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Does the patient-held record improve continuity and related outcomes in cancer care: a systematic review

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Abstract

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Keywords: cancer, continuity of care, patient involvement, patient-held record, systematic review

Objectives To assess the effectiveness of the patient-held record (PHR) in cancer care.

Background Patients with cancer may receive care from different services resulting in gaps. A PHR could provide continuity and patient involvement in care.

Search strategy Relevant literature was identified through five electronic databases (Medline, Embase, Cinahl, CCTR and CDSR) and hand searches.

Inclusion criteria Patient-held records in cancer care with the purpose of improving communication and information exchange between and within different levels of care and to promote continuity of care and patients' involvement in their own care.

Data extraction and synthesis Data extraction recorded characteristics of intervention, type of study and factors that contributed to methodological quality of individual studies. Data were then contrasted by setting, objectives, population, study design, outcome measures and changes in outcome, including knowledge, satisfaction, anxiety and depression. Methodological quality of randomized control trials and non-experimental studies were assessed with separate standard grading scales.

Main results and conclusions Seven randomized control trials and six non-experimental studies were identified. Evaluations of the PHR have reached equivocal findings. Randomized trials found an absence of effect, non-experimental evaluations shed light on the conditions for its successful use. Most patients welcomed introduction of a PHR. Main problems related to its suitability for different patient groups and the lack of agreement between patients and health professionals regarding its function. Further research is required to determine the conditions under which the PHR can realize its potential as a tool to promote continuity of care and patient participation.

Introduction

In many countries there has been increased specialization in hospital practice and expanding team membership in primary care, which has resulted in a tendency for care to fragment.¹ This has implications for the management of patients, in particular for those with long-term diseases such as cancer. Patients can have long and complex health-care histories requiring care from a range of service providers in the community, in hospitals and hospices at different stages of their care pathway. Several studies document the considerable number of professionals that patients may encounter.^{2,3} Care provided by the different professionals involved does not always progress smoothly and gaps in care can and do occur.

Incomplete documentation and a lack of rapport between professionals regarding a patient's condition, treatment history, prescribed medications and personal circumstances impede the provision of quality care. As a consequence, inadequate symptom control may be administered, psychosocial needs overlooked and inappropriate referrals made. This can lead to unnecessary hospital admissions, repeated diagnostic tests and decisions against patients' wishes, resulting in a waste of scarce resources.^{1,4}

Inadequate information transfer and breakdown of communication can happen at an organizational level, for example at the point of discharge from the hospital, and at a professional level, for example between doctors, nurses and social workers. Information transfer happens largely through informal communication between professionals, which is often inconsistent and not comprehensive, and usually does not transgress boundaries.⁵

More formal procedures such as the patient-held record (PHR) – also known in other contexts as 'logbook', 'patient travelling record', 'personal record', 'client record', 'shared care record', 'care diary' – have been designed to facilitate continuity of care. A PHR can take a number of forms, from a dynamic tool used by the patient and all health-care professionals

providing care to the patient, to a print-out from the patient's medical record or general information sheets. It is designed to inform and involve patients in their care and to facilitate communication between the different groups of people caring for the patient.⁶ PHRs are well established in other care contexts such as obstetrics, paediatric health and chronic illness^{1,7} where they have been used successfully in improving communication and involving patients in their own care. Such a mechanism to improve continuity of care has not yet been reviewed in a rigorous way.

Aim

This article aims at assessing the effectiveness of the PHR in cancer care and identifying impediments to its optimal functioning and evaluation.

Methods

Identification of the literature

Relevant studies were identified by searching:

- Computerized databases: MEDLINE (1966 to April Week 3 2004), EMBASE (1980 to 2004 Week 18), CINAHL (1982 to April Week 5 2004), the Cochrane Database of Systematic Reviews, CDSR (first quarter 2004) and the Cochrane Controlled Trials Register CCTR (first quarter 2004).
- The reference lists of identified studies were searched for further relevant studies.
- An expert panel advised about recently published articles or ongoing research, as part of their function for the NICE Guidance for supportive and palliative care for those affected by cancer.⁸

Searches were based on the following strategy:

- Patient-held record OR
- Logbook OR
- Patient travelling record OR
- Personal record OR
- Client record OR
- Shared care record

AND

- Cancer OR

AND

- Evaluation OR
- Intervention OR
- Effectiveness

The PHR may have been used under different names not yet known to the authors and we acknowledge this as a limitation to the search strategy.

Inclusion criteria

An evaluation of a patient-held record in cancer care with the purpose of improving communication and information exchange between and within different levels of care and to promote continuity of care and patients' involvement in their own care.

