

Your Heart Matters

An evaluation
of the
British Heart Foundation Patient Held Diary

August 2005

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Acknowledgements

This evaluation relied on the cooperation of the many people that took part in the research process. I would like to thank:

Kathryn Carver, Diane Card, and Sue Bryant for their advice and support as the lead cardiac nurses who originally designed the diary and organised the distribution of the diary to patients, along with Stephanie Lillie, Sadie Brookes, Wendy Joyce and Fiona Lough and other health professionals who gave their time to look at the diary and suggest improvements or gave their support to the diary;

All the cardiac patients at Addenbrookes, Hinchingsbrooke and Peterborough Hospitals who so generously gave their time to answer my questions and take part in discussions;

Those members of the British Heart Foundation Steering Group who provided advice and views on the diary, particularly Julia England, the project education officer at BHF;

Colleagues Dr Adrian Nelson, and Kathryn Nemec who originally designed the research study, Emma Wilkinson and Rose Uché for help with the patient survey and Dr Dione Hills for supervision and support in the drafting of the final report.

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15 August 05

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| <p>Final Report</p> <p>An Evaluation of the BHF Patient Held Diary</p> |
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Executive Summary

An evaluation of the British Heart Foundation Patient Held Diary “Your Heart Matters”

1 The diary

The Patient Held Diary (PHD) is a document containing both educational materials about coronary heart disease, signposting to where further information can be found and pages which can be filled in and completed by the user for their own purposes. These pages provide space where users can record their health readings such as blood pressure, cholesterol and weight; their progress in tackling their risk factors such as smoking, exercise etc; areas to keep track of medication and symptoms and pages to write down local and personal details.

The British Heart Foundation (BHF) identified the following objectives for the diary:

- A tool to help patients increase their knowledge about and self management of, their condition and increase their involvement in their care and treatment
- A means of increasing patients' awareness of local and national support services, including those provided by the BHF
- A way for health professionals to engage with their patients and meet "National Service Framework targets for patient involvement

The BHF had been investigating the improvement of disseminating patient information. A patient information pack was being considered in order to promote heart health education and promotion, and to increase awareness of facilities and services in the community. This pack would hold BHF publications, national and local information and individual patient health information and details. The work of the rehabilitation programme at Addenbrookes Hospital, Cambridgeshire which was developing a patient information record was brought to their attention and it was decided that the BHF would pilot a patient held record in association with Addenbrookes and the other hospitals in Cambridgeshire. A steering group, which represented a wide range of health professions and patient groups in East Anglia, was formed and the diary developed further for the pilot.

The views of patients and health professionals about their use of the diary would suggest that this diary is a useful resource for patients on discharge from hospital. In some cases it will aid communication between the patient and their health professionals. Its continuation is recommended with the suggestion that those agencies using the diary take time to raise awareness of its potential to

those health professionals in contact with their patients, particular given the desire of patients to have health professionals take an interest and support them. The diary also needs to be made simpler to reach a wider range of patients.

2. The evaluation

Researchers from The Tavistock Institute were commissioned to undertake an evaluation of the diary in two stages. The aim of the evaluation was to assess how patients, family and health professionals valued the usefulness of the diary and its impact in relation to the BHF objectives above.

Stage one of the research study evaluated the design of the diary. The second stage evaluated the use of the diary. The evaluation's sources of data came from several sources: semi structured interviews over the telephone and focus group discussion with patients; a survey of all recruited patients; telephone and face to face interviews with health professionals and desk based research on patient diaries or records.

For stage one on the design of the diary, all new patients admitted to Addenbrookes, Peterborough and Hinchingsbrooke Hospitals with myocardial infarction were approached to take part in the research study over a six month period in 2004. Diaries were distributed to 60 volunteer patients during this stage. Patients were invited to take home the diary for use at home and to participate in discussion groups and telephone interviews to give their views and comments on the design of the diary.

Stage one of the evaluation was completed in October 2004. A report with suggested amendments to the diary was presented to a BHF steering group and the design of the diary amended in light of comments received by patients and health professionals. Stage two of the evaluation, ran from January to July 05 and involved the recruitment of 88 patients from the three hospitals. This stage of the evaluation was an assessment of the use made by patients of the revised diary, its impact on their knowledge and relationships with health professionals and the value place on the diary by both health professionals and users. Focus groups, telephone interviews and surveys were used to obtain the views of patients and health professionals.

The evaluation's scoping review of literature on good practice in health promotion information, recent health policy in relation to CHD and the information needs of patients and their families found that the diary incorporated many elements of good practice and the findings of the evaluation echoed past research on the needs of patients in relation to patient held records.

3. Use of the diary by patients

The majority of patients had made some use of the diary. (85% of respondents from the second stage survey made use of the diary). Our first stage survey that had respondents in possession of the diary between 5 and 11 months found that although 31% of patients had stopped using the diary within the first four months, 25% were still using it from time to time at eight months.

Non use of the diary (15% of respondents from the second stage survey) was around not needing to manage their condition by writing and recording. The patients often felt well and were ready to get back to work. A few did not want to use the diary because it was a reminder of their illness.

About 27 (40%) of those interviewed in stage one and two felt that they made small use of the diary. Our two largest groups were those who felt well and those were in poor health. Patients' conditions can improve quickly and so from a health viewpoint, they may have difficulty realising the importance of continuing to manage their own care. Similarly, those in poor health may recover and have a different attitude to the diary at a later stage. It was therefore suggested that the diary should be made available in an alternative place such as phase 2 rehabilitation after discharge from hospital.

Of those patients who feel they are not making a lot of use of the diary, patients of seventy year plus are more likely to feel in poor health, not very good with paperwork and the "younger set" of fifty and sixty year olds are more likely to be feeling well and fully recovered so feel they have nothing to record, or do not want to dwell on their illness.

It should be accepted that there comes a time when there is less need to record once a routine has been established and that patients can self care without resorting to a written record.

A significant number of patients coming into the hospital refused the diary (40%). Being too busy and having too much to do was a frequently cited reason for not taking the diary (14%) followed by health reasons (11%). These two reasons are subject to change, and it may be that some patients will change their mind about using the diary later. Some method to give patients another opportunity to have the diary when less traumatised or beginning to recover would benefit these patients. Phase 2 rehabilitation sessions would be an alternative opportunity. Most patients felt that the hospital was the best place to receive the diary despite its problems of distractions and for some patients the difficulty of taking in all the information at that particular traumatic period in time. Their view was that they were more motivated at this stage and had the expertise of nurses to call upon. A high proportion of patients had misgivings about whether being given the diary in doctor's surgeries would be timely enough and many patients felt that unless

there was a specialist nurse at the practice, they would not get sufficient expertise at a surgery compared to the rehabilitation nurses.

Most frequent responses in the stage two survey about what patients were using the diary for were:

- A record of health and activities (65%)
- To record information and progress (59%)
- To discuss something with a GP or nurse (56%)

The majority of patients used the diary in a mixture of these categories, mainly around a record of health, but some preferred a more personal, reflexive record. Some patients felt that because they could see how much they had progressed through the diary record, this gave them confidence and made them hopeful. The diary could provide a more precise way of talking to the nurses about symptoms and feelings.

It is important to note that in one case the partner was the main user of the diary because the patient had a poor memory after his heart attack and that in interviews; other family members were reported as supporting patients to use the diary. It is recommended that this option of a family member being the diary holder is suggested to the patient if appropriate.

The general impression in the mixture of accounts about their presentations of the diary was that if requested there was no problem in getting nurses and doctors to provide blood pressure readings for their diary. Some patients mentioned how their doctors were very positive about the diary. The diary would appear to make the request easier for some patients because there is an official looking piece of paper to put the readings in and in some cases, the need to "fill in the diary", reminds the patients to ask for the blood pressure readings. As well as encouraging patients to ask for their readings, it could encourage health professionals to give the patients responsibility for this.

There was often disappointment expressed by patients if their health professional did not take an interest. In the survey 85% of those using the diary felt that interest by health professionals would motivate them to make more use of the diary. There was some indication in the review of research on patient records that the support of health professionals outside the rehabilitation team was an issue to be tackled.

The responses of rehabilitation nurses and Phase IV instructors were very positive. Stage one had concentrated on the content and improvements and stage two on whether professionals felt it would benefit patients and if they would use it with their patients. All felt the diary was a good idea and could be used by them with patients, although they felt that the diary should be handed out at an earlier stage in hospital rather than in rehabilitation and exercise classes in the community. Only one GP replied to our sending out of the diary with a request for

a telephone interview and he was very complimentary about its layout and design. Although he accepted the reservations that patients had about the ability of GPs to deal with the diary in surgery, he felt that it was something he would use with patients.

Sixty two percent of patients in the stage two survey felt the diary should be rolled out nationally to benefit other patients. Ten per cent did not feel this should happen, or did not know and 17% did not respond to this question.

4 The diary as a learning resource

The diary incorporates many of the good practices identified in “Health Literacy” and the CHD collaborative publication on patient records. Health professionals at stage two of the study have been complimentary about its content and design. Although there have been mixed responses from patients about the way they want to interact with the diary, there has been little negative comment about the content and it is more around tweaking for improvements rather than major change in terms of the content.

The diary has been designed to signpost patients to information rather than being a new source of information. Fifty nine percent of the 34 patients who had used the diary and responded in the survey said they used the diary to look for information and comments from five patients around why the diary should be introduced nationally were around their view that the diary improves awareness, knowledge and was a source of information for patients.

Our patients in stage two of the evaluation felt they had been given sufficient information in hospital and what they needed was to find out how the information applied to their individual circumstances. 56% of them were using the diary in their discussions with health professionals, mainly rehabilitation nurses. Over 30% of patients rated the diary as fairly useful with another 35% rating it as very useful. (No response was 26%. Not useful 7%)

5. The impact of the diary on interactions with health professionals and health behaviour

The diary on its own is not going to change behaviour, but it may provide a mechanism to remind patients to keep their own record of health, and its “sanctioned” presence may help the communication between patient and health professionals. It will help health professionals in the community have quicker access to the basic medical details they require from patients. It may remind them to give patients their figures on blood pressure and glucose readings.

Patients, like the health professionals find it useful to have information in one place. Those who are tackling particular risk factors find it useful to chart their progress and find that seeing the record or history of that progress gives them

confidence and hope at times when they are feeling low. Some patients find the keeping of a diary at a time of emotional upheaval a helpful experience that can be used in their conversations with health professionals.

