

Scottish Partnership Agency
for Palliative and Cancer Care
and
National Council for Hospice and Specialist
Palliative Care Services

Patient Held Records in Palliative and Cancer Care

Practical proposition or pie in the sky?

Report of a Conference
Newcastle October 1998

Patient-held records in palliative and cancer care. Practical proposition or pie in the sky?

Report of a Conference held on 2 October 1998 in Newcastle upon Tyne, organised by the Joint Working Party on Patient-held Records of the National Council for Hospice and Specialist Palliative Care Services and the Scottish Partnership Agency for Palliative and Cancer Care.

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Introduction

The Scottish Partnership Agency for Palliative and Cancer Care and the National Council for Hospice and Specialist Palliative Care Services set up a Joint Working Party on Patient Held Records in Palliative and Cancer Care in June 1997. Both organisations had become aware of growing interest in the idea of patient held records as an aid to communication among health care professionals and between them and patients and carers. The Working Party's aim was to provide a focus for the sharing of existing experience of the use of PHRs in this field and to explore further their advantages and disadvantages.

The Working Party's approach was two fold. Firstly it commissioned a randomised controlled trial of a patient held record. The study is underway in Scotland at present described by Dr Mike Cornbleet on page 3 of this Report. Results of the study are expected at the end of 1999.

Secondly, the Working Party organised a Conference to bring together practitioners in palliative and cancer care interested in using, researching or developing patient held records. The Conference took place in Newcastle on 2nd October 1998 and was attended by 140 delegates from across the UK and from hospital, hospice, primary care and community settings. Delegates evaluated the Conference highly for being both informative and thought provoking. The Joint Working Party hopes that this Report will carry that information and debate to a wider audience.

Acknowledgement

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The National Patient-held Records Project

Dr Mike Cornbleet, Medical Director, Marie Curie Centre, Edinburgh

Dr Cornbleet outlined the background to this study, which aims to determine the value for cancer patients in Scotland of the patient-held record that was devised and piloted in the Newcastle region.

Both cancer patients and the professionals involved in their care frequently complain that communications are poor. Primary care teams feel that information from hospitals reaches them too slowly, making it difficult for them to offer appropriate support and advice to patients whose needs are changing rapidly. Patients encounter a large number of doctors and other health professionals and sometimes receive conflicting messages. One study showed that cancer patients see a median of 36 doctors (ranging up to 98) though they subsequently remember seeing a median of six doctors! This highlights the difficulty of maintaining rapid and accurate communications. Out-of-hours cover is now unlikely to be provided by a GP with knowledge of the patient's current situation.

Several reports (e.g. the Scottish Cancer Co-ordinating and Advisory Committee report on primary and palliative cancer care) suggest that patient-held records (PHRs) might address some of these issues. However, there are also some potential problems and questions about the use of PHRs:

- PHRs won't replace other clinical records (e.g. kept by the community nurse or GP) so there will inevitably be duplication of records. Will this duplication mean that the PHR won't be written in?
- Will what is written be open, honest and complete or will doctors be uncomfortable with the degree of openness required?
- Will the record be kept up-to-date?
- Will patients really want the information and want it lying around the house?

For these reasons a prospective randomised trial of the PHR developed in Newcastle was undertaken. The Newcastle record was developed after extensive consultation and is being evaluated in the Newcastle area in patients with newly diagnosed bowel and lung cancer and in patients with advanced cancer who were identified by their GPs.

The Scottish study will determine whether a PHR devised after lengthy consultation in Newcastle and piloted in a different population is accepted and used in Scotland, and:

- whether the PHR is used and by whom
- whether the use of a PHR is an unacceptable burden to carers, both professional and lay
- whether it is liked by patients (and, if possible, which patient groups it is best for)
- whether it improves communication and liaison between primary care teams and other providers
- whether the availability of current information improves decision-making by doctors who meet patients for the first time 'out-of-hours'

- whether patients perceive their satisfaction with their care and their level of autonomy to have been improved
- what modifications to the PHR might make it more useful

Patients with active advanced cancer and with a life expectancy of around 6 months will be identified in two settings:

- (a) oncology outpatients at two oncology centres.
- (b) patients under the care of hospice home-care services

The 360 patients recruited will be randomised to receive a PHR or not.