The process of including and excluding studies in this review is presented in a flow diagram according to QUOROM statement⁹ (see Fig. 1).

Data extraction and analysis

Data were extracted onto standard forms, which recorded the characteristics of the intervention (according to its function, content and format), the type of study and factors that contributed to the methodological quality of the individual studies. Data were then contrasted by setting, objectives, population, study design, outcome measures and changes in outcome, including knowledge, satisfaction, anxiety and depression. The process of selecting the studies for inclusion and extracting data was independently checked by a second reviewer (I.J.H.). Disagreement was resolved through discussion between the reviewers until a consensus was reached.

Grading the evidence

The studies were graded independently by M.G. and I.J.H., using a standard system to assess the

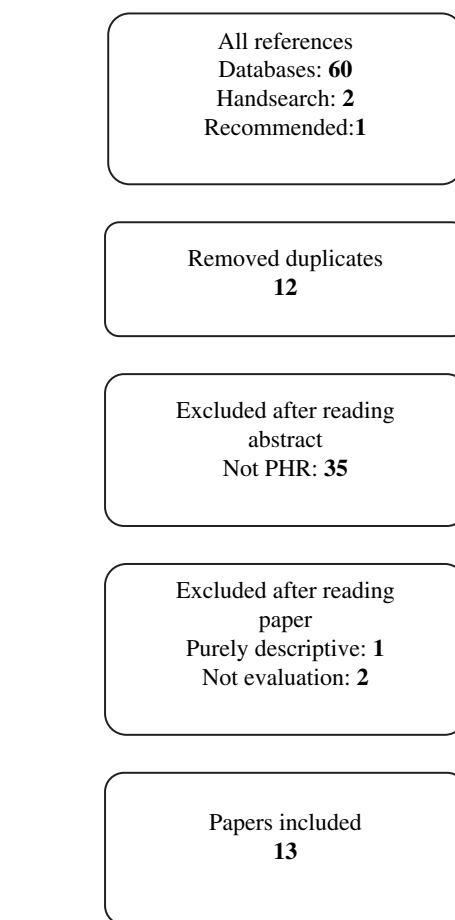


Figure 1 Studies included and excluded.

quality of randomized controlled trials (RCTs) in palliative cancer care, as used by Rinck *et al.*¹⁰ (see Table 1). This system was chosen as it consists of a set of quality criteria adapted to the complex problems typically occurring in trials in palliative care. For the grading of the non-experimental studies a data extraction sheet was used that covered nine areas based on a method developed by Hawker *et al.* Each area was rated on a 4-point scale from 1 (very poor) to 4 (good) (see Table 2).¹¹ The scoring system was used as this allows the integration of studies from different research paradigms. This tool offers assessment criteria that encompass different types of data resulting from different evaluation designs while remaining transparent and rigorous.

Table 1 Methodological quality of the RCTs (according to criteria used in Rinck *et al.*)¹⁰

Study	Accrual	Homogeneity	Randomization	Attrition	Intervention	Outcome assessment	Results	Total score
Van Wersch <i>et al.</i> ¹²	+	+	+	+	+/-	+/-	+	6
Latimer <i>et al.</i> ⁴	-	+/-	√	-	+	+/-	+	3
Finlay and Wyatt ¹⁴	-	+	+	-	+	+/-	+	4.5
Drury <i>et al.</i> ¹	-	+/-	+	+/-	+/-	+/-	+	4
Williams <i>et al.</i> ¹⁵	+/-	+/-	+	+/-	+/-	+/-	+	4.5
Lecouturier <i>et al.</i> ⁷	+/-	+	+/-	-	+/-	+/-	+	4
Cornbleet <i>et al.</i> ¹³	+/-	+/-	+	-	+/-	+/-	+	4

Score + if criteria fully applied; score +/- if criteria not fully applied; score - if criteria (mostly) not applied. + = 1 point; +/- = 1/2 point; - = 0 points; √, not reported. Maximum = 7; minimum = 0. RCT, randomized controlled trial.

Results

The nature of the evidence

We identified seven RCTs: one from the Netherlands,¹² one from Canada,⁴ and five from the UK.^{1,7,13-15} We found three observational studies¹⁶⁻¹⁸ and two qualitative evaluations,^{19,20} all undertaken in the UK, and a survey evaluation from Sweden.²¹

Types of interventions

The interventions were developed with the purpose of enhancing continuity of care (see Table 3). They were aimed at improving information on treatment and services, improving communication between different parties, and increasing patient involvement in their own care. The PHRs were meant as complementary documents to the existing medical and nurse records, not to replace them. In all the studies the PHR was initiated to be used by patients and any other person who was involved in the patient's care pathway.

