encouraged to contact either myself, your professional organisation, or a health and disability advocate on 0800 42 36 38 (4 ADNET).

Confidentiality

It is likely that you will know other members of the focus group. You will be asked to agree not to tell others the names of those who participated in the focus group discussion, or any information that they shared within the discussion. Only I will have access to the audio tape of the focus group discussion. Your name will not appear in the transcription of the audio tape, or on any notes made during the discussion. I will also make every effort to ensure you can not be identified within any reports of this study. However, because the use of a Patient Held Record for home based palliative care is unique in New Zealand, readers of the final report will be able to identify the study's location. During the study period, all data will be kept in a locked filing cabinet in my office. After study completion in December 2008, data will be stored securely at the Massey University School of Health Sciences for ten years and then destroyed.

Study timeframes

It is likely to take approximately one to two months to hold one discussion with several groups of health professionals, and individual interviews with several patients. The research will be published as a Masters research thesis after its examination in December 2008. All participants will be provided with a summary of the research if they wish after study completion. Study findings will also be submitted to health service journals.

If you are interested in participating, or finding out more about the study, please return the response section using the enclosed envelope or email me at denise.white@ by _____. Returning the response section does not place you under any obligation to participate, but merely indicates that you are willing for me to contact you to discuss the study further. **You may choose to include a support person in any further explanations regarding the study.**

This study has received ethical approval from the Central Regional Ethics Committee.

Researcher

Denise White

denise.white@

Research Supervisor

Lesley Batten

Lecturer

Massey University

06 356 9099 ext. 2247

L.Batten@massey.ac.nz



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Reviewing the use of a Patient Held Record within home based palliative care

Response Form

Returning this response form does not place you under any obligation to participate, but merely indicates that you are willing for me to contact you to discuss the study further.

I am happy for you to contact me to discuss the study further YES NO

AND

I would like to receive support/advice from the

Maori Health Unit

Please complete the information below so that I can contact you:

Name (please print): _____

Professional Status (e.g GP, Practice Nurse) _____

Phone number: _____ Date form completed: _____

The best time of day for me to contact you is

PLEASE RETURN THIS FORM USING THE ENVELOPE PROVIDED

BY

Reviewing the use of a Patient Held Record within home based palliative care: General practitioners and practice nurses information letter: Version one: July 2007

Appendix 6 Patient letter of invitation and response form



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Reviewing the use of a Patient Held Record within home based palliative care

Information sheet for patients

You are invited to help us find out how the ‘Blue Folder’ is working for everyone involved in home based palliative care

Introduction

My name is Denise White. I am studying towards my Masters of Philosophy at Massey University, and am also employed as

In 2005, along with the district nurses and Hospice Palliative Care Co-ordinators (PCCs), I introduced a Patient Held Record, commonly called the ‘Blue Folder’. This record is used for people receiving support from the district nurses and Hospice PCCs with an aim to improving their care. Although health professionals other than district nurses are under no obligation to use the ‘Blue Folder’, many have chosen to do so.

I would like to learn more about the effects of using the ‘Blue Folder’ within home based palliative care, and find out whether changes need to be made to it, or how it is used. To do this, I plan to seek feedback from people who have, or use a ‘Blue Folder’. This research is supported by Hospice and

About The Study

The specific aims of the study are to:

- Explore what impacts the ‘Blue Folder’ has on patients and their care, the sharing of information relevant to their care, and the co-ordination of their care.
- Identify if there is service improvement issues/service delivery gaps regarding any aspect of the ‘Blue Folder’.

Recruitment and involvement

Any patient receiving care from district nurses and Hospice PCCs is invited to participate in one short interview to discuss their views and experiences of the ‘Blue Folder’ with me.

If agreeable to you, this interview would take place at your convenience within the next one to two weeks, be less than one hour long, and be audio taped to assist with data collection unless you preferred otherwise. You may also wish to invite your family carer, support person, nominated spokesperson, or a member of the Maori Health Unit to participate in this discussion.

Your participation is voluntary, and choosing not to participate will not have any affect on your care. Even if you chose to participate, you may withdraw from the study at any time without giving a reason, and again, this will not affect your care.

If you choose to be interviewed, you are free to decline to answer any questions. In addition, should you experience discomfort or distress during my visit, I would stop and assist you to contact your health care professional for assistance.