Summary

- Patients inevitably meet a large number of doctors from many different disciplines in the course of this chronic illness.
- Doctors may not be aware of just how many other doctors are involved, let alone other health care professionals
- Outpatient follow-up may not always be cost-effective and clinically meaningful.

Will PHRs help to solve these problems?

The User's Point of View

Video interviews with patients who have used a PHR

Dr Lindsay Crack, Consultant in Palliative Medicine, Marie Curie Centre, Newcastle

Videos of interviews with three individuals who had used the 'Newcastle' record at the palliative stage of their cancer, demonstrated that while they all found the record helpful their responses were very different.

In a pilot study of the PHR developed in Newcastle, records were issued to 85 patients in the palliative stage of their illness at a district general hospital. The results from 40 records/patients had been evaluated. (Many patients had died.) Of these patients, 97% felt the record was useful, 87% showed their record to a relative, 71% found the record easy to complete, 77% found no difficulty in asking healthcare professionals to fill in the record, 84% found the record easy to carry, 70% used the record for information and 97% found the text large enough. Most sections of the PHRs were completed (see table below).

Points arising from the videos:

- All three patients found the record helpful; one patient was very positive about the record while the other two were more nervous about using it.
- Different patients use their PHRs in very different ways.
- All of the patients would have liked to have the record at the start of their illness.
- All of the patients thought the size and shape of this record were convenient (A5 landscaped soft plastic ringbinder).
- A big difficulty for patients was reading the handwriting of professionals.
- Two of the patients were nervous about asking oncologists to fill in the record.
- The record could be used to promote open communication within the family.

Organisation of the record developed after extensive consultation in Newcastle

Section	Contents	Use of this section (%)*
Personal details	Diagnosis, main treatments and other important information for the patient to add	84
What I have been told	For the patient to note what they understand of what they have been told	71
Personal diary	For noting the onset of symptoms and any questions the patient may want to ask the doctors or nurses.	68
Shared care follow-up notes	For professional carers' notes	74
Medicine chart	Listing the drugs used and their dosing regimes with the dates they are stopped or started and the reason for using them	74
Blood test results		61
Useful phone numbers	E.g. of GP, district nurse, specialist nurse, physiotherapist, social workers, etc.	61
Special treatments	To include radiotherapy/chemotherapy treatment schedules, possible side-effects and simple advice	48

*Percentage of records in which the section was used in the pilot study.

Reviewing the Situation : Experience of PHRs in Other Fields and their Acceptability in Palliative and Cancer Care

Dr Mark Drury, GP, ICRF General Practice Group, Oxford

Studies of the value of PHRs in patients with cancer demonstrated that about half of the patients valued the records but the use of the record did not have any impact on quality of life measures.

Although the idea of PHRs started in the 1970s, they have been little used except for antenatal records and, more recently, for parent-held child development records. Initial concerns that the records would be lost proved unfounded: records given to patients are less likely to be lost than those kept within the health system. Patients have had access to their own medical records since 1991 but this right has been little used. Of the few patients who did take the opportunity to read their records only 20% could understand them.

PHRs may now be valuable since there are often many professionals involved in the care of a patient and the patient is the only constant factor in this network. In cancer care there is a need for more rapid communication of reliable information and it is imperative to respond to the patient's wish for information. PHRs should improve communications between professionals and make communications more inclusive of patients and their relatives.

Dr Drury and the Oxford working group carried out a pilot study of the use of a PHR by 43 patients with advanced cancer and an estimated life expectancy of more than 3 months. The majority of patients used the records throughout the 12-week study. About half of the patients, relatives and professionals involved in using the records reported that the records helped them a great deal. Patients said that they felt more involved and professionals that they felt it made them more aware of patient's feelings. The diary and medication pages were the most useful features of these records. (A space for diagnosis had been deliberately avoided in these records.)

Preliminary results from a randomised controlled trial of the use of the record involving 600 patients attending radiotherapy out patients showed a neutral effect on quality of life measures and no difference between record and non record holding groups in the wish for information or desire to participate in decision making. Qualitative analysis of interviews is awaited and is expected to characterise a range of different outcomes.