The interventions used PHRs of different formats and contents. Personalizing information was mentioned as an issue in the use of the PHR, and most of the PHRs were therefore designed in a loose leaf format so that information specifically relevant to the patient could be included. This was not the case for Latimer's PHR,⁴ nor for the

structured and the informal record in Finlay and Wyatt's trial.¹⁴

In three studies the use of the PHR was monitored throughout the evaluation period. In Latimer *et al.*'s trial⁴ the record was reviewed at each visit of the patient to the palliative care clinic, and in Van Wersch *et al.*'s trial¹² and the other study with head and neck cancer patients²¹ a specially assigned social nurse acted as a 'log-book/diary coordinator'. In addition, two qualitative studies^{19,20} monitored the use of the PHR throughout the study period. In Johnson and Mayor's study²⁰ written updates were made to raise awareness among health professionals about the use of the record, and in Hayward's study¹⁹ posters were placed in the outpatient department waiting and treatment areas to remind patients to use their records. The other studies did not give such consistent encouragement for the use of the record.

Outcome measures

The evaluation of interventions with a PHR focused on:

- Outcomes of the intervention
- The design of the record
- Views on the record's use

All three were evaluated in the trials, while the non-experimental studies focused on either the design or the views on the record's use, or both (see Table 4).

Table 2 The non-experimental studies' methodological quality (according to the method developed in Hawker *et al.*)¹¹

Studies	Abstract and title	Intro and Aims	Method and data	Sampling	Data analysis	Ethics and bias	Results	Transferability	Implications and practice	Total
Latimer <i>et al.</i> ¹⁸	Fair: 3	Good: 4	Good: 4	Good: 4	Good: 4	Good: 4	Good: 4	Good: 4	Good: 4	35
Drury <i>et al.</i> ¹⁶	Good: 4	Good: 4	Good: 4	Fair: 3	Good: 4	Good: 4	Good: 4	Fair: 3	Good: 4	34
Finlay <i>et al.</i> ¹⁷	Fair: 3	Fair: 3	Good: 4	Fair: 3	Good: 4	NA	Good: 4	Good: 4	Good: 4	29
Hayward ¹⁹	Very poor: 1	Poor: 2	Good: 4	Very poor: 1	Fair: 3	Very poor: 1	Fair: 3	Poor: 2	Fair: 3	20
Johnson and Mayor ²⁰	Fair: 3	Good: 4	Fair: 3	Fair: 3	Poor: 2	Good: 4	Good: 4	Fair: 3	Good: 4	30
Sharp <i>et al.</i> ²¹	Fair: 3	Good: 4	Good: 4	Good: 4	Good: 4	Fair: 3	Good: 4	Good: 4	Good: 4	34

Each area was rated on a 4-point scale from 1 (very poor) to 4 (good).

Effectiveness

Outcomes of the intervention

Most studies showed limited benefits of the PHR in cancer care. In Drury *et al.*'s trial,¹ with a sample of radiotherapy outpatients, no effect on satisfaction with communication, participation in care or quality of life was found. In Williams *et al.*'s trial¹⁵ these findings were confirmed. However, the latter trial showed that the PHR had a significant impact on aspects of communication associated with greater involvement by patients in their own management. On those aspects which were more related to information seeking, retention and understanding, no impact was found. Lecouturier *et al.*⁷ found no differences between patients with and without a PHR in terms of satisfaction, communication and how well informed they felt by health-care staff. Patients with a PHR were less satisfied with the information given at the end of treatment than those without one. There were no differences in how well informed they perceived health-care staff to be. Baseline levels of patient satisfaction with communication left room for improvement, but the PHR did not succeed in achieving this. A positive finding from this study was that patients felt more actively involved in their care. Not long after this trial, Cornbleet *et al.*¹³ experimented with this same format in a different setting and obtained similar results. Again, the main finding was that no impact could be identified on communication between patients and hospital, primary care or hospice staff, or on satisfaction with communication. There was also no identifiable benefit in terms of improved information flow between primary and secondary care.

An earlier trial carried out in Canada⁴ achieved no differences in mood states, pain relief or satisfaction with care. There was also no additional use of health-care services. However, those patients under 65 years holding their own records reported decreased levels of uncertainty.

