

An Evaluation of a Patient Held Record in Cancer and Palliative Care

A randomised, prospective trial

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

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***Scottish Partnership for Palliative Care
1a Cambridge Street
Edinburgh EH1 2DY
Tel 0131 229 0538
Fax 0131 228 2967***

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An Evaluation of a Patient Held Record in Cancer and Palliative Care

A randomised, prospective trial

*Michael A Cornbleet
Medical Director, Marie Curie Centre, Edinburgh*

*Phyllis Campbell
Health Care Project Manager, North Glasgow University Hospitals NHS Trust*

*Scott Murray
Senior Lecturer in Primary Care, University of Edinburgh*

*Margaret Stevenson
Director, Scottish Partnership for Palliative Care*

*Senga Bond
Professor of Nursing Research, University of Newcastle*

*For and on behalf of
Joint Working Party of the Scottish Partnership for Palliative Care and the National Council for
Hospice and Specialist Palliative Care Services.*

Contents

| | page |
|--|------|
| <i>Preface</i> | 4 |
| <i>Executive Summary</i> | 5 |
| <i>Introduction</i> | 6 |
| <i>Methods</i> | 7 |
| <i>Ethical approval</i> | |
| <i>The Newcastle Record</i> | |
| <i>Eligibility</i> | |
| <i>Recruitment</i> | |
| <i>Follow-up</i> | |
| <i>Survey of health professionals</i> | |
| <i>Data analysis</i> | |
| <i>Results</i> | 9 |
| <i>Patient characteristics</i> | |
| <i>Communication with primary care staff</i> | |
| <i>Communication with hospital staff</i> | |
| <i>Communication with hospice/home-care services</i> | |
| <i>Patients' views</i> | |
| <i>Health professionals' views</i> | |
| <i>Discussion</i> | 14 |

Preface

Phyllis Campbell, Chairman, Joint Working Party on Patient-Held Records

This report is the result of a research study commissioned by the Joint Working Party on Patient-Held Records of the Scottish Partnership for Palliative Care and the National Council for Hospice and Specialist Palliative Care Services. The Working Party was set up in the light of widespread interest in the use of patient-held records in palliative and cancer care. The Working Party aimed to promote the sharing of experience of using patient-held records in this field and to undertake further work to explore their potential benefits.

A Conference organised by the Joint Working Party in Newcastle in October 1998 brought together 150 delegates who exchanged experience and ideas, and heard reports from current projects. To explore the issues further the Working Party commissioned a randomised controlled trial which was undertaken in

central Scotland by the Department of Nursing Research at the University of Newcastle. This report presents the results of that trial, which were first published in the journal *Palliative Medicine*, Vol 16, Number 3, 2002.

We are immensely grateful to all the patients and relatives who agreed to take part in this study, and to all the many hard-pressed staff who helped recruit patients and gave us their opinions of the patient-held record in "real life".

We gratefully acknowledge the invaluable and tireless efforts of Mrs Eileen Brand and Mrs Rene Stansfield (research assistants). Funding for this study was generously provided by Macmillan Cancer Relief, Marie Curie Cancer Care, Elizabeth Clark Charitable Trust, Janssen-Cilag plc, and the Beatson Oncology Centre, to whom we are very grateful.

Executive Summary

The Study

This study set out to evaluate prospectively the introduction of a patient-held record (PHR) in the management of patients with advanced cancer and palliative care needs. The study was conducted in 1999 in central Scotland.

Methods

The design was a prospective, parallel group, randomised controlled trial. Patients recruited into the study were either attending an oncology out-patient clinic in a cancer centre in Glasgow or Edinburgh, or were receiving home-care or day-care services from one of six hospice/specialist palliative care services across the central belt of Scotland.

244 patients with advanced cancer were recruited into the study, of whom 231 completed the baseline interview. 117 patients were randomised to receive the patient-held record and 114 to the control group receiving standard care. 80 patients with the patient-held record and 97 without were interviewed between four and six months later.

The main outcome measures were the subjective views of patient satisfaction with communication and perception of communication between patient and

health-care professionals, as determined by structured interview at baseline and after 4-6 months. A postal opinion survey of 83 health professionals known to have received the patient-held record was conducted 14 months after the PHR was first introduced and received 63 replies.

Findings

We could identify no improvement in the provision of information to patients, or in the satisfaction of patients with information provided by out-patient doctors, primary care teams or hospice staff. Overall, patients' perception of communication between all staff involved in their care with and without patient-held records was excellent in 24% and 21% respectively, or very good in 56% and 58% ($p=0.89$). The patient-held record made no difference to information passing between health professionals, or to the degree of family involvement. However most of those who had a record found it of some use and benefit.

Conclusion

This study provides no evidence on which to base the widespread promotion of patient-held records, although local projects with committed clinicians and patients may well prove popular and effective.