Conclusions

- Professionals should not write anything in a PHR that they would not say to the patient.
 - Blanket use of PHRs would probably not be helpful. Among cancer patients the records might be of most benefit in the active stages of the disease or in situations where communications needed to be improved.
 - Looking ahead, it might be beneficial if patients held their own main record (GP record), which was regularly updated by otherwise paperless practices, with the clinicians holding a single mutually accessible electronic record.
-

Developing and Researching PHRs: Practical and Ethical Issues

Professor Ilora Finlay, Professor of Palliative Medicine and Medical Director, Marie Curie Centre, Penarth

It is important to distinguish whether a PHR is medically driven (for communication between professionals) or patient driven. PHRs are greatly valued by some patients and a simple format is least intimidating.

An excellent computerised networked medical record system in Professor Finlay's area precludes the need for a medically driven PHR system. Professor Finlay's group investigated the value of a patient-driven system for improving communications with patients. The group compared a structured A5 format with a small A6 semi-structured notebook in a prospective randomised cross-over study. Out of the 78 patients initially enrolled 37 were evaluable. (Many patients did not want to cross over for a variety of reasons.) The diagnosis was not written on the record since some patients do not want the stigmatisation of cancer.

The two different types of records were used in very similar ways. About half of the patients found the record useful for recording appointments and medications and about a third had found it useful for recording symptoms (onset/severity) and general information such as phone numbers of professionals. Almost half of the patients used the PHR to record questions to ask the professionals and many found it valuable for keeping track of their treatment, keeping the relevant information together, and improving communication. A few said that the PHR increased their sense of control and/or their knowledge about their illness and treatment. On the other hand, almost half of the patients forgot to write in the record and about a third felt unable to request entries, were unsure how to use the record or considered it a duplication of record systems. Some patients were disinterested or too busy to use the record and some felt patronised or intimidated by it. A few found the record cumbersome or an unnecessary reminder of their illness.

The professionals were not using the records despite a huge publicity campaign; 21 patients reported that professionals were too busy to use the record and 11 reported professionals were disinterested in the PHR.

There are several important questions that should be addressed

- Will the proposed PHR be patient driven or medically driven?
- What communication do we want to improve? (Those who use the PHRs may be good communicators anyway. Bad communicators may not be improved.)
- Is the allocation of resources to PHR systems justified, for example, compared with investing in more oncologists?

Conclusions

- PHRs are valued by some patients.
 - They contain some rich information that isn't found anywhere else.
 - The format of the records must be simple and clear.
 - The records must not duplicate other systems (e.g. appointment cards).
 - The main barrier to the use of PHRs is lack of participation by professionals.
-

Management of Change: the PR of PHRs

Dr Kathryn Mannix, Consultant in Palliative Medicine, Marie Curie Centre, Newcastle

Dr Mannix drew from her experience of introducing PHRs in the Newcastle area. She emphasised the need for extensive consultation to ensure that the professionals who will use the record are involved in generating it.

The project on PHRs for cancer patients in the Newcastle area was initiated because GPs and district nurses could not get information quickly enough to make medical decisions or to help patients to understand their illness.

Initiating a PHR system is a major change for which the timing must be right. The ownership of the 'project' needs to be carefully considered. Extensive consultation at the outset is very important. The consultation process should be obvious and transparent; it is best done face to face and it should include feedback.

When designing/developing the Newcastle PHR Dr Mannix and colleagues had consulted: the Calman–Hine implementation team, primary care teams, hospital managers, hospital clinicians, palliative care organisations, health authorities, patient organisations and patients, academics and many other professionals. The consultation process had been personal, it grew out of primary care ownership (officially) of the project (but not the idea) and took 18 months. This process might need to be slightly different in another area.

The outcomes of the consultation process were

- a new format for the record
- obscured/shared ownership of the project
- a clear research plan
- requests from clinicians to participate in the study

The latter was an unexpected and rewarding demonstration of the interest of clinicians.

To make further progress with the change would need

- a successful pilot study
- well-publicised results
- to spread credit for success (unless unsuccessful)
- to address the problems that arise
- to accept new ideas
- to maintain enthusiasm

The factors that help to maintain enthusiasm are positive feedback from patients and professionals, constructive criticism, remembering why the project started, tactful handling of critics, setting realistic goals and not expecting too much.

Discussion

A group of local health care practitioners shared their experience of PHRs in a panel session in the morning and all the main speakers also took questions. Points arising from the two discussion sessions are reported here together. Points made by individual contributors did not necessarily reflect the view of the whole panel.