A more positive result was obtained in a Dutch trial¹² which reported that patients with head and neck cancer were better informed, received more support and experienced fewer

Table 3 Summary of the types of interventions

Study	Country	<i>n</i>	Target group	Setting of patient sample	Study duration	Intervention
Randomized control trials						
Van Wersch <i>et al.</i> ¹²	The Netherlands	84	Patients with head and neck cancer	Hospital	1 year pilot	<i>Function:</i> clinical and informal <i>Content:</i> information, communication section with pull-out folder <i>Format:</i> information + communication section
		94	Professionals	Offered after bad news		In communication: pull-out to take to consultations Subsidiary sections In information: standard (for all) and specific modules Ring-bound <i>Function:</i> Not mentioned <i>Content:</i> health-care summary, advanced directive Current treatments <i>Format:</i> not specified <i>Function:</i> structured record: medically driven; unstructured record: patient driven <i>Content:</i> structured: information, unstructured: communication <i>Format:</i> structured: (210 × 148 mm) pre-printed sections for different parties involved on different topics; unstructured: (148 × 105 mm) stapled together 'questions and answers' section for different parties <i>Function:</i> clinical plus informal (means of communication and aide-memoire) <i>Content:</i> communication/diary sheets for use by patient, family, professionals, carers Pages for appointments, medication, addresses and telephone numbers <i>Format:</i> A4-size plastic wallet
Latimer <i>et al.</i> ¹⁸	Canada	21	Cancer patients with palliative care needs	Hospital	8 week trial	
Finlay and Wyatt ¹⁴	UK	37	Cancer patients in different stages of their illness	Not mentioned preferred format	13 weeks Cross-over at 4–6 weeks	
Drury <i>et al.</i> ¹	UK	450	Patients with any form of cancer	Radiotherapy outpatient clinic	6 months	

Table 3 Continued

Williams <i>et al.</i> ¹⁵	UK	229 Not mentioned 344 166	Professionals (GPs) Carers Patients with different types of cancer Professionals	Hospital	16 months	<i>Function:</i> clinical plus informal (means of communication and aide-memoire) <i>Content:</i> Free text entries by patient, by professionals, details of medication, dates of appointments <i>Format:</i> Pocket-sized A6, four coloured sections (diary function and aide-memoire)
Lecouturier <i>et al.</i> ⁷	UK	137	Newly diagnosed with lung or colorectal cancer (hospital), patients with cancer at any stage (community) Outside RCT: 8 patients newly diagnosed	Hospital and community	7 months	<i>Function:</i> clinical plus informal <i>Content:</i> Seven differently coloured sections personal details, diary, communication, information <i>Format:</i> A5-size with a flexible loose leaf ring binder and a pocket to insert additional leaflets and appointment cards
Combleet <i>et al.</i> ¹³	UK	66 177 83	Professionals Patients with advanced cancer and palliative care needs Professionals	Oncology outpatient clinic, hospice or specialist palliative care service Improve communication, patient satisfaction acceptability to carers (informal and professionals)	4–6 14 months	<i>Function:</i> clinical plus informal <i>Content:</i> Separate sections for personal details, diary, communication, information <i>Format:</i> A loose leaf, soft-covered booklet that rolls up to fit into pocket or handbag. Pockets at the front and back for storing additional leaflets and relevant documents
Non-experimental studies Latimer <i>et al.</i> ¹⁸	Canada	24	Patients needing palliative care Professionals	Acute care hospitals and an ambulatory palliative care clinic of the regional cancer centre	8 weeks	<i>Function:</i> clinical plus informal <i>Content:</i> health-care summary, advanced directive, Current treatments <i>Format:</i> a simple cover sheet explaining the record and instructions for use was stapled to the record

Table 3 Continued

Study	Country	n	Target group	Setting of patient sample	Study duration	Intervention
Drury <i>et al.</i> ¹⁶	UK Prospective Single group evaluation	43	Patients with advanced cancer needing palliative care in the community, and their carers	Outpatient clinics at a hospice and from general practices	12 weeks	<i>Function:</i> clinical plus informal <i>Content:</i> separate sections for personal details, diary, information <i>Format:</i> A5 ring binder, plastic wallet on inside front cover loose leaf coloured card hard and soft-backed versions <i>Function:</i> patient-driven <i>Content:</i> Unstructured, empty lined pages <i>Format:</i> A7 spiral bound notebook
Finlay <i>et al.</i> ¹⁷	UK Prospective Single group evaluation	49 Not mentioned	Patients Carers, Professionals	Day care centre	Use of PHR between 14–1073 days	<i>Function:</i> clinical plus informal <i>Content:</i> Patient's details, information, patient's notes. <i>Format:</i> A6-size plastic ring binder. Plain cover to anonymize contents. Section for patient and for professional <i>Function:</i> clinical plus informal <i>Content:</i> Information, communication <i>Format:</i> Not specified
Hayward ¹⁹	UK Qualitative evaluation	500	Patients receiving chemotherapy at hospital and receiving hospice care	Hospital	Not clear	<i>Function:</i> clinical plus informal <i>Content:</i> Patient's details, information, patient's notes. <i>Format:</i> A6-size plastic ring binder. Plain cover to anonymize contents. Section for patient and for professional <i>Function:</i> clinical plus informal <i>Content:</i> Information, communication <i>Format:</i> Not specified
Johnson and Mayor ²⁰	UK Qualitative evaluation	67	Breast, haematological, colorectal, lung near to diagnosis Carers	District hospital	1 year	<i>Function:</i> clinical plus informal <i>Content:</i> information, communication <i>Format:</i> Not specified
Sharp <i>et al.</i> ²¹	Sweden Survey evaluation	31 145 42 28 47	Health professionals: Patients with head and neck cancer Carers Professionals	2 hospitals	PHR introduced before radiotherapy evaluation performed after completion of therapy	<i>Function:</i> clinical plus informal <i>Content:</i> information, communication <i>Format:</i> loose leaf A-5 size notebook, divided into 10 colour-coded sections