There was little evidence from patients that the risk factor section made much difference to their attitudes towards risk factors and that it changed behaviour patterns. No patient in focus groups or interviews suggested that the diary motivated them to change their lifestyle. Those that had decided to make a change, found the diary useful as a place to keep track and particularly as a record of their progress, which in itself gave them confidence and hope. It also gave some preciseness to discussions with health professionals about symptoms and emotions. Two patients in the stage two survey when asked what the main use of the diary was for them had written that it helped them focus on what they had to do to make changes. However, those patients who felt well, or did not feel they had risk factors to tackle, felt they had no reason to use that section of the diary. Most patients felt they were aware of the risk factors of a heart attack through the leaflets and discussions but felt the diary was a good general source of information.

6 Recommendations on the design, delivery and management of the diary

The findings of the design stage of the evaluation did appear to remedy many of the problems being experienced by patients but some of the elements were not full incorporated and reoccurred at stage two. The areas below could do with some more work but do not stop the diary from being currently used and valued by patients:

- Overall floppiness of the diary so that it can be folded up and pages stay open
- Title of being overweight is changed to something along the lines of watching your weight and diet
- Improved signposting to tackling diet
- Improved signposting to tackling stress
- Change of sub title to include "Personal" and "progress record" on the front cover is suggested
- A pictures on the symptoms page is considered as recommended at stage one to remind patients about recording symptoms.
- The risk factor tab title is not a term that works well with patients. The pages should be divided up in terms of Giving up smoking, keeping your heart fit, watching your diet and weight etc.

Before any roll out of the diary, those using the diary will need to consider the management of the diary and include plans for:

- Updating the diary and providing additional pages
- Electronic version on the BHF web site

- Consideration of a paper version compared to the current more robust version.
- How the diary complements / competes with other systems likely to be used by the patients
- Raising awareness and marketing the diary to health professionals in the area where the diary is to be used.

Discussions with patients before giving them the diary should indicate whether they are likely to make use of the diary. The way the diary is delivered to patients will influence them to take control of the diary. They should be encouraged to take out what is not needed, particularly if they feel the dividers make it more complicated, perceived messages about life style blaming or lack of risk should be explored in order to make patients more comfortable with the diary.

Patients did not want to be filling in paperwork, and often there was a decision to be made between the diary and other systems such as other rehabilitation exercise sheets, and other drug recording sheets. For this reason, it is recommended that any area taking on the diary should consider how the diary compliments and competes with other systems and raise the awareness of health professionals in contact with the patients about where the diary can be used with the patient and to avoid duplication of recording health readings and exercise where possible.

An electronic version is an option that should be considered by the BHF and hospitals using the diary. This would help disseminate the work done on the diary to other health colleagues, who may be in the process of producing diaries and notification about updates. Those patients who are computer literate may prefer to have an electronic version available.

To help overcome the perceptions of some patients that the diary is bulky and so complicated, the diary should be simplified further and if time permits, nurses may want to start with a basic minimum of sheets (section one, section three, appendix 1 and 2 and some blank progress sheets) The patient can then be asked if they want to take particular pages from section two on smoking, exercise, symptoms, blood pressure and weight or just record on the blank sheets.

Further information on this report can be obtained from

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1 Introduction and Background to the BHF Patient held diary

1.1 The diary

The Patient Held Diary (PHD) is a document containing both educational materials about coronary heart disease, signposting to where further information can be found and pages which can be filled in and completed by the user for their own purposes. These pages provide space where users can record their health readings such as blood pressure, cholesterol, and weight; their progress in tackling their risk factors such as smoking, weight, lack of exercise etc; areas to keep track of medication and symptoms and pages to write down local and personal details.

The British Heart Foundation (BHF) identified the following objectives for the diary:

- A tool to help patients increase their knowledge about and self management of, their condition and increase their involvement in their care and treatment
- A means of increasing patients' awareness of local and national support services, including those provided by the BHF
- A way for health professionals to engage with their patients and meet "National Service Framework targets for patient involvement"

Background to the diary

The British Heart Foundation had been investigating the improvement of disseminating patient information. The development of a patient information pack was discussed in order to promote heart health education and promotion, and to increase awareness of facilities and services in the community. This pack would hold BHF publications, national and local information and individual patient health information and details.

Initially a heart support group developed a pack with the help of a regional office. However, this pack was not considered to portray the professional image of the BHF and it was thought that the pack could be improved. The work of the rehabilitation programme at Addenbrookes Hospital, Cambridgeshire which was developing a patient information record was brought to the attention of the BHF Education department.

Following a meeting between the BHF and Addenbrookes Hospital, it was decided that the BHF would pilot a patient held record in association with Addenbrookes and the other Hospitals in Cambridgeshire. A steering group, which represented a wide range of health professions and patient groups in East Anglia, was formed. The diary was then further developed by the steering group for the pilot.

1.2 The Evaluation

Researchers from The Tavistock Institute were commissioned to undertake an evaluation of the diary in two stages. The aim of the evaluation was to assess how patients, family and health professionals valued the usefulness of the diary and its impact in relation to the BHF objectives above.

Stage one of the research study evaluated the design of the diary. The second stage evaluated the use of the diary. The evaluation's sources of data came from several sources: semi structured interviews over the telephone and focus group discussion with patients; a survey of all recruited

patients; telephone and face to face interviews with health professionals and desk based research on patient diaries. The methodology of the research, the recruiting of patients and the protocols of the research process are laid out in detail in appendix 1.

For stage one on the design of the diary, all new patients admitted to Addenbrookes, Peterborough and Hinchingsbrooke Hospitals with myocardial infarction were approached to take part in the research study over a six month period in 2004. Diaries were distributed to 60 volunteer patients during this stage. Patients were invited to take home the diary for use at home and to participate in discussion groups and telephone interviews to give their views and comments on the design of the diary.

Stage one of the evaluation was completed in October 2004. A report with suggested amendments to the diary was presented to a BHF steering group and the design of the diary amended in light of comments received by patients and health professionals. The summary and recommendations of that report can be found in Appendix 2.

Stage two, the final stage of the research study involved the recruitment of 88 patients from the three hospitals. This stage of the evaluation was an assessment of the use made by patients of the revised diary, its impact on their knowledge and relationships with health professionals and the value placed on the diary by both health professionals and users. Focus groups, telephone interviews and surveys were used to obtain the views of patients and health professionals involved in the study. The survey instrument for stage two of the evaluation can be found in Appendix 3 along with results of that survey.

The evaluation also included a scoping review of current literature on debates about best practice in health promotion information, recent health policy in relation to heart conditions and the information needs that people with heart conditions, and their families, have to express in past research on patient records and diaries.

1.3 The structure of this report

Section one of this report includes the present introduction and an account of the policy background to the diary in order to give some indication of where the diary sits within recent NHS initiatives and policies. It provides a brief indication of what research has already been carried out on diary related issues such as information provision for patients, and research on the use of diaries by NHS patients. A more detailed list of research studies can be found at appendix 4.

Section two provides the details of the evaluation of the BHF patient held diary and its findings. In order to focus on findings rather than the research process itself, the details of the research methodology and research issues are presented in Appendix 1. The main findings from the first stage of the evaluation which shaped the design of the diary are reported within the body of section two, but the detail is available in appendix 2. The survey from stage 2 is provided at appendix 3 with the numbers of patient responses.

Section three brings together the implications of these findings and recommendations of the report.

1.4 Background to the diary – the policy context

The diary started life within a hospital as one of many initiatives at a local level to support patients as part of the prevention of Chronic heart disease (CHD). CHD is considered the single biggest killer of men and women resulting in more than 110,000 deaths in England every year¹. The white

¹ The national Service Framework for Coronary Heart Disease: Winning the War on Heart Disease. Progress Report 2004. DoH 2004

paper *Saving lives: our healthier nation*² set a target of reducing the death rate from heart disease, stroke and related conditions by 40% in those aged less than 75 years by the year 2010. The National Services Framework for CHD (NSFCHD) published in 2000 was a framework to reduce incidence of CHD by setting out standards and cutting out variations in services¹ and the Department of Health's Priorities and Planning Framework: Improvement, expansion and Reform 2003-2006 confirmed CHD as a national priority.

Although the impact on CHD of social, ethnic and geographical inequalities is acknowledged, publicity and information for the public and the patient is mainly focused on promoting changes to diet, exercise, and smoking. The shorthand term used in this report for this is lifestyle changes. The education of the public and the individual, particularly those at risk of CHD or with CHD to understand risk factors and causes of CHD and make lifestyle changes around diet, exercise and smoking is seen as a major method of prevention of CHD.³ The diary is part of this education of patients.

The public and those patients who are diagnosed with CHD do not necessarily see the issue in the same terms as health professionals. People continue to smoke and not exercise despite the general publicity. There are numerous research studies⁴ around the attitudes of patients with chronic illness, or CHD and their compliance in taking up lifestyle changes. Any decisions about the content of the patient held diary will have to deal with the different views between patients and their health professionals about what is considered useful and needed in the diary.

The report "Supporting People with Long Term Conditions"⁵ stated that those that require more support with self management and self-care make up 70-80% of population with long term conditions. With better treatment, and growing survival rates from Myocardial Infarction, there are more patients who will need to monitor their illness and be supported to do this. The diary could be seen as a tool that signposts patients to support or that could be used by health professionals to support their patients undertaking life style changes or monitoring their health after a heart attack.

Those that designed the diary also felt that it was a tool that could help health professionals achieve National Service Framework targets. Standards of care for health professionals set out support mechanisms for patients with CHD. Standard 3 and 4 of the NSF for CHD⁶ that states "GPs and primary care teams should identify all people with established cardiovascular disease and offer them comprehensive advice and appropriate treatment to reduce their risks."

