Rural Palliative Care Resource Kit

Adelaide Hills
Division of General Practice Inc.

Patient Held Records in a Rural Palliative Care Program

A discussion paper

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Contents

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Introduction

Within the Rural Palliative Care Program, patient held records (PHRs) were compiled in many of the 8 projects. This work was based on the Griffith Area Palliative Service (GAPS) model where these records of case management and review[1] were successfully implemented within the remit of the time.

This document examines:

- the benefits and disadvantages of PHRs
- the ways in which PHRs can be used (showing other examples)
- information that can be incorporated
- some of the experiences from within the RPCP.

The information contained here is aimed at enabling those following to build on the lessons learned from within the literature and from practical experience.

There is perhaps not one single record or diary that will suit the requirements of every patient or every health professional, or meet the needs of every service. It is more likely that certain components or elements of a PHR, or some of the information contained therein will be more appropriate than others. The option to choose what is included in a diary or record is given within the toolkit of resources.

Medical records are maintained to record details of individual contacts, to monitor health status, monitor practitioners' health behaviours and to support legal requirements[2]. The concept of patient held records, notes and diaries have been discussed in the literature for some years, with those created varying in format, structure and content[3].

Palliative care patients will often have a lengthy and complex health care history. This can be difficult for them to relate to new health professionals as well as remembering things such as current medications, names of tests completed or others involved in their care[14].

Primary health care professionals, and especially GPs, report on problems such as the lateness and inadequacy of discharge summaries, lack of information regarding what the patient understood and has been told about their illness, absence of care management plans, and the lack of information regarding which health professionals were involved[5,,6]. This is especially true in out-of-hours situations where a source of information would be very welcome[7].

Benefits of PHR

It has been shown in clinical use, that these records are valued by patients and carers, and felt to be useful in principal by health professionals, who report them as beneficial[8,3,4,9,10]. The known advantages include helping patients to remember what has been said, facilitating communication between different professionals and facilitating communication between patients and health professionals[2811]. They have also been identified as creating important and beneficial changes to the way in which care has been co-ordinated[12].

PHRs can facilitate seamless care, with improved communication between primary and secondary care, giving health professionals access to up-to-date information about patients with palliative care needs at specific points in the care pathway[1,6,9,13] These records can also be useful when patients move from one care setting to another, enabling health professionals to refer to the record and receive information from the last person involved in that patient's care[4,6].

PHRs can have a positive impact by helping patients to feel more in control and to prepare for meetings with health professionals, empowering patients to have a greater involvement in their own management, informing and assisting patients along the care pathway[6,8,9,11]. They can help to reduce uncertainty, allowing a feeling of control in potentially frightening situations, and when used in the context of a diary, patients have also highlighted the value of writing in it as a therapeutic tool[4,9].

It has been widely agreed that patients should be increasingly involved in managing and maintaining their own health[14]. Participation in healthcare is increasingly advocated by organisations, enabling optimisation of health outcomes[15]. These records can help ensure that patients are part of the communication process, supplementing verbal information and enabling them to be an active member of their health team[3].

Use of a PHR has been shown to be valuable in groups of patients when health professionals use them routinely at an active or critical stage in their disease, or in settings where there is an identified need for improved communication[3,6,7,16]. In the event of poor communication and an inaccessible health record, replication of information management and clinical care can result. An example is inappropriate drug administration, with poor symptom control as a result, leading to unnecessary diagnostic tests or hospital admissions[4].

Having current, accurate health information readily available, can remove the need for the medical record to be immediately available if there is an admission required for an emergency, potentially avoiding needless suffering[2,4,10]. In cancer care, for example, there is often a need for more rapid communication of reliable information which could be in an inpatient setting, or perhaps when a GP is required to step in at a crisis point at home[5,7].

Disadvantages of PHR

Enthusiasm for PHRs amongst health care professionals has been tempered by the recognition that an inevitable increase in workload would occur, with duplication of records[6,9,10,17]. There is perhaps no evidence then, on which to base the widespread promotion of PHRs, as it has also been found (in mental health for example) that there is no overall benefit in clinical outcomes when patients are allocated a PHR[8,13]. In this case, the extra documentation may not be warranted or justified[8].