Introduction

There is a widespread perception amongst primary care teams that information from hospitals reaches them too slowly, and that the delays create difficulties for them in offering support and advice. This is a particular problem when the diagnosis involves malignant disease, where the patient's 'journey' can often involve several hospitals and a number of clinical teams. Recent evidence has emerged of the large number of doctors that patients encounter during the course of their cancer management, but the total number of health-care professionals that a patient has to deal with must be substantially greater¹.

In other contexts, the use of patient-held records is well established. In obstetrics², child health³ and chronic illness⁴, the patient-held record has been introduced to recognise the moves towards greater patient involvement in decision-making and to avoid duplication of record keeping. In cancer care, a number of small studies have suggested that the development of an acceptable patient-held record is welcomed by patients but is not without difficulty^{5,6,7,8}. Interest in the possible role of patient-held records in this area has been fuelled by the increasing use of GP co-operatives or deputising services for out-of-hours cover. This has raised anxieties in some quarters about the continuity of care and increased further the number of unfamiliar doctors that a patient may have to meet. There has therefore been interest in means of ensuring that clinically relevant and contemporary information is available to any health-care professional whenever they encounter a patient with palliative care needs. Proposals for the improvement of cancer services in the Calman/Hine Report in England and Wales⁹ and in the Scottish Cancer Co-ordinating and Advisory Committee in Scotland¹⁰ have included the recommendation of a primary-care centred model of care and seek to improve the involvement of patients in clinical decision making. The latter report saw patient-held records as a possible answer to some of

these concerns: "Further development of patient-held records, which could contain important details of the patient's management entered by all those involved in their care, should be encouraged".

However, the enthusiasm for patient-held records amongst health-care professionals has been tempered by the recognition that an inevitable increase in workload would occur. No currently available format of patient-held record could replace any of the currently maintained clinical records of GP, district nurse, hospital specialist(s), hospice in-patient or home-care teams. So maintaining a patient-held record, hand-written because it needs to be current, will be an additional burden. In addition, some (particularly doctors) may be uncomfortable with the degree of openness, patient participation and honest discussion of prognosis that will be entailed, and by no means every patient will welcome the greater degree of involvement and the bringing of clinical information into the home.

In the light of these uncertainties about the potential benefits and drawbacks of the widespread introduction of patient-held records in palliative care settings, the Scottish Partnership for Palliative Care and the National Council for Hospice and Specialist Palliative Care Services established a joint working party in June 1997. After reviewing many experiences with different designs and schemes to introduce patient-held records (including a one-day conference in Newcastle attended by 150 people), it was decided that the issue merited a prospective, randomised clinical trial with the aim of evaluating whether a patient-held record developed in Newcastle could be adopted and used in a different geographical area and with a different patient population. The extent to which the patient-held record improved communication and patient satisfaction, and the acceptability of the record to carers (lay and professional) were the end-points to be determined.

Methods

Ethical approval

Research Ethical Committee approval was obtained from the four local Research Ethics Committees initially involved (Lothian, Fife, Forth Valley, Greater Glasgow).

The 'Newcastle Record'

The record chosen for evaluation was developed in Newcastle¹¹ following a lengthy and detailed process of consultation. The record was designed as a loose-leaf, soft-covered booklet that would roll up to fit into pocket or handbag. It contained separate sections for personal details, 'what I have been told', personal diary, shared care notes, blood test results, useful telephone numbers and special treatments. Pockets at the front and back were designed for storing additional leaflets and relevant documents such as appointment cards.

In order to encourage a wide sense of ownership of the patient-held record, initial consultation in Newcastle involved: GPs; district nurses; community remedial therapists; hospital consultants and junior doctors; oncology, respiratory, breast and palliative care clinical nurse specialists; ward staff; out-patient staff; therapeutic radiographers and other hospital remedial therapists. Several drafts of the record were circulated for comment and modifications to a similarly broad spectrum of professionals, and to patient representative groups, Community Health Councils, Health Authority, local Trust Chief Executives and individual patients and their relatives in hospital and hospice settings.

The Working Party felt it inappropriate to replicate this enormous effort of consultative development, and were extremely grateful to the Newcastle team for permission to use their record in our study. A consequence of this decision, however, was that none of the professionals or patients to be involved in the trial had had any prior involvement with the record, and a significant obstacle to rapid acceptance was created if 'ownership' was to be a key factor in using the patient-held record.

Eligibility

Patients were eligible for entry to the study if they: had a diagnosis of cancer; were aged over 18 years; were

either attending an oncology out-patient clinic or receiving home or day-care services from a hospice or specialist palliative care service; had a prognosis of at least six months; were able to read English. The only exclusion criterion was a psychological condition or sensory impairment such that an interview would be either unwise or impossible.