The diary was also seen as a tool to aid the transition of the patients' baseline health data from primary to secondary care. Although the diary is handed out while in hospital, it will need the cooperation of other health professionals, particular GP practices to support patients to keep it up to date. A recent mechanism that has been introduced that aim to encourage health professionals to support patients with CHD. The new general medical services contract that came into effect in 2004, rewards the practice team for the quality of their management of chronic disease, especially at level one and two of the Chronic Disease Management Strategy. Financial

² Saving Lives: Our Healthier Nation. DoH 1999

³ NHS Direct online Encyclopaedia/www.nhsdirect.nhs.uk access May 05 prevention of Heart Attack web page,

National Service Framework CHD Chapter One, Effective Interventions and Policies. DoH 2000, 'Coronary Heart Disease - guidance for implementing the preventative aspects of the National Service Framework', Health Development Agency. Nov 2000

⁴ including Becker M 1974, Bury 1991, Frank A 1995, Beishon S & Nazroo J 1997, Tod A et al 2001

⁵ Supporting People with Long Term Conditions. DoH Feb 2005

⁶ The National Service Framework for Chronic Heart Disease. DoH 2000

incentives are awarded for the establishment of good processes to review and monitor patients with a range of illnesses such as diabetes and heart disease.”⁵

As well as support by health professionals, the patient as consumer and as being involved in their health has become a more prominent theme in the NHS. The BHF diary has been designed to be patient held, principally for use by the patients to help them manage their condition. Self-management programmes were originally from the United States and subsequently piloted in the UK, principally by voluntary sector organisations. Research⁷ on these 'user-led' model of self-management were felt to show that they can enhance the relationship between patients and their healthcare professionals and lead to improved clinical outcomes and patients' self-confidence. The Expert Patient Programme, set out in *Saving lives: Our Healthier Nation*² was launched in 2001⁸. It aims to motivate and raise confidence in patients, looking at how the condition impacts on daily life and ways in which patients can cope and control their condition on a day to day basis.

A speech by the Minister of Public Health on the expert patient programme at a conference of self management of chronic conditions in April 2004 put the self-management movement within a number of converging and complementary trends in health care including the increasing prominence of chronic illness, the importance of primary care, and the need to ensure that patients and the public are given as much choice and control as possible over decisions affecting their health and their lives.

There were three areas for further work outlined in the HealthCare commission report on the findings from the CHD survey of patients 2004⁹ to make improvements to implement NSF recommendations that relate to the role of the diary:

- Advice patients received when they were discharged
- Rehabilitation
- Links between GPs and hospitals

The diary acts as a signpost to information and where further support can be obtained and it was hoped that it would improve the transition from primary to secondary care with patients having their baseline health readings from hospital.

The following section outlines areas of good practice on providing information to patients

1.5 Information provision for patients

Guidance on the provision of good quality health information

Guidelines for those providing information for patients have been identified in *Health Literacy*¹⁰, a National Consumer Council publication. The first three points have been raised in the course of interviews with patients in this study and have implications for the delivery of the diary. The patients state of mind and priorities when information is given out needs to be considered because patients may be in shock, distracted, have more pressing concerns at the time and so the handing over of information may be ineffective at that moment in time and an alternative place or time for giving information may work better. The patient will be interested in those risk factors that are pertinent to their own situation.

⁷ Barlow JH *et al.* *Self-management literature review*. Psychosocial Research Centre, Coventry University, July 2000.

⁸ *The Expert Patient – A new Approach to Chronic Disease Management for the 21st Century*. DoH. Sept 2001

⁹ *Chronic Heart Disease Survey of Patients 2004* Healthcare commission published June 05

¹⁰ Sihota S, Lennard L. *Health Literacy*. National Consumer Council. June 2004

Health Literacy. Key points from the publication relevant to the diary

- Patients desire for and ability to use information varies during an illness or disease process.
- Numerous findings highlight the importance of individualising information as far as possible to help patients understand their own risk factors and take personal action.
- During the early stages of a disease process people have difficulty in assimilating health information.

Ideal sources of information have been identified in this publication¹⁰ as being:

- Accurate, up to date, reliable and practically useful
- accessible in language, format and tone;
- capable of customisation or personalisation;
- informative about conditions as well as treatments;
- available at the time of a consultation and consistent with best advice;
- linked to other reliable and consistent sources of information

Diabetes UK has general principles on its web site¹¹ that it suggests should be applied in the design of patient-held records, based on examples of existing records and advice from the Sheffield Diabetes Person Held Record Group. This document was last updated in Jan 03. It is however a medical based model of a record and some suggestions have been omitted as the interviews with heart patients have shown that too detailed and too complicated are barriers to uptake of the heart diary.

Suggestions for Patient held records from Diabetes UK

- Most records are approximately A5 size.
- They usually have several pages with a loose-leaf fastener so that pages can be added or removed in the future.
- The checklists for regular and annual reviews are often presented as a table, with the date down the side and items to check along the top (or vice versa).
- Given the wear-and-tear that a well-used record gets, a plastic or laminated cover is ideal, and such a cover should include a slot for loose-leaf temporary additions such as letters or blood test forms.
- Patient-held records should follow the Royal National Institute of the Blind (RNIB) guidelines for the visually impaired in regard to the font, spacing of text and contrast used.

Suggested materials that the web site¹¹ suggested could be included in the record were:

- Patient's contact details such as name, address, phone numbers, date of birth, NHS number, emergency contact name and phone number.
- Contact number of GP (including out of hours number), hospital consultant.
- Relevant aspects of patient's medical history.
- Explanatory notes. A short section or insert box explaining to the patient why this record is important and how to use it.
- Details of medication including name, dose and frequency of tablets, allergies.

¹¹ Diabetes UK web site at http://www.diabetes.org.uk/good_practice/patient/criteria.htm
accessed June 05

- Instruction for emergencies
- Education checklist. (Areas for the patient and health professional to cover in education sessions).
- Personal treatment plan. A plan agreed between patient and health professional giving targets, advised frequency of regular check-ups, etc.
- Space for patient's own notes.
- Glossary of medical terms.

Most of these are already included in the BHF diary.

The department of Health also has a toolkit for the production of patient information. The department of Health toolkit recommends an unstructured format, whereas the BHF diary has a strong structure because it has to combine records and information provision in a fuller way than most patient records

Key points from the Department of Health's toolkit for producing patient information¹²

- Use everyday language
- Patient friendly text
- Avoid instruction, explain why
- Be up to date
- Let people know of information available in other formats
- How the process of delivering information will be coordinated in the organisation
- Whether the information should be delivered in stages or as a series

Further relevant points on content, education, selection of patients and delivery of the diary are raised from a Report of a Conference held in October 1998 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 which are available on the latter's web site.

Point raised at the conference Oct 98 organised by the Joint Working Party¹⁴

- 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.
- 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.
- 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.

¹² Toolkit for Producing Patient Information Version 2. Department of Health 2003

¹³ <http://www.palliativecarescotland.org.uk/publications/phr.htm>

¹⁴ Point raised at the conference Oct 98 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

- The medication section is useful for communication between professionals and for patients.

- Education about Patient Held Records should be aimed at more senior professionals so that they can pass on their knowledge to the more transient staff at more junior levels.

- 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.
- It may be best to allow patients to select themselves. PHRs should not be issued to patients but offered to them and they should feel able to opt in or out at any stage.
- Patient Held Records 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.
- It will take time for GPs to get used to using these 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.
- 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 motivates them to use it.
- Patients need to be encouraged to write in the records—they are a new concept.
- 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.

Issues are raised by patients later in chapter two about the role of health professionals to support the use of the diary and the need for simplicity in recording.

1.6 Examples of research on patient held records / diaries and experiences of health professionals using diaries

Diaries or patient held records (PHRs) for patients to use in terms of self care, rather than as a method for researchers and health professionals to gather data have been used in several settings, including services for diabetes, mental health, cancer, maternity and child health and more recently in cardiac departments. In its reports on national service framework reviews on chronic heart disease in 2004, the Healthcare Commission has mentioned patient held records in North Hampshire and South West Dorset.

North Wales too has piloted a patient held diary. The consultation document 'An evidence based implementation plan for Tackling Coronary Heart disease in Wales' 2001-2005 considered that Primary care teams and local health groups should offer all those on the CHD management system a multi-factorial risk assessment, an appropriate treatment plan, a personally held record of their risk factors, information on how to influence the risks and regular follow up.

In our review of research findings, the majority of "patient records" are predominately about the keeping of a record of health readings. There are a growing number however that incorporate diary elements such as areas for patients to record their own material and having the

responsibility to maintain the diary as they feel fit, rather than something to be presented for the benefit of health professionals.

In most of these services, the patient records have been an addition to clinician held standard notes and although there have been some reviews and evaluation of PHRs, many diaries and PHRS have been piloted with no write up of the process and findings. Therefore as well as desk based research on reviews and research on patient held diaries or records, interviews were undertaken with four health professionals who were using patient diaries but who did not have evaluations of the diary and example diaries sought.

A table with a summary of publicised research findings, synopsis of presentations and conferences is provided at appendix 4 in order to provide some cross section of findings, although it is far from comprehensive. Although the diaries or records have been used with patients who have different conditions, many of the findings have presented themselves in the BHF patient held diary study and are looked at in detail in section two of this report.

Clinic randomised trials and more qualitative approaches outlined in past research in appendix 4 have not found any impact on the quality of life of patients (See Williams et al 2001, Oxford Working Group), or any improvement in the provision of information, or satisfaction with information (See Cornfleet 2002, Lecouturier et al 2002) or improved perception of communication between staff, or family involvement (See Cornfleet et al 2002).

However, such studies do find that the patients find them of use and benefit (See Cornfleet et al, Williams et al 2001, Lecoutier J, Crack L et al 2002, Essex et al 1990, Oxford Working Group, Finlay I) with the exception of one study that felt that patient held records may not be helpful for patients with long term mental illness. (See Warner J et al 2000).

A qualitative study by an Oxford working group reported patients with advance cancer feeling more involved and health professionals being more aware of patients' feelings.

One study (See Dr Harrison) reported that the patient-held record had made a major improvement in communication between health professionals, patients and carers. This study had sought to allay concerns of health professionals and felt that the record was reliant on commitment and support from both patients and health professionals as did speakers on a pilot study in Newcastle (See Crack L and Mannix K)

A randomised trial (See Williams J et al 2001) found that patients felt more in control, better prepared for meeting when they had a record. Disinterest, barriers by health professionals was reported in two studies (See Findlay I and Essex 1990)

The more clinical reviews with randomised trials are focused on outcomes and do not appear to report on the process of introducing a diary to patients.

Some common themes in the literature that relate to the diary is that the use of the patient record is more about patients having a tool to manage their recording and as an aide to communication and less about impacts on health outcomes, compliance and satisfaction with information. The role of health professionals outside the hospital or rehabilitation team to support patients is an issue.