Professionals should not write anything in a PHR that they would not say to the patient[18]. It is easier to be vague verbally though, than it is during documentation, something which may deter staff from writing in PHRs[19,20]. Many health professionals are not comfortable with the openness of information, the degree of patient participation and honest discussions of

prognosis that would ensue[13]. The possibility of greater litigation claims has also been stated as a concern by some health professionals[10].

Unless the use of PHRs is widespread, acknowledged and accepted as an integral part of clinical behaviour there may be difficulty in getting engagement from health professionals. It is difficult introducing something new into a routine, especially when it applies to some patients and not to all[19]. Ongoing and repeated marketing, especially with health professionals will ensure a greater degree of involvement and awareness[9]. However, in local projects with committed clinicians and patients, PHRs may well prove to be popular and effective[17]. This has been the experience in some of the RPCP projects, where the PHR is ideal for a local community where all are involved, or have been made aware of its use.

Negative responses from staff about PHRs can influence patients' views on them, with patients becoming discouraged by the disinterest shown by professionals[19,21]. There is a real need for commitment from staff at all levels for PHR to be optimally used[3,4].

Patients may also not want a greater degree of involvement, or want to bring clinical information into the home[13] PHRs can serve as a constant reminder of their illness increasing anxiety[10,21]. They have also been described as unnecessary and burdensome[21], something that was also reported by one respondent in the feedback from the AHDGP consultation process.

PHRs are reported not to have an effect on, or improve patient satisfaction with communication participation in care, or quality of life[13,10]. In general, the effectiveness of PHRs for discharge planning, or as a communication tool between hospital and the community, has also not been realised[3,19]. There is, however, the need to guard against considering PHRs a substitute for real communication[7].

There is often the perception by health professionals that patients will lose PHRs, but this issue hasn't really been reported in the literature[3]. However, as to whether patients took the PHR with them to appointments or not, has been influenced mainly by how staff reacted to it[19.] If staff feel the PHR is a waste of time, the patient may not want to broach the subject. This non-recognition or under-valuing by staff impacts on patients' behaviour and on their use of the PHR.

Establishing a PHR

When deciding on whether to develop and use a PHR, it is necessary to decide who they are for, how they will be used and who they will belong to. As PHRs can be used in different ways in different settings, confusion regarding their terminology and purpose is understandable[23]. There should be clear and fundamental distinction between the PHR and the medical record[7]. They can be both a management tool and a personal document for the patient[22]. Clarification is necessary at the outset.

Medical records have different forms and functions, when seen from the perspective of the individual and of the perspective of an organisation or health professional[2]. No PHR replaces all of the notes that are used widely by individual disciplines and by organisations[17]. Even then, within institutions, individual departments may have separate records[2].

PHRs will often be more medically driven collecting information usually held on a medical record[18]. They are carried by the patient, but are the property of the health service, and are stored as medical records, subject to the rules and regulations of storage after death[823].PHRs can be in addition to clinician held notes, or the patient may hold the only record for their care.

PHRs can also be intended as the property of the patient, remain private and confidential and usually not be retrieved after the patient has died[10]. When PHRs are compiled for use by patients, and intended for their use only, they may have a similar format to patient records (medical focus) but will be used in a different way by the patient. Their purpose as a source of information for health professionals would then become a secondary spin-off[9]. Perhaps writing in a notebook is as good as any of the PHRs produced, meaning that by default it is patient led rather than constrained by an agenda[10]. This cannot be ruled out as an option, and may prove to be a cost effective measure, giving patients complete control and ownership of a PHR, enabling them to use it at their own discretion[19].

Some patients will use a PHR as a therapeutic diary, or perhaps an *aide –mémoire,* recording personal information, reflections on the disease or on encounters with health professionals[7]. Privacy and confidentiality can then be maintained, which makes it more about giving people choices[10]. It would be nice to think that the aim of PHRs was to provide a flexible document that could be used according to the patients' own particular needs at any one time, but they are usually driven by health professionals to meet the needs of the service involved[918].