Table 4 Summary of the effectiveness of the interventions

Study	Evaluation Design	Outcome measures			Results
		Outcomes of intervention	Design PHR	Use of PHR	
Randomized control trials Van Wersch <i>et al.</i> ¹²	RCT I = PHR C = usual care	-	Content evaluated by checklist	<p><i>Questionnaire:</i> patients: quality of information, social support</p> <p>Psychosocial variables</p> <p><i>Professionals:</i> questionnaire information</p> <p>Contact with patients</p> <p>Harmonizing care</p>	<p><i>Content:</i> preference for smaller size, pull-out was valued, foreground interchange form</p> <p><i>Use:</i> C = need for logbook</p> <p>I = Patients: better informed, more support, fewer psychosocial problems (therapeutic). 91% had read PHR entirely</p> <p>Professionals: better informed about patients and fellow-professionals.</p> <p>2/3 of professionals used the PHR</p> <p><i>No difference in:</i></p> <p>mood states</p> <p>Pain relief</p> <p>Satisfaction with health care</p> <p>Additional use of health-care services</p> <p><i>Difference:</i> decreased level of uncertainty with the exception of those age 65 and over</p> <p>Preference for a smaller size of the informal record. The structured page lay out was slightly less preferred.</p> <p><i>Use:</i> Proportion of patients who used it not mentioned, but disinterest from professionals mentioned</p>
Latimer <i>et al.</i> ⁴	RCT I = PHR C = usual care	Mishel Uncertainty of Illness Scale Profile of Mood States General Satisfaction Questionnaire Utilization of Health Services	-	-	
Finlay and Wyatt ¹⁴	RCT Cross-over at 4-6 weeks I = structured C = informal	-	The preferred format by telephone interview and study of the entries in PHR	-	

Table 4 Continued

Study	Evaluation Design	Outcome measures		
		Outcomes of intervention	Design PHR	Use of PHR
Drury <i>et al.</i> ¹	RCT I = PHR C = usual care	Global health status Emotional functioning Cognitive functioning By EORTC QLQ-C30 Satisfaction with communication and participation by 19-item questionnaire	–	<p><i>Patients:</i> Questionnaire about the use of the record</p> <p><i>Professionals:</i> questionnaire about attitudes to patients holding their own records</p>
Williams <i>et al.</i> ¹⁵	RCT I = PHR C = usual care	Health related QoL by EORTC QLQ-C30 NHS resource and booklet use by telephone interviews	Health-care professionals' views on content Patients' views by a questionnaire	<p><i>No significant differences</i> between groups in any of the outcome measures: Patients in both groups expressed a high level of satisfaction with communication and participation in their care. GPs views on patients having access to their medical records</p> <p><i>Use: Patients:</i> 82.2% showed PHR to doctors, 61.7% wrote in it. <i>GPs:</i> 27.3 % had seen PHR</p> <p><i>Significant difference in:</i> Preparing for appointments, monitoring patients' own progress, feeling in control.</p> <p><i>No difference:</i> QoL, NHS resource use, communication.</p> <p><i>Use:</i> 53% preferred not to have it but those who had it found it of value. Low use by professionals but those using it preferred patients to have it</p>
Lecouturier <i>et al.</i> ^{7,27}	RCT I = PHR C = usual care	Patient satisfaction with information and communication Patients' views of PHR by face to face interviews	Outside RCT: 8 patients newly diagnosed were interviewed by telephone about their opinion of the introduction of the PHR at the time of diagnosis	<p><i>Only significant difference:</i> control group were very satisfied with information (86%) intervention group (58%). 53% found it useful, and 69% found that it would be useful for them in the future. Primary care professionals found it more useful than professionals in the hospital. Well received by recently diagnosed patients.</p> <p><i>Use:</i> 87% patients used PHR 83% responded to questionnaire, 4% reported not used</p>