Recruitment

Eligible patients were identified by a member of clinic or home-care staff and, subject to the approval of the doctor responsible for their care, given a trial information leaflet and consent form. Patients were then approached by one of the research assistants who arranged to conduct the baseline semi-structured interview at the patient's home.

Following the baseline interview, patients who agreed to participate were randomly allocated to the intervention group (who received the patient-held record) or the control group. Randomisation was performed in blocks and stratified by hospital or home-care. The patient's general practitioner was then notified of their participation and whether they had a record or not.

Patients allocated to receive a patient-held record were given a leaflet about it by the interviewer. Depending on local preference, patients allocated to receive a patient-held record were either given it by the interviewer or by the referring health professional at their next meeting. They were advised to take it with them whenever they attended hospital/hospice/GP surgery and to present it to any health professionals coming into their own home.

Follow-up

Follow-up information was collected in both the intervention and control groups approximately four to six months after the baseline interview, and full interviews were possible in all but two patients. There was no difference in mean interval between the control and intervention groups (132 versus 137 days). The interview was again conducted in the patient's own home or other location of their choice. In both the baseline and follow-up interviews, a mix of open and closed questions was included. The latter included

opinion questions with responses in the form of 5-point Likert scales ranging from very satisfied to very dissatisfied, or 4-point scales ranging from very well informed to not informed at all. Patients declining a second interview on two occasions were not contacted further. Repeated attempts were made to locate those lost to follow-up due to a change of address.