When establishing a PHR, consultation at the outset is very important. The process should be obvious and transparent, best undertaken face to face and should always include feedback[7]. Any process should include those who will be using or writing in the PHR, and could include patients, health and social care professionals, voluntary groups and those working after hours[691923]. This can facilitate the development of a truly useful record. It is essential to have this involvement from staff, as this can engender a certain degree of ownership.

Tools such as these are only as good as the information they contain and when used in the way they were intended. Arguably they are also only as good as the staff who use them, and it is imperative for these records to have a place in clinical care that all health professionals are engaged with their use[19].

Systems need to be developed to ensure the PHR is updated with new information and results as they become available[2]. They can then become a unique portfolio of information, specific to that person's illness and treatment[9]. A personal, portable, up to date health record can be an important adjunct to health care in a complex and mobile modern society[22].

When addressing the cost of PHRs it is necessary to look at whether they will be produced in-house or sent for printing. Is funding available or can it be obtained? Is it worth the cost involved for the benefit received? Is there commitment from management and staff? All need to be weighed up and discussed. The development of better versions of patient held medical records requires justification from cost and benefit perspectives, technical feasibility as well as the resolution of issues such as ownership, access and control of the clinical information contained within[2].

The format of diaries has varied, although there are some common denominators (Box One). A common size for these diaries is A5 or A6, allowing for easier transportation[3,10,21,23]. A flexible loose-leaf ring binder has been a popular choice, and many PHRs have different coloured pages for use by different health professionals, with section dividers[3623].

Box One: Common Diary Format

Diary Format

Most commonly incorporated into PHRs have included sections for:

- Doctors, nurses, support services, and other health professionals to write in (may be colour coded)
- A medication chart(s)
- Blood test results and appointments
- Pages to record personal details (including diagnosis and healthcare problems)
- Next of kin and contact information
- Patient and family's understanding of illness
- Personal diary section
- The names of health professionals involved, and useful telephone numbers
- Power of attorney, advance directives information
- Hospital admissions
- Care plans
- A pocket to put in extra medication charts or appointment cards

Information to incorporate into a PHR

In different care settings there will be variations on what will be incorporated into PHRs. Oncology units and Palliative care teams may have different requirements for PHRs. A common template for PHRs may be helpful, but given that there is no such thing as 'one-size-fits-all', it would be difficult to facilitate. The ability to be able to adapt or modify records is given on the AGPN website where some of the PHRs created within the RPCP versions are available for use. Also see Box Two for examples from other areas and disciplines.

Other information not mentioned previously that can be incorporated, include:

- **Questions to ask**
  Patients are more satisfied and feel they have spent more time with their Doctor if they are given the opportunity to ask questions, and when enabled to do this (and get answers) are more relaxed and more satisfied with the consultation[22.] A document that could be incorporated into a PHR is 'Questions to ask the palliative care team', developed by the Medical Psychology Research Unit at the University of Sydney. It is available to be downloaded in pdf format at the following PCA link.
  http://www.pallcare.org.au/Portals/46/docs/publications/Asking%20Questions%20Can%20Help.pdf

- **Pain Diary**
  Pain diaries are commonly used to help manage pain, and aspects of a pain diary can be incorporated, into these records[24]. This could be in the form of an algorithm, with guidelines for chronic pain management, promoting a consistent approach to pain management, and especially useful in the event the patient is not seen by their usual health professionals[23].

- **Symptom monitoring**
  Patients often monitor symptoms at home, and this could be incorporated, along with suggested therapies for symptom control[42325]. This would again promote consistent care across disciplines, perhaps in instances when patients are seen after hours.

- **Care Pathways and care plans**
  Integrated care pathways or care plan management tools can also be added[23]. Interventions and changes to the plan can be recorded, highlighting the choices made about care[26].

- **Medication Management**
  Aspects of medicine management can also be included[18]. Medicine charts are usually included in PHRs but more formal tools could also be incorporated, acting as a visible reminder, or aide-memoire for completion and subsequent medication intake[10,27]. Syringe driver compatibilities could also be included[23].