Table 4 Continued

Combleet <i>et al.</i> ¹³	RCT I = PHR C = usual care	Views of patient satisfaction with communication and perception of communication between patient and health professionals by structured interview	-	Health professionals' opinion on the PHR by survey	<p><i>No impact on:</i> Communication between parties. Satisfaction with information provided by out-patient doctors, primary care teams or hospice staff. Perception of communication between staff was good. Most patients had positive comments, 14% did not use it, 20% disliked features. <i>Use:</i> 86% of patients reported use by someone, 90% of those used it themselves, 84% said it was used by carers. 35% of hospital staff had asked for PHR</p>
Non-experimental studies	Prospective single group evaluation	-	<p>Content and use <i>Patients and family:</i> weekly telephone calls and questionnaire at end of study <i>Professionals:</i> single, isolated contacts by telephone interview; those giving ongoing care by questionnaire at time of exit patients</p>	<p>The PHR was shown to be feasible and helpful to patients, families, health professionals. Patients and families were enthusiastic about the record, there was no negative feedback. Health professionals felt that records pulled all information together in 'one package', provided a means of communication with community caregivers and served as an aide memoir. Considerable education and commitment is necessary to ensure compliance by all parties. <i>Use:</i> 94.1% patients used PHR, 84% of professionals had read in it</p>	

Table 4 Continued

Study	Evaluation Design	Outcome measures			
		Outcomes of intervention	Design PHR	Use of PHR	Results
Use of PHR Drury <i>et al.</i> ¹⁶	Prospective single group evaluation	–	Reported attitude to, views on content, and utilization of, the PHR. <i>Patients and relatives:</i> by personal interviews <i>Professionals:</i> by telephone interviews and questionnaires	Use of PHR	The findings show that the PHR is acceptable and helpful for those with advanced cancer in the community. Approximately half the patients, relatives and health professionals reported that the record helped them a great deal. <i>Use:</i> 93% of patients were still using PHR at follow up. 55% of professionals always looked at it, 36% always wrote in it
Finlay <i>et al.</i> ¹⁷	Prospective single group evaluation	–	How the PHR was used, by whom, documenting the number of days the patient had held the PHR, total number and class of entry, entrant and evidence of medication changes	Use of PHR	The patient driven, unstructured record allows a rich dialogue which informs communication between staff and the patient or relatives. The PHR is an effective aide-memoire. Its use is sometimes erratic and a few disliked it
Hayward ¹⁹	Qualitative evaluation	–	Preliminary evaluation: by self-completion questionnaire, this included questions on the use and relevance of each page. Patients and carers were asked to comment on problems that the PHR may have introduced. Re-assessment: voluntary questionnaire to be picked up in outpatient department and on ward.	Use of PHR	Patients and health professionals both found the PHR useful. It was helpful as an aide-memoire. Re-assessment: Health professionals felt more confident in their approach to the patient and family after reading the exact information about the patient's chemotherapy regimen. There were some problems with professionals who did not fill in the record

Table 4 Continued

Johnson and Mayor ²⁰	Qualitative evaluation	-	<p>How the PHR was used by patients, carers, health professionals by questionnaires.</p> <p>How the PHR could be improved</p> <p>When the PHR is best introduced</p> <p>Communication between patients and health professionals</p> <p>Patients who had returned the questionnaires were invited to take part in focus group discussions</p>	<p>Patients liked the record and placed importance on access to information early in the treatment process. They valued the health diary as a means of therapy and personal reflection and shared information with family and friends.</p> <p>Health professionals found it a good tool to exchange information between different parties.</p> <p>The majority of patients commented the PHR's content was not personal enough</p>
Sharp <i>et al.</i> ²¹	Survey evaluation	-	<p>Health-care professionals' views on content</p> <p>Patients' views by a questionnaire</p>	<p>85% of respondents found PHR had a positive effect on information and communication. It is recommended that they should be implemented in standard care for head and neck cancer patients.</p> <p><i>Use:</i> Patients: 80% always read the notes from clinicians, 21% believed that clinicians always read their notes.</p> <p>Professionals: 72% read notes from colleagues, 52% read notes from family members.</p>

I, intervention; C, control.

psychosocial problems. Professionals who worked with the logbook were better informed about their patients and about the care activities of fellow professionals than those who did not. They saw an improvement in their contact with colleagues and in the harmonization of care.