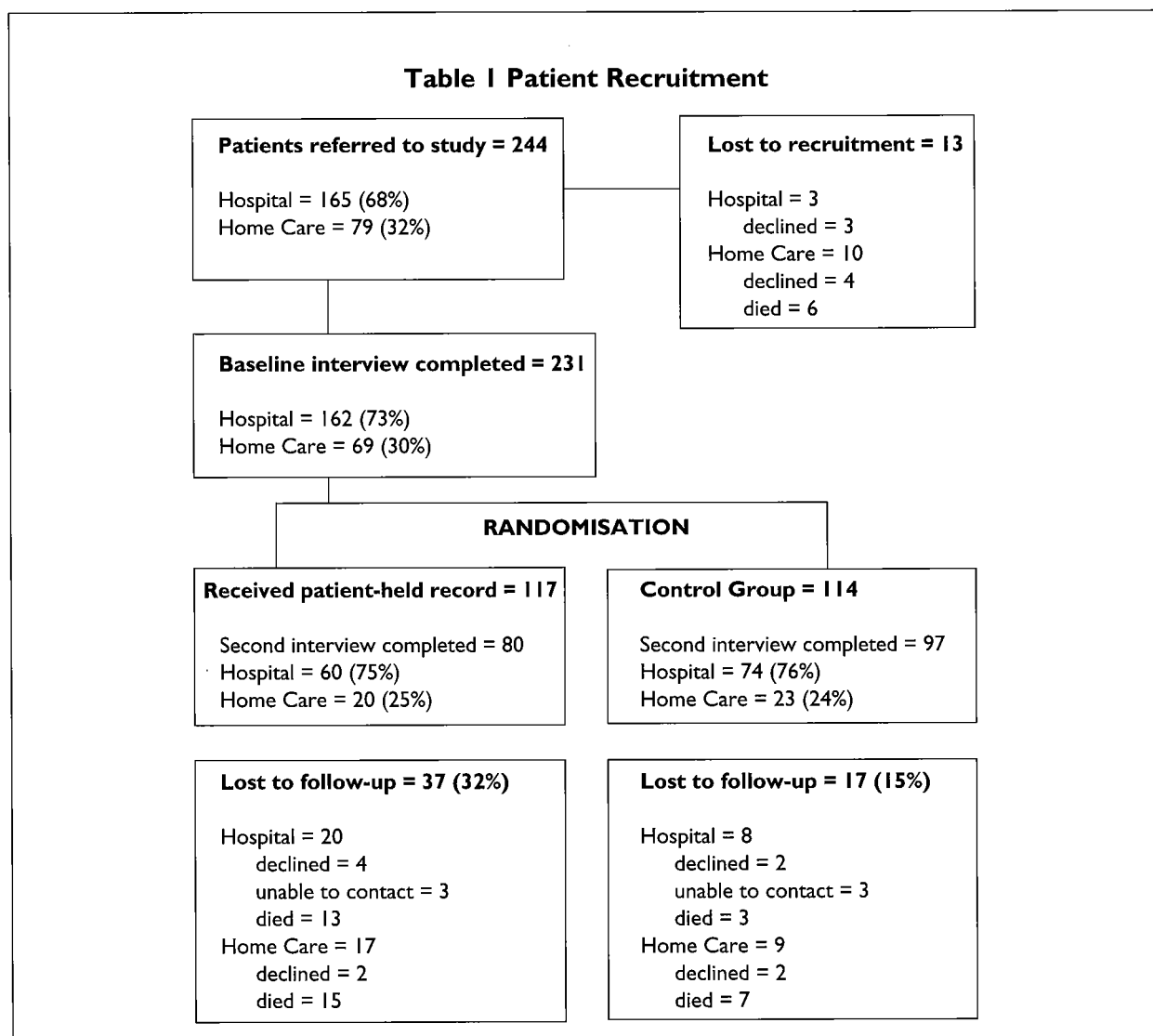
Survey of health professionals

A survey of health professionals dealing with patients who entered the study was initiated 14 months after the first patient was recruited. A randomly selected sample comprised hospital and hospice consultants; general practitioners; home-care, day-care and hospital nurses. They received a postal questionnaire addressing their experience of using the patient-held record.

Data analysis

All data were processed in Newcastle and coded by staff who were not involved in data collection or in

promoting the PHR in the study centres. An intention-to-treat analysis was performed so that patients were included in the group to which they were randomised, irrespective of whether or how the PHR was used. Interval data were analysed using independent 't' tests. Ordinal and nominal data were analysed using X² tests when more than four cells were available and Fisher's Exact Test when limited to four cells. Because of the skewness to the positive side of the continuum in most of the opinion scales, and the small numbers, in most cases data were collapsed into binary variables comparing the most positive response with all the others. The significance level was set at p<0.01 because of the large number of comparisons made, while those reaching p<0.05 are reported also. To detect meaningful and statistically significant differences between the groups at p<0.05 and 80% power, we required 146 patients in each group at follow-up, and for differences at p<0.01 our sample size should have been 212 in each group.



Results

Patient characteristics

244 patients agreed to participate when first approached, the majority from the hospital setting. 13 did not proceed to randomisation for the reason shown in Table 1, and 231 were randomised: 117 to receive a patient-held record and 114 to the control group. There was a greater rate of loss in the patient-held record group (32% versus 15%) with a higher proportion of these losses due to death. 177 patients were available for the follow-up interview 4-6 months later. The characteristics of the 177 patients recruited into the study and who completed a second interview are shown in Table 2. The randomisation process resulted in groups which were of near equal size and well-balanced in demographic characteristics.

Analysis of the baseline interviews showed that both groups had similar experiences of, and satisfaction levels with, their communication with professional carers and understanding of interprofessional communication at the outset of the study (Table 3).

Communication with primary care staff

Of those patients with a patient-held record, 56% had seen their GP within one month of their follow-up interview compared with 61% in the control group. Half the patients in each group had recently discussed their illness with their GP, and patients felt that their GP knew about the details of their illness and its treatment (88% versus 80%). No advantage to those with a patient-held record could be identified, although there remains scope for improvement (Table 4c).

Fewer patients were in contact with primary care based nurses, with about a third having had contact with either the practice nurse or district nurse between the two interviews. Although there was a proportion of patient encounters in which staff were perceived to be lacking in information, the overall satisfaction levels were again high and there were no differences between the intervention and control

Table 2 Patient Characteristics

| | Intervention (n=80) (%) | Control (n=97) (%) | p value |
|------------------------------------|-------------------------|--------------------|---------|
| Age | 58 (SD 12) | 60.3 (SD 14.1) | 0.12 |
| Gender | | | |
| male | 32 (40) | 47 (49) | }0.26 |
| female | 48 (60) | 50 (51) | |
| Lives alone | 11 (14) | 19 (20) | 0.29 |
| Place recruited | | | |
| hospital | 60 (75) | 74 (76) | }0.84 |
| at home | 20 (25) | 23 (24) | |
| Time since diagnosis | | | |
| <3 months | 20 (25) | 27 (28) | }0.82 |
| 4-6 months | 17 (21) | 18 (19) | |
| 7-12 months | 13 (16) | 12 (12) | |
| >12 months | 30 (38) | 40 (41) | |
| Disability | | | |
| unable to do light activities | 19 (24) | 24 (25) | }1.00 |
| able to do light activities | 61 (76) | 73 (75) | |
| unable to walk further than garden | 14 (18) | 17 (18) | |
| Current treatment | | | |
| surgery | 1 (1.3) | 4 (4.1) | - |
| radiotherapy | 118 (23) | 12 (12) | 0.07 |
| chemotherapy | 39 (49) | 41 (42) | 0.39 |
| other drug treatment | 27 (34) | 33 (34) | 0.97 |
| symptomatic treatment | 38 (48) | 37 (38) | 0.21 |