- **Cancer Information**
  General cancer information would also be helpful in smany instances[9]. These could be in the form of disease- specific inserts, with separate information on Chemotherapy or Radiotherapy, along with anticipated side-effects[6].

- **Clinical Trials**
  Within clinical trials diaries are commonly used. There is possibly a higher motivation to use a diary in these circumstances, as patients know their Doctor will review the diary, which could result in adjusted treatment[27]. This is a good example whereby using a diary becomes the norm, and is accepted practice by all patients and health professionals.

Box Two: Other examples of PHRs

Other examples of personal health records or diaries

- 'Red Book' NSW My Health Record
  http://www.health.nsw.gov.au/qcp/mhr/publications/mhr_booklet.pdf
- Breast Cancer Network Australia - My Journey Kit (includes a diary)
  http://www.bcna.org.au/cms/details.asp?NewsID=120
- Cancer Services Collaborative Pt- Held Records toolkit (NHS Modernisation Agency, UK)
  http://www.cancerimprovement.nhs.uk/documents/useful_documents/2003/Patient_Held_Records.pdf
- Pregnancy Hand-Held record, Department of Health South Australia
  http://www.dh.sa.gov.au/pehs/pregnancy-record/pregnancy-record.htm
- Patient-held record for asylum seekers and refugees, Department of Health UK
  http://www.dh.gov.uk/PolicyAndGuidance/International/AsylumSeekersAndRefugees/AsylumSeekersAndRefugeesGeneralArticle/fs/en?CONTENT_ID=4080751&chk=Vw8xyG

Evaluation

Any tool needs to be reviewed for effectiveness, and whatever methods are employed, there is a need to form and agree on the objectives of the record at the start of the process, in order to formulate evaluation criteria.

A range of approaches is available to integrate patients' views into healthcare delivery, but the methods used should be studied in the context of their intended application[28]. Within the NHS toolkit (Box Two, Cancer Services Collaborative) examples are given of 14 PHRs developed. 10 out of the 14 report a questionnaire as their evaluation method. This was the method employed by AHDGP in their initial consultation period, but the response rate was poor, despite a cover letter and reply-paid envelope. The possibility of the additional burden, especially for palliative care patients, in completing these questionnaires cannot be ruled out.

Another example of evaluation is a PHR for cancer patients, whereby a suggestion was made that patients could be followed up on a regular basis over a period of time using questionnaires, interviews or discussions in order to assess their use and views of the record at different stages in their illness[9].

Conclusion

It is possible for PHRs to provide comprehensive and portable patient information, but finding an appropriate way of doing this, which is acceptable to all involved is far from easy[2]. A summary of the benefits and disadvantages of these records is given in Box Three.

Comprehensive consultation is required before deciding whether to go ahead with a PHR. Optimally all health professionals will be engaged, thereby facilitating what can be a useful communication tool. It cannot be emphasised enough though, that these records are not to be used in place of the important conversations that need to take place. These records can also have therapeutic value as a personal, reflective diary for the patients' use on their journey.

Box Three: Summary of Benefits and Disadvantages of PHRs

Important Points

Benefits of PHRs

- Most often valued by patients and carers, who find them useful and convenient.
- They can be a record of what has been said and happened avoiding the need to continually repeat information to new health professionals
- They can be a therapeutic tool if used as a diary
- They can empower patients along the care pathway, enabling a greater degree of involvement in care
- They can facilitate communication between patients and health professionals, and between primary and secondary care
- They are immediately available in out of hours situations, and are useful for rapid communication

Disadvantages of PHRs

- They are a duplication of records, an increase in paperwork that may not be warranted or justified
- As a hand held medical record health professionals are reluctant to write in them
- Patents are discouraged by the professionals' disinterest, and sometimes too uncomfortable to request entries from them
- They're only as good as the information they contain, and need to be updated
- They are a constant reminder of illness and can be burdensome to complete
- A PHR doesn't affect quality of life, or demonstrate an overall benefit in clinical outcome
- Not every patient wants to use them or be involved in their care
- They aren't suitable for those with literacy or language difficulties, or for the elderly confused