Latimer *et al.*'s trial⁴ found that the intervention group had less expenditure on health and social service, although this result was not statistically significant. Two other studies^{1,15} found no major differences in resource use between the two groups. The only cost attributable to the intervention was the cost of the production of the record itself.

The design of the record

After having established the usefulness of an unstructured PHR in a pilot study¹⁷ which showed that a PHR complements care and allows rich dialogue, Finlay and Wyatt¹⁴ assessed the preferred format of a PHR in oncology and found a preference for the smaller size of the informal record, although the structured page layout was slightly less preferred.

Lecouturier *et al.*⁷ found that the timing of introducing the PHR at or around diagnosis was acceptable. Moreover, several other studies suggested the PHR could best be introduced early so that patients would have the opportunity to become more involved in their care.^{4,13,20}

Views on the record's use

Patients' views on the use of the PHR are largely positive,^{7,15,17,19–21} whilst a small proportion of patients dislike it.^{7,14} Health professionals considered them of some benefit,^{12,15,16,20} although in some studies hospital-based health professionals considered them more helpful for their primary care colleagues and patients.^{7,13} In practice, the value of a PHR was limited by low involvement and a lack of interest from health professionals.^{7,12–16,20} Reservations by health professionals towards the PHR were related to worries about more paperwork,^{4,7,15} the duplication of medical records,^{4,7,13} intruding into their privacy²¹ and upsetting patients by providing additional

information on their illness.^{7,13} Drury *et al.*¹⁶ however showed 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. Lecouturier *et al.*⁷ and Latimer *et al.*⁴ found that no patients lost the PHR and that patients were reliable in managing the record. A few studies found that the ways health professionals and patients valued the PHR were linked.^{7,16} In Lecouturier *et al.*⁷ the lack of interest by health professionals worked to discourage many patients to the extent that some stopped presenting it to staff, while more patients who had not received a negative response to the PHR from staff rated it as positive. Drury *et al.*¹⁶ found that if the GP was using the record, the patient made more use of it independent of the frequency with which the patient was seen.

Another discouraging factor in the use of the PHR was unfamiliarity with the concept of the PHR. As it was a new tool which had been initiated at the start of the study it did not feature in the usual conduct of consultations and as such it was often left to patients to take responsibility to present it to the doctor.^{7,13}

Discussion

One of the major problems that needs to be addressed in cancer care is the continuity of services that patients need throughout their care pathway.²² A PHR has been judged to be one of the options to enhance continuity between services, especially considering its success in other areas such as obstetrics and paediatric health. However, the PHR interventions evaluated through this review did not achieve the benefits described in other care contexts. The evidence so far on the PHR in cancer care has produced equivocal findings on three levels: (i) the recurring null results for most of the outcomes measured in the RCTs which do not confirm the positive results in pilot studies or studies with a qualitative design; (ii) the perceived usefulness of the PHR by health professionals but their lack of interest in the actual use of the record; (iii) the

diverse attitudes of patients in the acceptance and use of the PHR: some reject it while others become enthusiastic when they use it.

These contrasting findings sum up the main problems in researching such a complex intervention as the PHR. Methodologically, the papers list major limitations to the conduct of trials in this area. Latimer *et al.*⁴ experienced significant difficulties with recruitment and maintenance of patients with palliative care needs, which is consistent with other studies working with this population.²³ The same problem was reported in Finlay and Wyatt's randomized cross-over trial.¹⁴ In Drury *et al.*'s trial¹ the feasibility of the PHR for patients with cancer in the community shown by their pilot study¹⁶ could not be confirmed by a different population in a different setting which makes it difficult to demonstrate a measurable improved outcome, even if valued. Williams *et al.*¹⁵ mentioned that recruitment to a study of this sort was not easy. The single difference in outcome in Lecouturier *et al.*'s trial⁷ was that intervention patients were less satisfied with the information given at the end of treatment than controls, which may have resulted from chance or raised expectations of improved communication that were unfulfilled. Unequal size of patient groups was mentioned, as well as the fact that the study was underpowered to give a clear result. Cornbleet *et al.*¹³ also reported that their study was underpowered due to the failure to recruit the intended number of patients and a high level of satisfaction at baseline which limited the scope for improvements.