Panel members

Richard Gamlin, Lecturer Practitioner, St Benedict's Hospice, Sunderland (Chairman)

Dr Tim Carney, GP, Burnbrae Medical Group, Hexham

Dr Mike Cornbleet, Medical Director, Marie Curie Centre, Edinburgh

Dr Lindsay Crack, Consultant in Palliative Medicine, Marie Curie Centre, Newcastle

Dr Mark Drury, GP and Research Fellow, ICRF General Practice Research Group, Oxford

Professor Ilora Finlay, Professor of Palliative Medicine and Medical Director, Holme Tower Marie Curie Centre, Penarth

Marjorie Gazzeni, Community Nurse, Burnbrae Medical Group, Hexham

Dr Kathryn Mannix, Consultant in Palliative Medicine, Marie Curie Centre, Newcastle

Alison Sharpe, Colorectal Specialist Nurse, Royal Victoria Infirmary, Newcastle

Patient or medically driven?

There should be a clear and fundamental distinction between the PHR and the medical record. Medical communication can be entirely computerised. PHRs are to enhance communications with the patient.(IF)

A smart card (for the medical record) might eventually be part of the PHR. (LC)

Content and format of the record

An unstructured notebook format is least intimidating for patients—most can cope with it and don't find it a threat if they can't write/spell well.(IF)

The records should contain more information, for example about chemotherapy and its possible side effects.(MG)

Confidentiality/security may be a problem. (e.g. One patient was worried that someone might realise that she had morphine at her address.) One solution is to put the GP's details on the record but not the patient's name and address.

The section for patients to write in what they have been told reveals the differences between what the patient has been told and what they understand.(LC)

Doctors need to check that patients understand what they are trying to communicate. This is an important aspect of professional development.(TC)

Doctors find it a culture-shock to have to write things down in language that the patient will understand. This takes time and there is inevitably some reluctance.(LC)

The medication section is useful for communication between professionals and for patients.(TC)

Education about PHRs

Education about PHRs should be aimed at more senior professionals so that they can pass on their knowledge to the more transient staff at more junior levels.(LC)

In pilot studies (that she has been involved in) education about using PHRs has been done as they've gone along. Ideally it should have been done in advance. (AS)

Patient selection

Selection of patients who would benefit from a PHR might be appropriate. Some patients feel patronised by being given a PHR or find it an offensive reminder of their illness.(MD)

It may be best to allow patients to select themselves.(IF)

PHRs should not be issued to patients but offered to them and they should feel able to opt in or out at any stage. (LC)

When to introduce a PHR

PHRs may be most useful for cancer patients if they are introduced at the diagnosis stage since this is the time of greatest anxiety for patients. They may also be particularly useful at the palliative stage when communication can be difficult. (MD)

Patients are not asked to enter pilot studies at the time of diagnosis but 1–2 weeks later at a nurse-led clinic. Most think it will benefit them and their carers and agree to enter but a few refuse.(AS)

Getting professionals and patients to use the records

It will take time for GPs to get used to using these records for cancer patients, as it did for them to get used to using other PHRs such as antenatal records. At present it is difficult to remember to use the records and patients often forget to mention them; it will eventually become second nature to use them.(TC)

Extensive consultation about the format of records may produce similar formats in different areas. Another aim of the consultation process, however, is to involve the professionals in generating the PHR and thus motivate them to use it. (KM)

Patients need to be encouraged to write in the records—they are a new concept. (MG)

It is important to provide nurse time to go through the purpose of the records with patients. Doctors don't have time to do this.(AS)

Refusal to participate in a study is not the same as refusing a PHR. (audience)

Who benefits from the record?

The main use of PHRs is to help the patient communicate with all carers. Probably the most important part of the record is the medication list which gives information about medications the patient is actually taking. (IF)

Out-of- hours doctors find the records very helpful as an immediate source of information on the patient's condition. (LC)

PHRs are particularly useful to patients who want to be involved in their own care. (MG)

Relatives may benefit in the terminal stages by writing about their relative ('had a good night' etc.). (LC)

Some patients are frightened to write anything. Not every patient wants to be involved.(AS)

Some patients view the records as belonging to the doctors and are therefore inhibited from writing in them. (LC)

Potential for the Future**Dr Derek Doyle (Honorary Vice-President of the National Hospice Council and the Scottish Partnership Agency)**

Bringing the conference to a conclusion, Dr Doyle, acknowledged the need for change but recognised that the solutions we arrive at today will not be a perfect or a permanent model. We must guard against considering PHRs a substitute for real communication at the heart of which is the ability to get alongside people and create an atmosphere of trust in which patients feel free to ask questions. Listening and understanding are of far greater value than paper records and electronic databases. Dr Doyle hoped that the development of PHRs would act as a catalyst for improvements in the quality of care as a result of better communication.