Reviewing the use of a Patient Held Record within home based palliative care: patient information letter: Version One : July 2007 1



Confidentiality

In an effort to prevent causing you disturbance, I have sought advice from _____ the Hospice PCCs Team Leader before sending you this invitation. Therefore, she is aware that you have been invited to participate. I will also check with _____ before phoning any patient who responds to this invitation to ensure that it is still appropriate to arrange to meet with them. However, I will not inform _____ or anyone else of your decision regarding participation.

All information you share with me will remain confidential, and I will make every effort to ensure you can not be identified within any reports of this study. However, because the use of a Patient Held Record for home based palliative care is unique in New Zealand, readers of the final report will be able to identify the study's location.

In the event that you tell me about a situation that suggests a health professional has behaved in an incompetent or unprofessional manner towards you, I would provide you with information regarding your avenues for laying a complaint.

During the study period, all data will be kept in a locked filing cabinet in my office. After study completion in December 2008, data will be stored securely at the Massey University School of Health Sciences for ten years and then destroyed.

Project Procedure

After the study is completed in December 2008, a summary of the research will be available for patient participants or their families if they wish. The research will be published as a Masters research thesis, a copy of which will be available for those wishing to read it. Study findings will also be submitted to health service journals.

Project Contacts

If you have any questions or concerns regarding this invitation, or about your rights as a participant in this study, you may wish to contact a Health and Disability Advocate, telephone 0800 42 36 38. Alternatively you are welcome to contact either myself using the number provided below, or

If you are interested in participating, or finding out more about the study, please return the response section using the enclosed envelope, or email me at denise.white@ by _____. Returning the response section does not place you under any obligation to participate, but merely indicates that you are willing for me to contact you to discuss the study further.

If I receive a response from you, I will ring to arrange a time to meet and answer any questions you may have. You may wish to include your family carer, support person, nominated spokesperson, or member of the Maori Health Unit in this meeting.

Researcher

Denise White

denise.white@

Research Supervisor

Lesley Batten

Lecturer

Massey University

06 356 9099 ext. 2247

L.Batten@massey.ac.nz

This study has received ethical approval from the Central Regional Ethics Committee.

Reviewing the use of a Patient Held Record within home based palliative care: patient information letter: Version One : July 2007 2



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Reviewing the use of a Patient Held Record within home based palliative care

Response Form

Returning this response form does not place you under any obligation to participate, but merely indicates that you are willing for me to contact you to discuss the study further.

I am happy for you to contact me to discuss the study further

YES NO

AND

I would like to receive support/advice from the

Maori Health Unit

YES NO

Please complete the information below so that I can contact you:

Name (please print): _____

Address _____

Phone number: _____ Date form completed: _____

The best time of day to phone is _____

Or – an alternative person you would prefer me to contact in order to arrange to meet with you

Name (please print): _____

Address _____

Phone number: _____

**PLEASE RETURN THIS FORM USING THE ENVELOPE PROVIDED
BY _____**

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Appendix 7 Patient participant consent form



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Reviewing the use of a Patient Held Record within home based palliative care

PATIENT PARTICIPANT CONSENT FORM

This consent form will be held for a period of ten (10) years

- I have read and understand the information sheet dated _____ and have had the details of the study explained to me. My questions have been answered to my satisfaction, and I understand that I may ask further questions at any time during or after the interview.
- I have had the opportunity to use a range of options for support to help me ask questions and understand the study, and I have had sufficient time to consider whether to take part.
- I understand that taking part in this study is voluntary (my choice) and that I may withdraw from the study at any time during or after this interview, and that this will not affect my future health care.
- I agree / do not agree to the interview being audio taped.
- I wish / do not wish to have an audio recording of this interview to be returned to me*.
- I wish / do not wish for an audio recording of this interview to be returned to any family members who have not participated in this interview if they request a copy in the future*.
- I wish / do not wish to see a summary of this interview's discussion to comment on.*
- I agree to take part in this study under the conditions set out in the information sheet.

I _____ (full name printed)
hereby consent to take part in this study.