There were three evaluations found of cardiac patient records from the Managed Clinical Network Team, Dumfries and Galloway, the Cardiac Network group and the University of Wales Bangor and East Suffolk Patient record. All three reported that the diary had been piloted, found useful and continued.

Two examples of other diaries which were found and that would appear to be of good design and elements of their design appropriate for our heart patients were:
Salisbury Health Care NHS Trust personal diary for the breast clinic
East Suffolk Personal record for heart patients

1.7 Learning to be incorporated into the design and production of the diary

Findings from past research and reports on patient records and guidelines on information for patients are reflected in the present research study:

- Interviews with the patients in this study have confirmed the key point in Health literacy¹⁰ that for some patients the desire to use information varies during their illness and that in the early stages of a disease process people, while in hospital, some patients have difficulty in dealing with information.
- The diary does conform to many of the guidelines about content and text that have been highlighted in this section. The issue of customising the diary to individual use is considered later in this report along with views of patients about the amount of information in the diary.
- The diary is a tool to signpost patients and carers to where they can find information and to link the information with tackling risk factors. The support of health professionals has been mentioned in guidelines and research studies in this section and will be raised later in the report.
- Management of any publications has implications for updating and revision.
- The guidelines on information provision indicated that wording in patient information should be accessible, non jargon and friendly and this report will consider any further amendments since stage one on the design of the diary that still need to be incorporated into the diary..
- Simplicity and how to make the material less intimidating is a theme within this section that is echoed later in our report on the design of the diary.

The next section looks at the research process and its findings. Issues in this section from the guidelines and previous research are considered again in patient feedback and findings on how patients react with the diary.

2 The research process and research questions

2.1 The research process

This section looks briefly at the research process and profile of patients recruited. A more detailed look at methodology and instruments is available at appendix 1. It then considers each of the research questions of the evaluation and the findings that have emerged from the research. The research questions for the evaluation were:

- How do patients assess the diary's design and overall concept?
- What do patients say about their use of the diary?
- How well does the diary work as a learning resource?
- How does the diary affect patients' health related behaviour?
- How does the diary improve patients' communications with their families and health professionals?
- How does the diary affect patients' mental and emotional well being (sense of empowerment, involvement, understanding and control)?

The aim of the evaluation was to assess the design of the diary from the view of patients and health professionals. The study would explore the use of the diary by patients in terms of its value as a learning resource; its effect on the patient in terms of supporting them managing their condition, whether it promoted changes in behaviour and understanding their condition and how health professionals viewed the diary in terms of their use of it with patients.

The first stage of the evaluation took place between January and July 2004 and explored the design of the diary with patients and health professionals. The findings were reported to a BHF steering group in September 2004, recommendations agreed and the suggested improvements incorporated into a revised diary. The outline of this stage and the findings are attached at appendix 2.

In the second stage of the evaluation, 88 patients from three hospitals were recruited to take home the revised diary. This stage of the study was looking at what value patients placed on the diary and what use was made of the diary. It took place between February and July 2005. The findings from this stage provide the main focus of this report, although the results and views from the first stage are also drawn upon. Evidence to support the views in this report are drawn from data collected in stage one and two and include seven focus groups involving 29 patients and carers, 45 telephone interviews and two surveys completed by 23 patients at stage one and 40 patients at stage two. Full data tables from survey two are available at appendix 3.

The profile of patients recruited to the second stage of the study

The nurses at two hospitals in the project approached every patient admitted into hospital with a heart attack with the offer of the diary during the period February to end of June 2005. They kept a record of who refused as well as those who accepted and put down some indication why it was refused. The third smaller hospital recruited when able. The table below shows the number of patients recruited at the hospitals, with Addenbrookes being the main recruiter of patients at stage 2, although at stage one, Peterborough Hospital recruited similar proportions of patients. Two hundred and thirteen patients were approached over the recruitment period and 88 were recruited to take diaries.

Table 1 Number of patients recruited at the hospitals at stage 2

| Hospital | No of patients recruited | % |
|----------------|--------------------------|------------|
| Addenbrookes | 69 | 78.4 |
| Peterborough | 16 | 18.2 |
| Hinchingbrooke | 3 | 3.4 |
| Totals | 88 | 100 |

As seen in table 2 below, there were less females represented in our survey and telephone samples compared to the population of patients admitted into hospital. Generally women were more likely to be over represented in the 75+ age range in the number of patients that came into the hospital (patients approached) and therefore have more numbers in the category of patient that is less likely to take part in a survey, which may account for some of the discrepancy but not all.

Patients recruited did not reflect the full range of patients coming into the hospital. Those aged 87 to 96 were not represented and the mean age of our recruited patients was younger than that of the patients that came in to hospital by four years.

We were not aware that we recruited any Asian patients but one interview with an Eastern European patient was recorded.

Table 2 Comparing patients recruited to those who were admitted into the hospital.

| | Patients approached N=226 | Patients recruited N=88 | Survey 2 responses N=40 | Tel interviews N=27 |
|---------------------|---|------------------------------------|--|------------------------------------|
| Mean age of patient | 68 | 68 | 64 | 65 |
| Age range | age 34 – 96 (62 years) | Age 35 – 96 (61 years) | Age 39-86 (47 years) | Age 44-83 (39 years) |
| Gender | 64% male 29% female 7% not recorded | 74% male 26% female | 85% male 15% female | 85% male 15% female |
| Ethnicity | 85% white British 2% Asian 1% Eastern European 13% unknown | No recorded data | Not recorded | Not recorded |

Any study using volunteers will have a bias towards those more motivated and able to take part in research. Those volunteering for research are likely to be more at home with discussions and paperwork.

We undertook more telephone interviews than initially proposed as learning from the first stage of the study had indicated that telephone interviews were more likely to result in reaching older patients, those that were back at work, unable to drive, less comfortable in group discussions etc than focus groups. In the time restraints of stage two, it was not practical to sample as it was surprisingly hard to get hold of patients in their home, and so the researcher took who ever she could get obtain on the telephone and simply worked her way through the list of patients several times.

As the stage of recovery or length of time in possession of the diary was likely to have an influence on the use of the diary, the length of time between discharge and interview was noted. Stage 2 contained 10 more interviews where over 13 weeks had elapsed since the diary had been given to the patient. This, plus the focus on the use of the diary seemed to result in patients having less focus in stage two on the “limbo stage” that had been reported in stage one of the evaluation. This was where patients are waiting for appointments and not knowing what they were able to do with regards to exercise and tackling risk factors and so feeling they had little to put in the diary.

Table 3 Length of time between discharge and interview. (telephone interviews and focus groups)

| | 4-6 weeks | 7-12 weeks | 13-16 weeks | 17 - 20 weeks |
|------------------|------------------|-------------------|--------------------|----------------------|
| Stage 1 N=28 | 13 | 13 | 2 | 0 |
| Stage 2 N= 40 | 14 | 14 | 7 | 5 |
| Totals | 27 | 27 | 9 | 5 |

2.2 Research Question: How do patients assess the design of the diary?

Improvements to the design of the diary

Stage one of the evaluation of the diary explored the design of the diary with patients and health professionals. 28 patients and seven nurses gave comments on the diary during this stage of the evaluation. The recommendations of that stage are outlined in appendix 2. At this stage, there had been a lot of confusion from patients about the layout of the diary and where information was located. The diary was revised and reprinted at the end of 2004. In the second stage of the evaluation, there was substantially less comment around the content and design of the diary. Some themes still persisted and will need to be considered if the diary is to be produced on a larger scale. These were:-

- The redesigned diary has not incorporated all the elements of “floppiness” so that it could not be folded up and so there were calls for it to be small enough to be put in a pocket or fit easier into a handbag. The pages would also not stay open in the new layout.
- There was however, a lot of praise about the layout of the diary that came unprompted from health professionals and patients and little by way of confusion about where information was located.
- There were a handful of patients who felt that the diary was “a deluxe model” and could have been produced more cheaply if it had been paper. There was an impression that some of those who refused the diary were put off by the thickness of the diary and who may be more comfortable with a paper version as this appears simpler. This could be tackled in two ways – the diary could be made thinner, simpler, or part of the delivery of the diary is to take out that which is not needed when handing over the diary. This also reflects good practice guidelines in section one about a lot of material being intimidating for patients.
- The researcher found that the word diary conjured up expectations that the diary needed to be filled in every day, that it was wordy, and given that most patients were using it more for recording health readings, it might be useful to change the front cover wording. However, only 17 out of 40 patients (42%) felt that progress record was a more apt description than diary when asked in the stage 2 survey.
- Bearing in mind the guidelines in section one about avoiding jargon, interviews reveal some ambivalence about the term ‘risk factors’. It is suggested that the risk factor tab should be divided up in terms of Giving up smoking, keeping your heart fit, watching your diet and weight etc rather than headed as risk factors.
- Generally small is considered best in guidelines, but the diary needs to incorporate information signposting as it is more than a record of health readings. A compromise solution is suggested as patients have different views on the size of the diary but would appear to agree that it should fit into a pocket or handbag. The Personal record from

East Suffolk is taken as the template for size and floppiness. This means that the diary can be folded and put into a pocket or handbag.

Size

Patients were asked in telephone interviews and in the stage 2 survey about the size of the diary. Patients were asked in the survey whether they agreed to the statement, that it would be better if the diary could fit into a pocket or handbag. 60% agreed, but 40% did not. Only 15% agreed with the statement that it was the right size. In our telephone interviews, when patients said it was too big, the researcher would probe, and this was always about the issue of carrying it around. Apart from one patient who wanted his readings on a card the size of a credit card, the suggestion that the diary was made so flexible that it could fold in half and not so bulky was felt to be acceptable by these patients. (The East Suffolk Personal Record example being seen as the exemplar for this.)

Use of the term "Diary" to describe the booklet

It became apparent that the term diary made a lot of patients feel that they were not using it if they were not filling it in every day. On the other hand some patients were expecting a blank page for them to fill in what they wanted to record as if it was a personal diary. The researcher asked some later interviews about the change of title from diary to personal record, or progress record. Again, this received mixed responses. "My personal record" or "my personal progress record" could be easily fitted on the front cover above the title "Your Heart Matters". The word "Personal" to reinforce that the diary belongs to the patient as some patients still were expecting health professionals to take charge, or ask them about their diary. Only 40% in the survey felt that progress record was preferable to diary but the researcher felt strongly that it was an influence in how patients perceived the diary.

Feelings that the diary was 'complicated'.