One might wonder whether the RCT is the most appropriate design for the evaluation of this kind of intervention. Randomized trials provide information on the value of an intervention ignoring the wider context such as health professionals' and patients' attitudes, beliefs and preferences, expectation and satisfaction, which are the very components that determine the effective use of the PHR. Instead of giving exclusive attention to the results of RCTs when looking for evidence on the PHR, the difference in results between experimental and observational evaluations should be con-

sidered. Although some pilot studies have served as a basis to develop randomized trials in this area, the lack of consistency in structures, processes and outcomes measured in these trials suggests that insufficient mapping of the appropriate nature of interventions has been done prior to testing these in a wider framework. Here, the phases outlined in the MRC Framework for the design and evaluation of complex interventions are essential to refine research protocols ensuring acceptability and feasibility of interventions.²⁴ Different formats and different aspects of the content of the PHR have been experimented within the trials so that no consensus has been reached about what works best. The variety of objectives addressed in the trials reflects the confusion about the concept of continuity of care. Sometimes the focus was on information provision, communication between varying parties, coordination of services, experience of care. Haggerty *et al.*²⁵ considered all these part of a multi-aspect definition, but this has not yet been integrated in the intervention studies working with solutions to enhance continuity of care. Careful definition is a precondition for useful research in this area. The same applies to patient involvement in their own care that the PHR aims to promote. In this field too, it is not yet clear against which criteria the effectiveness of interventions should be judged. The development and use of consistent measures across studies is needed to allow comparison.²⁶

The successful use of the PHR is further compromised by the low level of engagement that health professionals showed towards the record. The PHR was often not used by professionals as intended: for the sharing of care with patients. Professionals tended to use it as a means of communication with other professionals¹⁵ rather than with patients. Another study¹³ found that the PHR served separate functions for health professionals who treated it as a document to confer technical information, and for patients for whom the record represented a vehicle through which to express their values and views about treatment and future care. In all the studies the PHR was intended to function both as a clinical and as an informal

document. The importance of the latter function in the management of a patient's care was sometimes overlooked.¹³ Even with its 'patient-driven' purpose, health professionals have a crucial role to play in the acceptance and successful use of the PHR.^{1,27}

Despite the fear that a PHR could be detrimental to patients at or soon after diagnosis, it was found acceptable and useful by them.⁷ This finding could have important consequences for the content of the instrument. Their needs may differ considerably from patients with advanced disease and more tailored packages could be provided to patients at particular points of their illness. Early introduction of the PHR may be beneficial so that patients can discover its advantages and adopt it gradually as part of their care. It is essential to find out more about the particular profile of the patient who is best served by what the PHR stands for. Navigating independently through the health-care system, which the PHR aims to facilitate, assumes the command of a considerable body of knowledge and skills. It is possible that the PHR fits a particular patient group, such as those with a high level of literacy, or those with a chronic condition who, due to constant exposure to services or medication, become highly knowledgeable about their illness, its treatment, and the way in which it is best to interact with professionals. Other patients may be served better by more pre-organized mechanisms such as care pathways, depending on their personal understanding of continuity of care.

The PHR may be a valuable instrument in cancer care where decisions are complex and risks and benefits need to be balanced. It recognizes that this can involve a long process of thinking and consulting others depending on changing circumstances, moods and opinions. This represents a shift away from other decision aids or forms of information-giving, which imply a more passive attitude, patients absorbing health messages and acting as prescribed. The PHR acknowledges that continuity of care is a multidimensional concept involving different values given to different aspects of continuity

between patient groups and individuals.²⁵ Managing a fluctuating and uncertain illness trajectory, with the assistance of a PHR, needs some essential supporting conditions. Some of these have been outlined^{13,20,21,27} but should be further investigated with empirical work that pays attention to real-time processes. Conditions conducive to its successful use include a high degree of commitment of all the relevant staff and motivation of patients. A clear view of the PHR's function is needed which can be realized by introducing it, fully explaining its use, and monitoring it by a specially nominated person. It requires that the PHR is initiated at an early stage of someone's illness so that it is incorporated into the clinical culture and that everyone is prepared to use it on a regular basis.

Conclusion

This systematic review has tackled the evidence on the PHR in cancer care which represents a study area with substantial heterogeneity, in study quality, study design, population, context and application of interventions. This review has comprehensively appraised the literature on this topic and has included all study designs. The randomized trials present findings on the effectiveness of the PHR in cancer care, with only limited benefits. With one exception in the area of head and neck cancer where the PHR succeeded in its intended objectives, the instrument has only shown evidence of an absence of effect when evaluated by the RCT. This review has shown that the PHR does not cause any harm. The non-experimental studies provided a fuller picture of the impact of the PHR. They showed the more positive potential functioning of the instrument, as well as some of the essential mechanisms by which it could work. Future research should continue with exploratory work to understand the conditions in which the PHR can be used most effectively. Part of this is the identification of groups of enthusiasts among patients who could benefit most from this intervention. Conceptual clarity is needed about areas such as continuity of care and patient involvement.

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