Table 3 Comparison of patient information at baseline interview

| | Intervention (n=80) (%) | Control (n=97) (%) | p value |
|---|----------------------------|-----------------------|---------|
| Self | | | |
| Kept informed about illness | 52/80 (65) | 55/96 (57) | 0.30 |
| Kept informed about treatment | 56/80 (70) | 66/95 (70) | 0.94 |
| General practitioner | | | |
| Discussed illness with GP | 54/79 (68) | 58/95 (61) | 0.31 |
| Kept informed about illness | 43/70 (61) | 45/84 (54) | 0.33 |
| Kept informed about treatment | 42/70 (60) | 42/79 (53) | 0.40 |
| Kept informed about problems | 42/62 (68) | 41/70 (59) | 0.28 |
| GP kept informed by hospital | 42/66 (64) | 45/73 (62) | 0.81 |
| Easy to ask GP questions | 76/78 (97) | 70/93 (75) | <0.01 |
| Satisfied with info from GP | 52/78 (67) | 59/96 (62) | 0.48 |
| Nursing Staff | | | |
| Satisfied with info from community nurse | 20/32 (62) | 27/35 (77) | 0.19 |
| Satisfied with info from specialist home-care nurse | 29/32 (91) | 22/26 (85) | 0.49 |
| Hospital Staff | | | |
| Satisfied with info from hospital staff | 33 (67) | 37 (65) | 0.79 |
| Communication could have been better | 17 (33) | 21 (36) | 0.70 |

groups and the same proportion of those who ventured an opinion felt that practice staff kept each other very well informed (56% versus 54%) (Table 4e).

Communication with hospital staff

There were no differences between the proportions that had had a stay in hospital since the baseline interview (30% of the control group versus 29% of the patient-held record group). With those doctors identified by patients as their 'main' doctor, the large majority considered they were given opportunities to ask questions and given as much information as they wanted. A variety of positive (and negative) comments were couched in terms of personal characteristics of doctors and whether they were regarded as honest; the manner in which information was given; ability to put patients at ease and take their perspective; willingness to provide time to ask questions and the detail of information provided.

Nursing staff played a large part in out-patient treatment and clinic sessions. Opinions of communication with nurses were very positive, with over 93 % in both groups rating very satisfied. All of the comments were positive, with friendly helpfulness and making time to talk rating particularly highly.

When asked specifically about their views of how well hospital staff kept each other informed, about 60% in both groups rated this as very good (Table 4b). There was again no detectable difference in terms of satisfaction with information giving or communication

between the groups who had or had not had the patient-held record.

Communication with hospice/home care services

A quarter of patients were recruited from amongst hospice home-care patients, and a third of patients in each group had received hospice home-care services by the time of the second interview. The sample size however is too small to draw any meaningful conclusions, as some patients had only had an initial assessment. While the intensity of contact with hospice home-care staff varied, patients were very positive indeed about communication and without exception felt that they had opportunities to ask questions and had been given as much information as they wanted. Clearly the patient-held record was not able to make any difference to patients' views of the quality of communication with home-care staff as assessed in this study, when it was already so acceptable.

The overall comparison between the satisfaction with information giving or communication between the groups who had or had not had the patient-held record is shown in Table 5. There were no significant differences in outcomes on the measures chosen between the groups. The findings are very similar to those observed at baseline and were relatively uniform between services and professions, with high to very high levels of satisfaction expressed.

Patients' views of the use of the patient-held record

Of the 80 patients randomised to receive the patient-held record, four declined to answer questions about it as they had not used it and two were too ill to sustain the interview although their record had been used. Of the 74 able to be interviewed, 64 (86%) said that someone had used the record. Reasons for not using the record included: a feeling that it was given too late in the current course of treatment, that it was too much of an imposition at a time when patients were already stressed, that they didn't want to have responsibility for it, and that since staff already kept their own notes there would be nothing in the patient-held record of value to them.

Of the 64 patients whose records had been used, 90% said they had used them themselves, of whom 10% had only read the record. It was used by the whole range of health professionals, and patients had taken their patient-held record to a range of different clinics (Table 6).

In the home, patients themselves were the most frequent users. 88% of the 64 patients reporting that the record had been used made use of it themselves.

Table 6 shows for each setting the type of professional staff or family who were offered it and how they used it. The denominators relate to those instances reported by patients and not to the sample who ever used the record. Patients perceived clinic doctors to be more inclined to write in the record than to read what others had written, but the act of writing is more readily observed or recalled. Patients described a range of staff responses to the record – ranging from 10 positive comments through seven neutral to four negative comments. Only 12 patients used their record while an in-patient, and it was more frequently nurses than doctors who were involved.