Of the 83 patients that declined to take part in the research, 8 patients said something to the nurses about the diary looking complicated. Nurses handing out the diary also spoke of patients feeling it was complicated. This would appear to be as much about bulkiness, looking rather official and therefore an expectation that there would be a lot to have to undertake. An interview with one of the nurses who had handed out the diary, and who had also handed out a more simple paper based diary at the hospital prior to the BHF diary felt that this had not been an issue with the previous thin paper diary. Section 1.6 detailing previous research and example of patient records would also suggest that a simple format is less intimidating.

Twenty percent of the stage two survey respondents (8 patients) felt the content of the diary was too complicated. These 8 patients were aged between 44 and 86 with no age group particularly represented. Only 40% of the respondents agreed with the statement that it was easy to understand. Some patients felt that having the diary in sections was still unnecessarily complicated and just wanted blank pages to record their pieces of information. This was also the wish of some patients who were writing down thoughts and progress and using it more like a diary than to record their health readings.

About four patients felt that the diary was too expensive in its production given their lack of use of it and felt that the BHF money could be spent better. It was seen as a deluxe model. This may also contribute to the feeling that the diary is complicated, or be intimidating for the patient. One patient described it as "more like a manual rather than a diary."

If the diary is only used for a limit period of time, then it may be worth considering that a paper version, would not only be more economic, but also not put off those patients who saw the "deluxe" model as too complicated. (The Salisbury Breast clinic diary being an example of this).

Alternatively, the diary could be slimmed down so that only the basic sheets of recording are handed out, but those that wish to record more, or tackle particular areas such as smoking or exercise can have additional pages.

Potential for Electronic diaries

A few patients mentioned the internet as a source of information and using home computers. One patient felt that he would prefer his diary on the computer.

It may be worth considering having an electronic version available for computer literate patients, and for those that want to download additional pages, or for other organisations designing diaries to use.

Groups not being reached – those with poor literacy skills, those with other first languages

The diary is not designed for those with poor reading and writing skills. Nurses handing out the diary felt that they could guess which patients would take up the diary and these were likely to be patients who would take up rehabilitation options and engage with health professionals. Certainly those interviewed were articulate people, mostly at ease with written information but not necessarily engaging with rehabilitation classes. Of our patients approached, 3 of 35 patients were not offered the diary by nurses because of language difficulties. Six of the 83 patients (7%) approached who refused the diary, did so because of language problems or because they felt they were not good at paperwork.

Because of the nature of it being research, some patients interviewed admitted that they only took the diary because they wanted to help out with the research and would not have taken it otherwise. A few were glad they did, and had used the diary, but others had not used the diary and two of those interviewed felt that the diary was best used by those who were better at reading and writing, which implied they felt they did not have these skills. The BHF also has a patient record card for those who do not have writing skills and simply want a record of their health readings.

The pilot of this diary has not looked at the reaction of black and ethnic minority groups to the diary. It was unable to consider what would be useful to patients from different cultures in the form of a diary.

2.3 Research Question: What concepts are held about diaries, empowerment and self care?

This section considers some concepts around the diary that affect the response of patients. It looks at patient and health professional expectations of how a diary should be used, what messages are conveyed by the diary to patients, and attitudes towards empowerment and self management.

What does a diary bring to mind for patients and health professionals?

As discussed in the previous section, the title conveyed for many patients, something that had to be filled in regularly, if not daily. Hence if they were asked if they had used the diary, their first answer would be “no, not really” but subsequent conversation would reveal that they had put in their health readings, used it from time to time to note symptoms but as they recovered and had less to remember around their illness, they no longer needed to use the diary or it was updated infrequently. The word diary brought to mind something that was about words rather than recording, but most of them were using the diary as a record of health readings.

However, the use of a diary as a way of seeing progress, recording feelings and what had happened, was particularly important and therapeutic for a minority of patients. Four of the patients interviewed in stage one and two, were using the diary in depth to make a record of what had happened, or noting their moods and activities, looking to find some indication of what were the triggers to their behaviour. It also provided a way of seeing progress over a difficult period of time.

The self reflective diary was seen as a particularly useful tool for these patients and they were very enthusiastic about using the diary.

The concept of the diary for those health professionals that had designed the diary originally was primarily focused on tackling risk factors. It was also a way of helping the patient keep track of progress, keep key information in one place, a record that could be used by both patient and health professionals to look at symptoms, risk factor reduction, a record of health readings and patient questions and a reminder of where information could be found elsewhere. It was a resource to be kept by the patient, but shared with their health professionals. This latter point is raised in more detail later in the section about interactions with health professionals.

There are elements of a patient held record in the diary. The Coronary Heart Disease Collaborative sought to pull together lessons on developing patient held records in its toolkit.¹⁵ The toolkit looked at different levels of patient interaction with their record defined as access, contribution, participation and partnership. Such a record was seen as a shared resource.

"The patient is invited to contribute to the information they contain, such as monitoring their own blood pressure and weight, keeping a diary on angina pain etc. This information is utilised in the management of the patient's care".

CHD Collaborative. Developing patient Held Records.2001¹⁵

Many of the suggestions around good practice of developing a patient record outlined in the toolkit have been applied in the development of the diary but the supporting role of health professionals in the region has not yet been tackled by the hospitals. The Dept of Health report "Public Attitudes to self care Baseline Survey" February 2000 reinforces the supporting role of health professionals in self care. Later in this report we will see that the support of health professionals has been raised by the patients themselves in the study.

Attitude of patients towards empowerment and self management

Nearly all patients felt they had sufficient or good information. This is reinforced by the CHD survey of patients in 2004¹⁶ which found that most patients said they had the right amount of information with only 11% saying they had too little and 3% saying they had too much.

Some of the patients interviewed in our study were unable to take it all in while in hospital, while others felt that they had more time in hospital to sit and read compared to being at home. Managing their condition needed guidance over and above what is provided on paper and in videos. Despite all the leaflets and information given, patients explained that this information was not all encompassing. They had to know how it applied to their individual circumstances.

"I had plenty of leaflets and information but no understanding of how it applied to me; I didn't know what I could and couldn't do". (Mary, patient fitted with pacemaker. Case A28)

Interviews in stage one of the study revealed a proportion of patients who were "in limbo". They were awaiting operations or consultations and not sure about what they were capable of doing given their ill health and not convinced that the risk factors in the diary applied to them. This attitude to risk factors and being in limbo has been the subject of previous research.¹⁷

So at the time of the interview, the patients in limbo did not engage well with the diary, although many did keep a record of health readings. It was not seen as relevant to their needs. Their heart

¹⁵ CHD Collaborative. Developing Patient Held Records". NHS Modernisation Agency 2001.

¹⁶ CHD Survey of Patients 2004 / 2005 HealthCare Commission

¹⁷ Fielding, R. (1987) Patients' beliefs regarding the causes of myocardial infarction: implications for information-giving and compliance. *Patient Education and Counselling*, 9, 121-134)

attack was “out of the blue” or they had been “unlucky”. The diary with its emphasis on risk factors did not convey to them how they could prevent another attack.

When patients have their awaited operation or are reassured by consultants and rehab nurses that they can take up activities again, and then we will see in the second stage of the study, most patients in our telephone interviews felt they could move forward.

Patients in our telephone interviews also said that they knew what was required of them to improve their health. Apart from those that felt they did not have risk factors, most had an idea about how they were expected to make changes. However, the interviews for this study were not asking about the changes they were making to their routines to improve their health and there is research that shows that patients tend to have low self confidence in their ability to perform self care¹⁸.

Many patients were doing long walks on a regular basis, watching their diet and attending rehabilitation classes. Some felt that the rehabilitation sessions were not particularly useful for them. They knew what had to be done so the lectures were not of interest and the exercise sessions did not feel taxing. But nevertheless there were a high proportion of patients that at least had the intention to self care.

So for patients, empowerment and being able to take control, requires being in a position to know what they can do given their individual condition and circumstances. This will require the support of health professionals and is not something that can be solely conveyed through information.

Lack of time in hospital and at appointments may mean that the nurses write in details in the diary but patients perhaps should be encouraged from the start to write in the details themselves. One patient (A28) was annoyed that the hospital nurse had written the blood pressure readings in her diary without even asking her while another patient (A53 age 58) lets the nurses put everything in the diary and sees the diary as a record that she holds for the health professionals.

The illness diary

A theme that has emerged strongly from interviews with patients at both stages of the evaluation is that the diary was useful when patients were not well but recovering. This also can be seen as a period when they have something to record, when there are changes and new ways of doing things. This is likely to be when in the early stages of making adaptations to their routine, probably when they are recovering, on the way to feeling well and able to changes. If they are too unwell, or feeling unable to go forward on making changes because they are waiting on consultant interviews or surgery and so are unsure as to what they are able to take on in terms of risk reduction, then their engagement with the diary is only in terms of recording initial health readings such as blood pressure and symptoms.

“this diary is really for those who are in recovery from heart attacks and getting better” Patient (D11) who did not feel he had any of the traditional risk factors to tackle. He was waiting to get a triple by pass, so not feeling able to undertake an exercise routine)

The main use of the diary is at a time when the patient is not so well, but making progress and able to have some way of tackling their illness. This was acknowledged by many patients when they considered whether the diary should be introduced in GP surgeries if they had not received the diary in hospital. Hospital was seen as a better place to hand out the diary because patients were more motivated then to do whatever was needed to get better.

“When you’re feeling ill, you’ll do anything to make it right, then as you get better, you get less worried” (Patient A11 on why the hospital is the best place to get the diary)

¹⁸ Carlson B, Riegel B, Moser D. Self care abilities of patients with heart failure. Heart and Lung 2001. Sept-Oct; 30 (5) 351-9

At the other end of the spectrum, those that are well and feel recovered, feel that they have no need to reflect on symptoms, health readings or keep track of their progress. This perception of "feeling well" is subjective and around the expectations of the individual. This can be a good thing as research has demonstrated that perceived health was predictive of psychological recovery, return to work and readmission to hospital.¹⁹

Examples of those who feel well or unwell and have not made a lot of use of the diary

Peter age 67. Has been waiting six months for this check up with a consultant. Apart from being breathless, feels well. He is not noting down his symptoms around breathlessness. (Case A50)
"because my recovery has been good, and it's all been so positive, I've not used the diary, but if I had not been so well, I probably would have and would have recorded things in it".