Personal reflections of RPCP experiences with PHRs

The following testimonials are from those involved with the RPCP, and give differing views and experiences on these records

Establishing a PHR in the Adelaide Hills Palliative Care Project

The consultation process started with researching the literature and searching for other examples. This included things like the NHS Cancer services collaborative 'Improvement Partnership' Patient- held records toolkit, the SA pregnancy hand-held record, the SA 'blue baby book' (in use since 1981), the Breast Cancer Network Australia 'My Journey' diary and via RPCP colleagues. From this process the first draft was constructed and a piloting phase took place.

The 1st draft was given to 6 patients currently attending appointments. They were given a cover letter, a feedback form and a reply paid envelope. It was taken to any meeting attended (included the multidisciplinary team), shown to the Palliative Care nurses and community nurses, the project governance committee and the AHDGP staff. Any feedback was reviewed, which then informed the 2nd draft.

The 2nd draft was then given to any new patients registered with the Palliative Care service, with an offer of both A4 and A5 size, with attached cover letter, feedback form and reply paid envelope, and was reviewed again by health professionals.

There was minimal response to the questionnaires from patients about the use of the diary. The only changes made were the inclusion of a sliding scale drug chart, and the family tree was taken out. The latter was felt to be more useful for health professionals than the patients, to which the concept was unfamiliar.

The diary is now offered to all patients by the Palliative Care Nurses. This offer is made when registering with the service, but this is often late in the disease pathway. Members of Allied Health and the community nurses are often more involved with patients with chronic diseases or those who have been more recently diagnosed, so they also supply the diaries.

Patients can find using the diary a bit overwhelming initially. One respondent said "too tired", and couldn't be bothered, which is not an unreasonable response. The Palliative Care CNC then implemented a system whereby a visit by a volunteer is offered, to help find and enter the initial information required. This also introduces the concept of volunteers.

In this setting, a patient diary has been created. It becomes the property of the patient, is private and confidential, and is not retrieved after the patient has died.

The diary has now been disseminated to 6 rural clinical palliative care services, 3 rural Divisions of General Practice, 2 country Health Services and by the Repatriation General Hospital for use by rural and remote patients. Many other groups are adapting it for their own local use.

Active and ongoing promotion of the diary has been via Division and Project newsletters, and in face to face multidisciplinary meetings and link nurse groups. With a larger population of patients now using the diary there is a need to formally evaluate its' use. This will include the ease of use, clinical use, and its impact.

Deb Rawlings
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Establishing a PHR in the GAPS Project

In the GAPS program (Griffith Area Palliative Care Service) the consultation process started with looking at the NSW Health Personal Record ('Red Book') and at the Cancer Council of NSW patient held diary. Conversations were also held with the medical records department of the local Health Service to help inform the decision regarding a patient-held medical record or a patient diary.

It was decided that a medical record, owned by the health service and carried by the patient, fit the needs of the project as opposed to a patient owned diary. This point is highlighted in the consent form, so that there is no doubt. This record then contains the specialist components of the palliative care service medical record.

Much of the information contained within the record aligns with the requirements of the information collected at the time and recorded on the PalCIS database. This encompasses the symptom and functional assessment scales, and the phases of care recorded on the admission form. The consent form covers not only participation in the GAPS Project, but also in case conferencing and care-planning, and a patient-centred health care record.

The addition of a genogram (a common tool used in specialist palliative care services) was added in specifically for the record, and the home visit checklist (a tool often part of community nursing records) was used within the remit of OH&S standards when visiting the home. Continuation notes were also a part of the record for ongoing communication and record keeping.

The record was used extensively during the GAPS project, and was taken with a patient as far away as New Zealand. Only one record was ever lost, which was a concern raised by some stakeholders when these records were implemented.

The PHR employed in the GAPS program was simple and sustainable, with no ongoing costs. It has been in place since 2001.

Ian Hatton
Griffith Area Palliative Care Service Project Manager, Murrumbidgee DGP

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