In chemotherapy and radiotherapy clinics, it was again more frequently nurses to whom the record was presented, and it was infrequently asked for by staff. The overwhelming impression emerging from patients' comments is one of wariness and uncertainty on the part of the clinical staff as to what was being asked of them. This may be an inevitable consequence of the introduction of a record developed elsewhere and in which there is no feeling of local awareness, and may have implications for the introduction of a record into more general use. 37 patients offered their record at their general practice, most often to a GP. Patients

Table 4 Comparison of satisfaction with communication at follow-up interview

| | Intervention (%) | Control (%) | p value |
|---|------------------|-------------|---------|
| a Communication with main out-patient doctor | | | |
| Very satisfied with information about treatment | 43/58 (74) | 45/61 (74) | 1.00 |
| Very satisfied with information provided | 60/78 (77) | 62/86 (72) | 0.59 |
| b Patient views of communication between hospital staff | | | |
| Informing each other very well about illness | 44/74 (60) | 47/70 (67) | 0.39 |
| Informing each other very well about treatment | 46/72 (64) | 43/65 (66) | 0.86 |
| Informing each other very well about problems | 45/73 (62) | 46/67 (69) | 0.48 |
| c Communication with primary care staff | | | |
| GP provides as much information as I want | 68/77 (88) | 78/89 (88) | 1.00 |
| Very satisfied with information from GP | 60/79 (76) | 59/94 (63) | 0.07 |
| d Patient views of communication between GP and hospital doctors | | | |
| GP kept very well informed about illness | 49/72 (68) | 53/76 (70) | 0.86 |
| GP kept very well informed about treatment | 48/68 (68) | 49/71 (69) | 1.00 |
| GP kept very well informed about problems | 49/69 (71) | 53/74 (71) | 1.00 |
| e Patient views about information available to community nurses | | | |
| Community nurses knew details of illness | 20/23 (87) | 27/29 (93) | 0.64 |
| Community nurses knew details of treatment | 18/22 (82) | 24/29 (83) | 0.89 |
| Very satisfied with information | 16/22 (73) | 24/29 (83) | 0.50 |

Table 5 Overall views of communication between all staff involved in their care

Satisfaction with communication between all staff involved in their care

| | n=80 (%) | n=96 (%) | p value |
|---------------------|----------|----------|---------|
| Excellent | 19 (24) | 20 (21) | }0.89 |
| Very good | 45 (56) | 56 (58) | |
| Less than very good | 16 (20) | 20 (21) | |

described staff response in this setting as positive in 10 comments received and neutral in five.

Only two patients used the record in their own homes involving five different types of health professional – four nurses and a GP. All recorded positive comments including the record replacing their own diary. There was a substantial use of the record by other family members, with 54 (84%) of those who used the record reporting that at least one other family member had used it also. Reactions ranged from indifference to taking charge of it and making all of the entries after the hospital visit. Where communication within the family was regarded as open and supportive, there was little feeling that the record contributed significantly, though some patients did report that they felt their family were more comfortable reading the record than discussing the illness with them.

All sections of the record were used, with varying degrees of enthusiasm and frequency (Table 7), although no section was completed universally. The least used sections were the 'Other information about me' (38%) and, surprisingly, the section for recording important telephone numbers (25%).

Health professionals' views of the patient-held record

A short self-completion questionnaire was distributed to 83 health care professionals in November/December 1999 to collect data about their views and use of the patient-held record. The survey included 28

hospital doctors, 25 hospital nurses, two palliative care doctors, 22 palliative care nurses, three GPs and three community nurses. 63 questionnaires were returned, one of which was completely blank, for an overall response rate of 75%. Since only three primary care staff returned questionnaires, they have been analysed with the palliative care staff and referred to as the 'community sample'.

45 (73%) of respondents were aware that patients under their care had been given the patient-held record, but only a third of respondents felt that all of their patients with a patient-held record offered it to them while 16% never did so. Only nine (35%) of hospital staff said that they had asked for the record whereas 13 (68%) had done so (p=0.03). A clear feeling emerges from the comments that it was regarded as up to the patient to take the initiative to produce the record and ask for it to be written in.

Three respondents said there were occasions when they decided not to make entries in the patient-held record. All related to issues of confidentiality and one mentioned information which 'could be harmful to the patient' without further elaboration.

The majority of respondents (90% of nurses and 70% of doctors) thought that the patient-held record had been of benefit, but this was largely because they thought it of benefit to the patient rather than to themselves (Table 8). More community respondents found it useful for themselves than did hospital staff (82% versus 41%), and more community respondents

Table 6 Occasions when patient-held record written in or read by health professionals

| Setting | Patient-held record offered or asked for (%) | Patient-held record written in or read (%) |
|--------------------------------|--|--|
| Hospital – out-patient clinics | 60/74 (81) | 50/60 (83) |
| Hospital – in-patient wards | 14/16 (87) | 12/14 (86) |
| Chemotherapy/radiotherapy | 50/60 (83) | 39/50 (78) |
| Hospice – day or out-patient | 16/18 (89) | 14/16 (87) |
| Hospice – in-patient | 1/1 (100) | 1/1 (100) |
| General practice | 42/58 (72) | 35/42 (83) |
| Patients homes | 5/5 (100) | 5/5 (100) |