Margaret age 60. Waiting for angioplasty. She is feeling well and has started a new job and working part time. She doesn't know what she should be doing in the way of exercise but feels that after the angioplasty she will have a better idea. (Case P23)
"I don't think it's (the diary) appropriate for me. It's for people that are, you know unwell, who don't know much about heart disease. "

Mary age 54. Heart attack in February followed by Pacemaker fitted in March. Feeling that she has no energy to record anything or get interested even though she considered herself "the diary type". The interview took place about four weeks after her pacemaker had been fitted. She acknowledges that this uncharacteristic attitude is related to her condition. (Case A28)

We will see later that those using the diary tend to use it in two different ways. Some patients were using the diary as a record of health readings and facts, while a smaller group were using it to record feelings and to note progress in a more therapeutic way. The use of the diary is also governed by how well or unwell a patient feels. All such themes contribute to the diary being of use for a limited time period, but there are some exceptions to this.

In section 2.5 we shall see that although many patients were taking on self management of their condition, changing their diet, exercise routines etc, there were a high number of patients who wanted their health professional to be involved in the diary. They wanted some interest and possibly some direction from health professionals to support them.

Attitudes towards the messages of the diary on risk factors

We reported in the first stage of the evaluation about the confusion experienced by many patients around the messages they perceived in the diary in the risk factor area, that the disease was preventable if changes were made to lifestyles and their perceptions that they did not have the risk factors in terms of diet, smoking and lack of fitness. There seemed less certainty in this group of patients around whether their cholesterol level and stress levels put them at risk. Both these factors are not so visible and there is less consensus generally about their role in heart attacks.

Whether this attitude toward risk factors is seen as a state of denial, the fact that the operation and treatment now makes them feel well, or the reality that some patients have heart disease with no apparent risk factors, the diary's emphasis on risk factors can set up barriers to its use by this group. This set of patient may feel powerless because they cannot see what they can do to make a difference.

¹⁹ Maeland JG, Havik, OE. Self assessment of health before and after a myocardial infarction. Social Science and Medicine 27 1988 597-605

Seven of the 27 patients interviewed in stage one presented themselves as patients who did not feel they had risk factors. The focus at stage 2 meant that this area was not explored so much with patients, so the stage one patients have been used for analysis in this area. Table 4 below shows however, that the majority of this group still made use of the diary.

Table 4 Patients in interviews who felt that they did not have risk factors and their use of the diary

| | No of patients who felt they did not have any risk factors to be tackled | No within this group that said they did not use the diary | No of patients in this group that did use the diary |
|-------------------|--|---|---|
| Stage one N=27 | 7 (26%) | 3 (11%) | 13 (48%) |

N= Patients who took part in telephone interviews and focus groups

NB: This was not a direct question asked in stage two.

Anger was also expressed in one focus group, that patients were “to blame” for their illness and there was no acknowledgement in the diary that “age was a risk factor.”

“I feel that too much emphasis has been placed on this aspect with its implied indication that heart problems are largely a lifestyle choice” (Stage 1 D19 Carer)

The diary certainly doesn’t acknowledge the association between the prevalence of chronic disease and position in the social structure²⁰.

Not everyone needs a diary to manage their condition

As indicated in Health Literacy¹⁰ patients’ ability and wish to use information will vary during the course of an illness. In our 27 interviews in stage one, 14 patients (50%) said they were not using the diary to record anything. Looking at their profiles, 6 patients were interviewed within 6 weeks of discharge, two were very well and thinking about returning to work, and a couple were waiting for consultant appointments and were unwell, in what had been termed “in limbo” and did not know what they were able to undertake in the way of exercise.

Five of our 40 patients (12%) in the stage two interviews and focus groups said they did not feel the need to record their management of the illness in the diary. They were making changes but not keeping a record. Apart from initial readings and information on their drugs put in by the nurse in hospital, the majority of these patients felt they did not need to record for various reasons including they had a good memory and were able to recall what they needed, they were well and did not have anything to put in the diary, the management through pills, exercise, giving up smoking, etc was now a routine and did not need recording. They were not unmotivated, but simply not managing their illness through the diary.

Example of Non user of diary – motivated and managing her condition

Bertha, age 76, has looked at the diary but has not used it to record anything. She has changed her habits of a lifetime. She has finally given up smoking (she started at age 16). She is pleased with herself because she feels she has done well in keeping away from foods that are not good for her, and is trying to do regular exercise as the doctor tells her. She thinks the diary is useful for people who are better than her at reading and writing things down. (Case A11)

However, most of these patients still considered that the diary had been useful, whether as part of the information provision they were given, something easy for a family member to read, or just the baseline record of their health readings. There were comments about the diary “makes good

²⁰ Sharp I (ed) Social Inequalities in Chronic Heart Disease: Opportunities for Action. London. National Heart Foundation 1998

reading” about liking the layout of the diary and content of the diary and very little confusion about where material was located that had marked the comments in the first stage of the evaluation.

Patients attitudes to the diary will be echoed later in the report when we see the different ways patients have used the diary and its value to their recovery. Whether they use it in a more wordy way, detailing feelings and progress or simply as a record of health readings and activities is likely to determine how long the diary is used and those patients who recover very quickly and feel well may not see any point in using the diary.

2.4 Research Question: What do patients say about their use of the diary?

How many patients recruited to the study made use of the diary

There were two surveys in this study. The first survey went out at the end of stage one to all 53 patients that had been recruited. The focus was on the design of the diary. A survey went out at the end of the second stage of the study to the 88 patients that had been recruited. The surveys had a response rate between 43% and 47%. Second stage patients had received a revised diary and the focus of the interviews was on their use of the diary. Some questions appeared in both surveys. As table 5 shows, in both surveys the majority of patients used the diary. The following section looks at the detail of this use and non use.

Table 5 Responses to the survey questions on whether they had used the diary

| Responses | Stage 1 n= 23 | Stage 2 n=40 |
|---|------------------|-----------------|
| Those that said they had used the diary | 19 83% | 34 85% |
| Those that said they had not used the diary | 4 17% | 6 15% |

How long did patient use the diary?

Our first survey was sent out to patients that had been recruited and who would have had the diary in their possession between five and 11 months before receiving the questionnaire.

Of the 23 patients who replied to the survey:

- 35% (8 patients) said they were no longer using the diary when they received the survey
- 35% (8 patients) said they still used the diary from time to time.
- 13% (3 patients) did not provide us with this information on the survey form
- 17% (4 patients) had not used the diary at all.

The stage one survey showed patients had made use of the diary between 3 and 11 months. Table six below divides up 16 survey respondents in terms of those that had stopped using the diary and those that were still using it and the length of time involved. Thirty one percent of those patients that had used the diary had stopped within the first four months, but 25% were still using the diary at eight months. For those still using the diary, the survey provides a snapshot of the current position, but no indication of how much longer they may continue to use the diary.

Table 6 Length of time diary was used – Stage 1

| No of Months diary used | No of patients who stopped using the diary N=8 | No of patients still using the diary N=8 | Percent of those using diary |
|--------------------------------|---|---|-------------------------------------|
| 3 | 3 | | 19% |
| 4 | 2 | | 12% |
| 5 | 1 | | 6% |
| 6 | 1 | | 6% |
| 7 | | 1 | 6% |
| 8 | | 4 | 25% |
| 9 | 1 | 2 | 19% |
| 10 | | 1 | 6% |
| total | 8 | 8 | 100% |

Telephone interviews at stage one revealed that a lot of patients who were unwell or feeling well were not using the diary at the time of the interview. This was often in the first six weeks after discharge. However, this was not reflected in the stage 1 survey. It is possible that over time more of the patients took up the diary or those that replied were more likely to be those using the diary as compared to those who did not use the diary and so felt less motivated to respond to the questionnaire.

Stage two survey patients had the diary between one and five months at the time of the survey, so this survey did not cover such a long period of time owing to delays in setting up stage two of the project. Of the 35 patients who had used the diary, 20% (7 patients) had stopped using the diary at the time of the survey and 77% (27 patients) were still using the diary at the time of the survey.

Table 7 shows that of the 7 patients who had stopped using the diary, 6 patients (17%) stopped at a point between 1 and 2 months after receiving the diary.

This may reflect the discussion in our previous section that for many patients, the diary was used at a time of illness, change and adaptation. Once well, or in a routine, it was not needed.

Of those patients still using the diary:

- Fourteen patients (60%) had been using the diary for between 1 and 3 months.
- Seven patients (20%) were still using the diary at four months after they received it
- Seven patients (20%) were still using it the diary five months after they received it.

Table 7 Length of time diary was used – stage 2

| Months used / in possession | No. of patients who finished using the diary | No of patients still using the diary | Totals N=35 | Percent 100% = 35 | No of patients in these categories that said rehab nurse took an interest in diary |
|-----------------------------|--|--------------------------------------|-------------|-------------------|--|
| 1 | 2 | 4 | 6 | 17% | 4 (still using) |
| 2 | 4 | 4 | 8 | 23% | 1 (stopped using) 2 (still using) |
| 3 | 1 | 6 | 7 | 20% | 3 (still using) |
| 4 | 0 | 7 | 7 | 20% | 5 (still using) |
| 5 | 1 | 6 | 7 | 20% | 4 (still using) |
| total | 8 | 27 | 35 | 100% | 19 |

Analysis of the data shows that of the 27 patients still using the diary in our stage 2 survey, 18 of the patients had stated that rehabilitation nurses had shown an interest in the diary. Looking at patients who were in the longer length of time of using the diary, of the fourteen patients using the diary at 4 and 5 months, over 60% (9 patients) said rehab nurses had taken an interest. It is not known whether the interest was in the past, or whether these patients were still in contact with rehabilitation nurses.

Reasons given by patients in the stage 2 survey for giving up using the diary were:

- Having reached a position where the entries were repetitive, the same, a routine had been established (2)
- Patients felt they had recovered (6)
- Too complicated (1)
- The diary made the patient feel like an invalid (1)

Frequency of use for those using the diary

We asked survey respondents about their pattern of usage. The results are in table 8 below. Stage one survey respondents who had the diary for at least five months before were more likely to say that they used the diary a lot at first but much less now (37%). Stage two survey respondents were more likely to say they had used it now and then (28%) as this group had not had the diary for such a long period of time.