Signature: _____ Date: _____

Support person participating in interview _____

Support person signature: _____

Researcher's signature _____

*(patient completes at conclusion of interview)

Researcher
Denise White

denise.white@

Reviewing the use of a Patient Held Record within home based palliative care: Patient participant consent form: Version one: June 2007 1



Appendix 8 Patient participant consent for release of transcript



Massey University

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Reviewing the use of a Patient Held Record within home based palliative care

PATIENTS' WISHES REGARDING THE USE OF THEIR INDIVIDUAL INTERVIEW DISCUSSION

This form will be held for a period of ten (10) years

Date _____

Dear _____

Thank you for meeting recently with me to discuss your experiences and views about your 'Blue Folder'. At the end of our meeting, you indicated that you would like to see a summary of your interview to comment on. Attached is a copy of that summary for you to read. If you are happy for me to use this summary for my study, could you return it to me, along with any comments you wish to make about it. I will take your comments into account in my study.

You are also free to decide that you do not wish for me to use this summary in my study, without the need to give a reason. Your wishes will be respected and kept confidential, and will not have any affect on your care. You are welcome to discuss any questions, comments or concerns regarding this summary with me in person. I can be contacted on using the details below.

Yours sincerely

Denise White,

denise.white@

No matter what your decision:

- Please tick the appropriate box and sign the relevant section below.
- Please return the summary, any comments you wish to raise about it, PLUS this signed form using the enclosed envelope.

If possible, it would be appreciated if your response could be provided within 10 days.

Participant's wishes

I confirm that I have had an opportunity to read and comment on a summary of the interview conducted with me. I agree that this edited summary and extracts from it and my interview may be used by the researcher, Denise White in reports and publications arising from the research.

YES NO

Patient's signature: _____ Date: _____

Full Name - printed _____

PLEASE RETURN THIS FORM, ALONG WITH THE SUMMARY AND ANY COMMENTS - USING THE ENVELOPE PROVIDED BY

Reviewing the use of a Patient Held Record within home based palliative care: Patients wishes regarding the use of the summary of their individual interview discussion: version one: July 2007

1



Appendix 9 Health care professional participant consent form



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Reviewing the use of a Patient Held Record within home based palliative care

HEALTH CARE PROFESSIONAL FOCUS GROUP PARTICIPANT CONSENT FORM

This consent form will be held for a period of ten (10) years

- I have read and understand the information sheet dated _____ and have had the details of the study explained to me. My questions have been answered to my satisfaction, and I understand that I may ask further questions at any time during or after the focus group.
- I have had the opportunity to use a range of options for support to help me ask questions and understand the study, and I have had sufficient time to consider whether to take part.
- I understand that taking part in this study is voluntary (my choice) and that I have the opportunity to withdraw from the study up until the focus group begins, and that choosing to do so will in no way affect my employment
- I wish / do not wish to see a summary of the discussion from this focus group to comment on.
- I agree to not disclose anything discussed in the focus group
- I agree to take part in this study under the conditions set out in the information sheet.

I _____ (full name printed)
hereby consent to take part in this study.

Signature: _____

Researcher's signature _____

Date _____

Researcher
Denise White

denise.white@



Appendix 10 Letter accompanying summary of focus group discussion for attendee



Massey University

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Reviewing the use of a Patient Held Record within home based palliative care

COPY OF A SUMMARY OF FOCUS GROUP DISCUSSION FOR PARTICIPANTS

Date _____

Dear _____

Thank you for your participation in the recent focus group discussion at which you talked about your views of the 'Blue Folder' used within home based palliative care. At the end of this discussion you indicated that you would like to read and comment on a summary of the discussion. Attached is a copy of that summary.

As highlighted on the focus group consent form that you signed, this summary is an amalgamation of the views provided by every person who participated in the focus group. Therefore, it is not possible to withdraw your individual contribution from this summary. However, you are welcome to provide comment on this summary for me to consider as I commence the study's data analysis phase.

If you choose to do so, it would be appreciated if I could receive your comments on this summary within 10 days. I would also like to remind you that as per the consent form you signed, the contents of this summary is confidential and can not be disclosed to others.

You are welcome to discuss any questions, comments or concerns regarding this summary with me in person. I can be contacted using the details below.

Yours sincerely

Denise White

IF YOU WISH - PLEASE RETURN THIS SUMMARY ALONG WITH YOUR COMMENTS USING THE ENVELOPE PROVIDED

BY _____

Reviewing the use of a Patient Held Record within home based palliative care: copy of a summary of focus group discussion for participants: version one: July 2007

1