Table 7 Analysis of frequency of entries in the patient-held record

| | Hospital Recruited Patients 57 records | | Hospice Home-Care Recruited Patients – 28 records | |
|--------------------------------|---|-----------------------------------|--|-----------------------------------|
| | Number of records (%) | Mean number of entries (Range) | Number of records (%) | Mean number of entries (Range) |
| Personal details | | | | |
| Name and contact details | 54 (95) | | 28 (100) | |
| GP/other staff details | 54 (95) | | 27 (96) | |
| Diagnosis | 49 (86) | | 23 (82) | |
| Main treatment | 55 (95) | 7 (1-36) | 24 (86) | 5 (1-24) |
| Other information about me | 21 (37) | | 11 (39) | |
| What I've been told | 39 (68) | 5 (1-18) | 19 (68) | 2 (1-10) |
| Personal diary | 40 (70) | 4 (1-23) | 14 (50) | 5 (1-32) |
| Shared care follow-up notes | 37 (65) | 4 (1-23) | 22 (79) | 9 (1-68) |
| Medication | 38 (67) | | 23 (82) | |
| Blood tests | 31 (54) | | 10 (36) | |
| Telephone numbers | 12 (21) | | 8 (29) | |
| Special treatments | 0 | | 1 (4) | |

thought it helpful to hospital colleagues than hospital respondents thought it useful to primary care colleagues (53% versus 40%). Interestingly, less than half of community respondents thought it likely to be helpful to primary care colleagues, and no comments were made by patients or professional staff of any use of the patient-held record in the out-of-hours setting. In general, the community sample regarded the patient-held record as useful for more purposes than did their hospital counterparts, with the majority of both groups feeling that it was useful in helping patients understand what was happening. 71% of the community sample but only half of the hospital sample gained information from the record about patient progress. There were specific and detailed comments about individual patients and clinical situations in which the record had clearly contributed to the information flow, but there were also respondents who thought the patient-held record of no or uncertain benefit and additional work. The

main difficulties reported were that because the record was incomplete, it could not be relied on as a source of up-to-date information, and there were problems finding time to complete it as it was a duplication of effort.

Respondents were asked finally whether they would be willing to implement a patient-held record for routine use for all patients with cancer, for patients with advanced cancer or for patients requiring palliative care. Of the 45 respondents who had experience with a patient-held record, those willing to answer the questions were more positive than negative, but half the doctors did not respond regarding those with advanced cancer, and there was a substantial minority of nurses who responded negatively or did not respond. The view was expressed that the patient-held record should be introduced earlier, preferably at the time of diagnosis and when the patient was generally fitter so that there would be a continuous record.

Discussion

There has been a widespread enthusiasm for the introduction of patient-held records, and a general assumption that they must be a 'good thing'. However, the main finding from this prospective, randomised trial was that no apparent impact of the patient-held record, for good or bad, 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. Whilst most of the patients who had experienced the record had positive (and sometimes euphoric) comments, a significant minority (14%) did not use it and 20% identified features they disliked, including the perceived additional responsibility and having to ask health professionals to complete it.

Although a large study, we were unable to recruit the intended number of patients to give the statistical power we had hoped (360), and there were several reasons for this. The intention to follow the use of the record for 4-6 months in a patient population with advanced cancer required an assumption to be made about prognosis that many of the referring clinicians (nurses and doctors) were clearly uncomfortable with. Assessment of prognosis even in the presence of clearly advanced disease is known to be unreliable¹², and many patients were not referred for inclusion in the study if there was any doubt about their likelihood of survival. Further, the record was not one that any of those asked to recruit patients had been involved in developing. This decision was taken early in the

deliberations of the study, as it was felt that so much effort had been put into the consultation process in Newcastle that it would be wasteful to duplicate that work, and in all probability produce a similar record after a substantial delay. Nonetheless, the lack of any local ownership resulted in uncertainty about the use of the record, despite considerable efforts to explain the project to all those likely to encounter it. Not all health professionals were aware that patients under their care had a PHR, and this must in part reflect patients' unwillingness to proffer the record to 'too busy' people looking after them. Unless adoption of such a record is close to universal the content cannot be relied on as being up to date, and further utilisation is effectively discouraged.

When it became clear that recruitment was slower than anticipated, we approached additional centres to participate. Unfortunately, moving from four to five areas covered by separate Research Ethics Committees necessitated a submission to the Multicentre Research Ethics Committee (MREC). Considerable delays were incurred in this process when the study design was challenged by the MREC after the design approved by the local committees was already implemented, and it proved impossible to recruit from additional areas in the time available. Difficulties with the operation of the MREC system have been reported elsewhere^{13,14}.