Table 8 Frequency of use

| Responses on how often they used the diary | Stage 1 n= 19 | Stage 1 % | Stage 2 n=34 | Stage 2 % |
|---|---------------|-------------|--------------|-------------|
| Those that used it now and then | 5 | 26% | 10 | 29% |
| Those that used it but have stopped | 6 | 32% | 7 | 20% |
| A lot at first, now much less | 7 | 37% | 6 | 18% |
| Not used it much at any time | 0 | | 4 | 12% |
| Didn't use much at first, more later on | 1 | 5% | 1 | 3% |
| Use it everyday | 0 | | 2 | 6% |
| Other including – just used at exercise class – just a record of blood pressure | 0 | | 4 | 12% |
| Totals | 19 | 100% | 34 | 100% |

Usefulness of the diary

Patients were asked to rate the usefulness of the diary in survey 2. The results are in table 9 below and show 72% rate it as useful.

Table 9 Rate usefulness of diary

| | | Frequency | Percent |
|---------|---------------|-----------|---------|
| Valid | not useful | 3 | 7.5 |
| | fairly useful | 14 | 35.0 |
| | very useful | 15 | 37.5 |
| | Total | 32 | 80.0 |
| Missing | System | 8 | 20.0 |
| Total | | 40 | 100.0 |

Who was not using the diary?

Table 10 provides the number of respondents in the surveys who reported that they had not used the diary.

Table 10 Non use of the diary

| Survey response | Stage 1 N=23 | Stage 1 % | Stage 2 N=40 | Stage 2 % |
|---|-----------------|--------------|-----------------|--------------|
| Those that said they had not used the diary | 4 | 17% | 6 | 14% |

There were only a small numbers of patients in the surveys who said they did not use the diary at all. Reasons given in the surveys for not using the diary were:

- Too complicated, not user friendly (1 response stage 2)
- Patient couldn't concentrate (1 response stage 1)
- Patient felt he could remember and did not need to record (1 patient stage 1)
- One patient did not have a heart condition (1 response stage 1)

Six patients did not respond to the question that asked the reasons why they had not used the diary. The ages of the patients who did not use the diary were spread between 39 and 85 with no particular age group over represented.

The reasons for not using the diary in the stage two telephone interviews were similar to those at stage one.

Eight of 40 patients (20%) interviewed in focus groups and telephone interviews said they did not use the diary to record anything at the time. Reasons given in telephone interviews and focus groups with patients who did not use the diary were around not needing to write down their management of their condition, feeling too unwell, or feeling full recovered with nothing to record. Again, similar to stage one, interviews and focus groups tended to have slightly higher reporting rates about non use than the survey. It is not known whether the survey gets a lower percent of non use because over time this changes or whether those who fill in the survey are more likely to be users of the diary.

There were a few that did not want to get involved in the diary because they did not want to think about their illness. Typical responses were "*I was hoping to forget it really*" and "*I don't want to dwell on it*". Health professionals may consider these patients to be in denial. They did not want to engage in conversation with the researcher in any detail, and so it is not known if they were similar to patients that are making adjustments to accommodate their illness, but not recording them or whether they are not making any changes in their lifestyle.

Characteristics and views of patients using the diary but feel they are not making much use of it. Over the course of interviewing around 65 patients in focus groups and telephone interviews in stage 1 & 2 of the study, there were about 27 patients (40%) who felt they had not made a lot of use of the diary. Typically they had made a few entries, put in their health readings and had not added anything for a while. The feelings and characteristics of such patients were:

- If you have a good memory and are well organised it doesn't need a written record
- There is no need to spend time dwelling on your illness, you should get on with life
- People who felt they had recovered very well and had nothing to keep a record of as they have no symptoms or perceived risk factors
- Feeling too unwell to make the effort with the diary or in limbo awaiting operations and consultations

A summary of the patients' experiences (Interviews and focus group participants) from both stages 1 and 2 who felt they had made little use of the diary has been categorised below in table 11. It is important to note, that the amount of use expected of the diary is subjective.

Table 11 Patients who felt they made very little use of the diary and age (stage 1 & 2)

| No of patients | Characteristic | Ages |
|----------------|--|---|
| 6 | Poor health and not able to make the effort | 79, 53, 76, 60, 77, 76 |
| 2 | Feeling unwell but leave it all to doctor | 86, 70 |
| 2 | Not good at paperwork, but making changes without resorting to record in diary | 71, 76 |
| 12 | Feeling well, no symptoms so feel they have nothing to record | 60, 66, 44, 58, 55, 81, 78, 56, 61, 67, 77, ? |
| 3 | Waiting to see consultant or operation don't feel anything to tackle and record. May also be feeling unwell. | 67, 72, 61 |
| 2 | Well and don't want to dwell on illness, be reminded of it, or be treated as ill | 55, 66 |
| Total 27 | | |

Those patients of seventy year plus are more likely to feel in poor health, not very good with paperwork and the "younger set" of fifty and sixty year olds are more likely to be feeling well and fully recovered so feel they have nothing to record, or do not want to dwell on their illness.

Our two largest groups were those who felt well and those were in poor health. Patients' conditions can improve quickly and so from a health viewpoint, they may difficulty realising the importance of continuing to manage their own care. Similarly, those in poor health may recover later and have a different attitude to the diary.

Patients who did not want to take part in the research – would they be diary users?

Of more significance in number of the non diary users, are those patients who did not use the diary because they did not take part in the research study. The numbers of patients who declined or accepted to take part in the research are seen below in table 12. They may have been put off by the fact that it was research and so felt this would be onerous. On the other hand, for some of the patients interviewed, the diary was accepted because they wanted to help with the research, although in interviews, the majority of such patients said they would have taken the diary anyway.

Of 213 patients admitted for heart attacks in the three hospitals over the recruitment period, 40% declined to take part. (83 patients)

Table 12 Participation in Research

| Status | No of Patients | % of patients |
|------------------------|----------------|---------------|
| Declined | 83 | 40% |
| Accepted | 95* | 44% |
| Hospital did not offer | 35 | 16% |
| Totals | 213 | 100% |

- Although 95 accepted. Consent forms for 7 patients did not arrive until too late in the process to be included in the survey or interviews.

Table 13 categorises the reasons recorded by the nurses for reasons given by patients if they declined to take part in the research

Table 13 Reasons given to nurses for declining diary and research

| Reason | Number of patients n=83 | Percent of those that declined |
|---|-------------------------|--------------------------------|
| It looked too complicated | 10 | 12% |
| Do not like paperwork | 2 | 2% |
| Language problems | 6 | 7% |
| I'm too busy, too much to do | 13 | 16% |
| I've got too much information | 4 | 5% |
| Health problems | 11 | 13% |
| I'm too old | 7 | 8% |
| No reason given | 9 | 11% |
| Taking part in another trial or other system already in use | 4 | 5% |
| Not interested | 17 | 20% |
| Total | 83 | 100% |

Research²¹ has indicated that patients can feel overwhelmed by information or be unable to take it all in while in hospital. Such themes were also brought up in interviews and focus groups. Being too busy and having too much to do, was a frequently cited reply to why they did not want to take the diary followed by it looked complicated. Both responses may change later when they are not in hospital. Therefore the study asked questions of patients in interviews about receiving the diary at a GP surgery which is looked at in more detail later in this section.

What is the diary being used for?

Table 14 lists the categories patients were given to indicate what type of use they were making of the diary. Most frequent responses in our stage two survey about what patients were using the diary for were:

- A record of health and activities (65%)
- To record information and progress (59%)
- To discuss something with a GP or nurse (56%)

Table 14 Reasons for using the diary – Stage 2

²¹ CHD Collaborative Toolkit. Learning from Patient and Carer Experiences. NHS National Patients' Access Team. Third Edition June 2001

| Responses | Stage 1 n= 19 | Stage1 Percent of cases | Stage 2 n=34 | Stage 2 Percent of cases |
|---|------------------|-------------------------------|-----------------|--------------------------------|
| To write down thoughts and questions | 7 | 36% | 10 | 29% |
| To show family carers or friends | 4 | 21% | 6 | 18% |
| To discuss something with a GP or nurse | 11 | 58% | 19 | 56% |
| To record progress | | | 20 | 59% |
| To look for information | | | 20 | 59% |
| A record of health and activities | | | 22 | 65% |
| To record tackling risk factors* | 9 | 47% | | |

* This question was broken down into other questions for the stage 2 survey.

Eighty two percent of those using the diary in the stage two survey (28 patients) were using the diary in two of the categories and 29% were using the diary in four or more categories. It was the minority of patients 15% (5 patients) that reported they were using it simply for one reason.

Writing down thoughts and feelings, seeing progress

For 4 of the patients interviewed, the recording of what had happened, or noting their moods and activities gave them some indication of what were the triggers to their behaviour, and also acted as a way of seeing progress over a difficult period of time. The diary aspect was seen as a particularly useful tool for these patients. For three patients, this seemed mainly self reflection, but for one patient, it provided some “preciseness” about what was happening to him emotionally that he could discuss with rehabilitation nurses. There were however, many more patients that could see that the diary provided some history and record of progress and provided some sense of achievement.

Examples of patients who record progress and feelings and feel this is the main benefit of the diary for them.

Linda. Age 57
Linda had given up smoking but was still getting cravings and everything revolved around not having another cigarette.
“I started the diary when I was doing five minutes a day (exercise) to get it up to 30 minutes a day was an achievement as far as I was concerned. I was really chuffed so wrote it down, as much as anything as a landmark record.....In a year’s time I will have forgotten how awful it was not to have a cigarette, I think I shall enjoy reading it then, even if I don’t use the diary any more”

Mike Age 58.
He is using the diary to understand why he gets so angry and what the triggers are. “There isn’t a manual to tell you what emotions you will go through, the fear of the unknown”. He writes a lot down about how he is feeling. When he has been angry he can relate it to what is down in the diary and see what has triggered it. When he sees the nurse later in the week, he can be more precise about what has happened. “Without the diary I would forget all the things that have happened, so it helps me talk to the nurses”

Donald Age 71

He finds that it is easy to forget when things happen, how long ago it was but with the diary he can look it up. He finds it useful to record such things. "it gave me confidence, when I was a bit low, I could look back and see I was a lot worse then. It tends to make me more positive when I do that"

The use of the diary by family members.

In telephone interviews, patients were asked if their family saw the diary. Men often would refer to the support they were getting from their partners. Older patients spoke of daughters or sons checking that they had filled in the diary or in some way taking an interest. 18% in the second stage survey said they had used the diary to show family. In our focus groups, four spouses attended with the patient. In one case, the wife was the holder of the diary.