Key Points of Conference

The following Key Points from the Conference are reproduced with permission from CLIP (Current Learning in Palliative Care) Update Service, Issue 3, 1998. Manchester: Hochland & Hochland.

PHRs Offer Some Advantages:

- They are a record of what the patient has been told and understood.
- They are a record of changes in treatment, especially medication and visits of professionals.
- They give increased control and autonomy to patients.
- They provide rapid communication between services.
- They are useful in out of hours calls at home.
- They provide accessible information which improves consultations.
- Partners and relatives use them to record their own observations and comments.
- They record whether services have been refused.
- Most patients find them useful, understandable and convenient.

PHRs Have A Number Of Disadvantages:

- They can produce duplication of existing records with a risk of reducing quality of all the records.
- They increase the amount of time spent in recording information with the resultant increased burden on health care professionals.
- Some patients see them as patronising, frightening, intimidating or as an unpleasant reminder of the diagnosis.
- Not every patient wants to be involved with their own care in this way.
- They may not be suitable for frail or elderly patients or those with writing, reading or language difficulties.
- There is a lack of clarity if PHRs are professional records or simple communication aids.
- Professionals would need education in the use of PHRs.
- Confidentiality may be compromised by PHRs.
- PHRs may become too large if used from the time of diagnosis.
- Despite advantages, many GPs (45% in one study) think that the extra work outweighs any value of PHRs.
- Some patients feel unable to ask health care professionals to put in entries into a PHR.

- Implementing PHRs requires a cultural change.
- PHRs are likely to be used by health care professionals who are already good communicators.

Some Conclusions:

- PHRs are valued by some patients and can contain rich information.
- A structured PHR format is difficult to implement and may not be accepted unless there is a thorough consultation process that produces a cultural change.
- A simple, unstructured PHR format and medication chart may provide the improvement in communication and autonomy that patients find useful.
- PHRs should not duplicate professional records and information technology may provide the best format for such professional records by avoiding duplication while providing extensive access.
- PHRs are not a replacement for good communication, but should be a catalyst to bring about changes in professionals.
- Further development on PHRs should wait until current studies are completed and published.

Poster Presentations

Multi-professional patient-held record for cancer care.
Armagh and Dungannon Health and Social Services Trust. Florence Doran,
Macmillan Home Care Sister

Medical oncology department patient-held record.
St James's University Hospital. Leeds. Kate Hayward, Clinical Nurse Specialist

Patient held records for patients with terminal cancer.
St Hilary Brow Group Practice. Robin Williams, Nurse Clinician

Developing patient-held records in primary care.
Public Health Resource Unit, Oxford. Kate Saffin, Researcher.

Patient-held records for cancer patients. Ayrshire and Arran Community Healthcare
NHS Trust.
Jane Neilly, Nurse Adviser in Cancer Care

Patient-held records in cancer care: promoting patient involvement and partnerships
in care.
Newcastle Marie Curie Centre. Dr Lindsay Crack, Consultant in Palliative Medicine.

Samples of PHRs

Records on display ranged from the unstructured tiny notebook bought by the patient, which was used by Prof Finlay's group, to a fully structured A4 file of patient notes with sections for letters, summaries and consultations, test results, patient notes, medicines, reminders etc. Most records were A5 size folders, booklets or record cards divided into sections for professionals' records, medications, appointments and personal notes by the patient.

Bibliography

Mark Drury, Jean Harcourt and Michael Minton. **Acceptability of Patients with Cancer holding their own Shared-Care Record.** *Psycho-Oncology*, Vol 5: 119-125 (1996)

Ilori Finlay, Nicola Jones, Penny Wyatt and Judy Neil. **Use of an Unstructured Patient held Record in Palliative Care.** *Palliative Medicine*, Vol 12: No.5 1998

Christine McCann. **Communication in Cancer Care: Introducing Patient Held Records.** *International Journal of Palliative Nursing*, Vol 4: No.5 1998

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Through these groups they elect the Council of Management of the SPA. The Council comprises 12 elected members, 2 Assessors from the Scottish Office and an Observer from the National Council.