When problems with 'communication' are discussed amongst health-care professionals, almost inevitably the suggestion will arise that an up-to-date, portable

Table 8 Is the patient-held record of benefit?

| Do you think there has been any benefit in using the patient-held record for... | Hospital (n=22) (%) | | | | Community (n=17) (%) | | | |
|---|---------------------|--------|------------|-------|----------------------|----|------------|--------|
| | Yes | No | Don't know | N/A | Yes | No | Don't know | N/A |
| Your patients | 18 (82) | - | 3 (14) | 1 (5) | 15 (88) | - | 1 (6) | 1 (6) |
| Yourself | 9 (41) | 8 (36) | 3 (14) | 2 (9) | 14 (82) | - | 1 (6) | 2 (12) |
| Hospital colleagues | 6 (26) | 1 (5) | 14 (64) | 1 (5) | 9 (53) | - | 5 (29) | 3 (18) |
| Primary care colleagues | 9 (40) | 1 (5) | 11 (50) | 1 (5) | 7 (42) | - | 5 (29) | 5 (29) |
| Palliative care colleagues | 5 (23) | 1 (5) | 14 (63) | 2 (9) | 7 (41) | - | 3 (18) | 7 (41) |

N/A = not answered

record available to, and used by, all of the large number of professionals involved would solve the problem. The discussion then moves rapidly on to an electronic solution utilising the latest in information technology. What are often overlooked in these debates are the two quite separate and perhaps irreconcilable functions of a patient-held record. From the patient's perspective, the record is mainly a way of getting their wishes and feelings into the debate about their management, and so a diary function creates a usually welcome sense of empowerment (those who don't welcome this involvement will simply opt not to use it). From the professional perspective, however, the information requirement is quite distinct and primarily technical (eg results of investigations, recent blood counts, treatment plans). While the patient's writings in a patient-held record will be read and taken account of, this is not seen as an essential part of the consultation. The design of the Newcastle Record included sections addressing both of these functions, but may have fallen between stools, in that neither patient nor health-care professional seems to have been clear about the intended function of the record.

The outcome measures chosen were subjective views of patients concerning aspects of communication between themselves and health professionals and of communication between health professionals caring for them. The baseline data showed that communication was already perceived as good, with nearly 70% of patients very satisfied. However, a third felt improvements could be made, but not necessarily by a patient-held record. This skew to the positive necessitated a collapse of the scales to make binary variables, weakening the power of the study. The high

level of satisfaction at the outset also limited the scope for improvements achievable by the PHR.

In a climate of evidence-based medicine, we undertook to seek the evidence that would justify introduction of patient-held records. We cannot conclude that the widespread introduction of a patient-held record of this type should be recommended, and the results of this study are similar to the findings of the Newcastle study¹¹. It is, however, clear that local projects with a high degree of professional commitment and a clear view of the function to be fulfilled by the record can be very popular and effective with motivated patients. These are most likely to be successful if introduced early in the patient's illness by clearly committed health professionals, so that the record is incorporated into the clinical culture and all parties expect to use it on a regular basis. The problem of duplication of effort remains, however, and is still likely to hinder widespread adoption.

The final word should go to the wife of a patient who died, written in the Personal Diary section of his record. He began completing the diary himself, recording advancing disease and a range of symptoms. He also wrote in the shared care section himself when he visited hospital or had home visits. There was a single entry by a health professional, a specialist home care sister. His wife wrote before she returned the record: "My husband thought this Personal Record was a very good idea and very helpful to a patient. However, to work properly it needs the full co-operation of doctors, nurses and other professionals who do not always have the time or indeed the inclination to write things down. I hope what is contained in these pages will be helpful to your study".

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Scottish Partnership for Palliative Care

The Scottish Partnership for Palliative Care works to ensure that people in Scotland who have a progressive life-threatening condition, such as cancer, motor neurone disease or advanced heart failure, receive good palliative care.

The Partnership brings NHS bodies and voluntary and professional organisations together to promote better understanding of palliative care, to make it available to all those who need it and to improve standards of care everywhere for patients and families. It contributes to national thinking and policy in relation to palliative care, and promotes improvements in service delivery at local level. Following its tenth anniversary conference on Responding to Need not Diagnosis the Scottish Partnership for Palliative Care is taking the lead in Scotland in promoting access to palliative care for all.

Find out more at www.palliativecarescotland.org.uk

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Scottish
Partnership
for Palliative Care

1a Cambridge Street

Edinburgh EH1 2DY

Tel 0131 229 0538

Fax 0131 228 2967

office@palliativecarescotland.org.uk

www.palliativecarescotland.org.uk