Example of spouse being the diary holder

Glenda is the main use of the diary since her husband Ben came out of hospital. He has difficulty remembering things since the heart attack. She found there were too many things going on in the hospital to distract her during the short periods of time she was in hospital visiting and welcomed the idea of getting the diary from the GP on a one to one basis without distractions.

Case No.

When offering the diary to patients, nurses would ask if a member of the family might want the diary if the patient felt they could not manage it because of poor literacy, language skills, memory loss etc. However, this offer was not taken up by any one at the hospital.

Nevertheless, the role of the partner in the management of chronic illness needs to be a consideration when looking at which patients may benefit from the diary. Research²² has shown that the needs of carers can be differently focused to the patient and overlooked.

The diary as a personal record of health readings and appointments

In the stage two survey, 65% of those using the diary (22 patients) said they were using their diary to keep a record of their health readings.

In the telephone interviews, quite a few patients had their own blood pressure monitoring machine, but others were just recording changes when they visited the doctor or rehab class. One patient (A42) felt that when he had showed the doctor his diary, this had prompted the doctor to provide him with a blood pressure monitoring machine as he had a place to keep a record. Three patients in stage two interviews when prompted admitted they did not know what the figures for blood pressure meant, so therefore they saw no point in recording them. It was sufficient to know from the doctor that it was fine.

Example of patient who does not understand his blood pressure readings

Donald age 56, having problems when he overdoes it. The nurses put his blood pressure readings in the diary while in hospital. He has not updated them. The GP took his blood pressure and said it was fine. He doesn't understand what the figures mean, so what is the point of asking for them. (Case A80)

A feeling of insecurity, of something may happen were highlighted in a few conversations. Having the diary to keep information in one place was particularly beneficial for these patients. One patient carried the diary around with her as her record. She felt secure having the information with her in case something happened. She took it on holiday with her. But for another, there was some anxiety about being a keeper of a record of health. She expressed the concern that if anything was to happen to her, if she did not keep her diary up to date, a mistake might be made if the

²² Moser DK, Dracup KA, Marsden C. "Needs of Recovering Cardiac patients and their spouses: Compared views" Int. Journal Nursing Student Vol 30 No 2 pp105-114 1993. Pergamon Press Ltd

diary was used as the main record of her medication and readings. A few patients spoke of letting their family know about their condition, and where the diary and spray were kept in case anything should happen to them while family were around.

A few patients were recording diabetic readings. This was mainly because many of the patients who revealed they were diabetic during the course of the interviews, had been diabetic for many years and had other systems already in use. Newly diagnosed patients also had been given charts along with their drugs and equipment to record diabetic readings. Diabetic patients interviewed felt the diary did not have enough space for regular entry for those recording their readings several times a day.

The diary as a personal record of changes in behaviour and tackling risk factors.

Many patients mentioned watching their diet, taking up walking or exercise and a few had given up smoking. Some had kept a record of this, while others did not feel the need to record it. This section looks at the views of health professionals about how they could use the diary with their patients and clients in exercise and rehabilitation classes and how patients reported their use of the diary in the various risk factors areas of section two of the diary.

Exercise and Rehabilitation sessions

The interviews with health professionals were mainly with rehabilitation nurses and phase IV instructors. Their focus was on getting the patients to change their behaviour particularly around exercise, a better diet and giving up smoking.

They all felt that the patients varied in their knowledge of risk factors and prevention. Phase IV instructors were likely to get patients that were more motivated because they had made the choice to continue with supervised exercises and had a better understanding of risk factors if they had been through the phase III rehabilitation classes. They all felt that the diary could be a useful tool in their work with patients to support them make changes and keep track of progress.

56% of stage 2 survey respondents (19 patients) using the diary said they had used the diary to discuss something with a health professional. The survey and our interviews would indicate that this is likely to be a rehabilitation nurse and often patients would be recording their progress in exercise classes along with health readings. Four patients mentioned a doctor as the health professional that took an interest in the diary.

Two of the hospitals provided reminders about the diary when inviting patients to rehabilitation sessions by suggesting patients brought along the diary. At Peterborough hospital, and Papworth hospital, there is a separate exercise diary which patients mentioned as where they kept a record of their exercises and so did not use the diary's exercise area.

Other patients mentioned writing their readings down from rehabilitation sessions in the BHF diary. One patient (A42) spoke of other patients at the rehabilitation session that have these diaries and with whom he regularly compare notes.

It is suggested that when raising awareness with health professionals about the diary, that where other systems of recording are being used alongside the diary, the diary is at least acknowledged, some role found for it if possible, and some check made if the patient has started recording in the diary and any preferences for where they prefer to keep the record.

Keeping some record of exercise being undertaken did not necessarily require rehabilitation supervision. Patients use the diary in the early days to record their experience of taking walks and gradually lengthening their distances. There came a certain point when there was nothing new to record and then they would stop putting in entries in the diary.

Weight and Diet

Patients mentioned keeping track of their weight in the diary. The focus groups in stage one on the design had suggested that this area might provide some information around diet. Patients had less knowledge about how they could reduce cholesterol in their diet and were interested in help to know which foods were not suitable or to be encouraged.

Signposting here on diet could probably be improved. Being overweight is not a very positive tab for this section. It is suggested that this label could be amended to watching your diet and weight.

Stress

Many of those patients, who felt they did not have risk factors, did however acknowledge the role of stress in their lives. One focus group with a police officer and court officer had a particularly in depth discussion with the nurse who came in at the end of the discussion and there appeared to be a need to provide some support around tackling this risk factor which is not mentioned by this diary but which has been given some space in the Papworth diary. Better signposting in the diary to ideas and support on reducing or being able to cope with stress would be beneficial here.

Record of symptoms

Those undertaking exercises whether on their own or under a rehabilitation programme mentioned using the symptoms pages either to keep track of how much they could do without getting into difficulties and to see how it progressed, or to have a record for discussion with nurses about when they had symptoms, or as part of their rehab exercises. Many people talked about the symptoms they were experiencing in their interviews and when prompted said they did not record them. Cardiac nurses in stage one felt this area would be good for those with angina. Stage 1 had suggested a picture in this area to remind patients about this area of the diary.

Diabetic section

This area is rather sparse, but our interviews have shown that many patients with diabetes use other systems already and do not change their recording to the diary. It is likely that a diabetic patient held diaries will be coming on stream over the next year or so. This section should not be handed out unless the patient is diabetic. A diabetic patient suggested that the symptoms area is put in the diabetic section, particularly if the patient is newly diagnosed to record hypos. There is not enough space to record the amount of readings taken by diabetic patients of their blood levels. A newly diagnosed patient will need a supply of additional sheets if s/he is going to use the diary for this purpose.

Summary about how the diary is being used by patients

This section has reported that the surveys reveal that 83-85% of those that agreed to take the diary have used the diary and this is about a third of those patients admitted into the hospital with a heart attack over the research period. Between 17% and 31% of patients stop using the diary between 1 month and three months, between 20% and 50% are periodically using the diary five months later. Some patients have reported using it eight and ten months later.

The diary is being used to record health readings, share information with health professionals and help patients keep track of their progress. A small group of patients are putting more detail of their progress and symptoms in the diary and have found this useful because it gives them an indication they have progressed, it helps them be reflective and more precise about what is happening to them. It has some therapeutic benefits to explore feelings in this way.

Patients use the diary less when they are unwell and feel unable to make changes and recover. At the other end of the spectrum, if patients feel they are fully recovered, have no risk factors to monitor, or do not need to record their management of their illness, then these factors limit their use of the diary. The majority of responses in the stage two survey reported that they used the diary from time to time.

Until the time a patient has decided that they have something to track and record, or feel well enough, then they may not use the diary. These "non users" may change their attitude at a later stage and the diary could be offered at rehabilitation sessions.

In our interviews with patients, family support to keep a record in the diary was mentioned and one spouse was the main holder of the diary.

The use of the diary in the patients' interactions with health professionals is reported in the next section.

2.5 Research Question: Does the diary improve patient communication with health professionals and influence health related behaviour?

Interactions with health professionals

The difficulties of communication and the nature of unequal relationships between doctors and their patients is well documented²³ In telephone interviews and focus groups, patients were asked about their dealings with GPs and nurses, whether they felt confident about asking for their health readings or raising questions about the content of the diary. They were asked if any health professional had taken an interest in their diary.

In the introduction in the diary itself, it was suggested that the diary should be taken along to hospital or doctor appointments. Although doctors were informed that their patient had taken part in the research, it was not expected that this would be particularly noted by GPs given the lack of response about getting a copy of the diary. There had been no marketing of the diary during the research stage, so most GPs were unaware of the diary and so it was the patients who would bring up the subject.

Nineteen patients (47%) in our second survey had used the diary to discuss something with a health professional, predominately rehabilitation nurses. Only four patients in the survey said that a GP had shown an interest in the diary.

Example of Patient using the diary with health professionals

Albert (case A36) lives alone, now 80 years old, he keeps a record of his symptoms and weight loss. The nurse comes in once a week and fills in the diary for him. "I see it as useful for myself and nurses and doctors"

This apparent lack of interest by GPs may also be a product of the patients view that doctors do not have time to go into the detail of what is going on in the patients lives, they may be reluctant to raise the diary with the doctor and prefer to have the conversations with a nurse. So patients may choose not to bring up the subject of the diary.

"It's best in hospital. You have to be in and out too quick at the doctors. A nurse would be able to give you more time". (Ernie Age 83 who felt there was more time in hospital to read things and ask questions. Case A82)

However, once in the community, rehabilitation nurses are not always in contact with patients. Not all the patients interviewed attended sessions, even if it was offered. This perception of taking up the doctor's time may prevent patients from being proactive. There were good stories of doctors expressing an interest in the diary. Such doctors were "marvellous people" There were also bad stories about only being able to ask two questions when visiting the doctor and strict time limits. Most patients felt confident to ask for health readings from the GP but did not feel that

²³ for example, Mishler E 1985, Foucault M 1975, Zola I 1981, Articles in The Sociology of Health and Illness: Critical Perspectives. 6th Edition. P Conrad (ed) Worth Publishers. 2001

the GP would have time to talk about life style changes. There was also some lack of confidence in some patients that the doctor had enough specialist knowledge to deal with their questions. These patients would approach the rehabilitation nurses for advice. The consensus from patients was that a GP surgery was not ideal unless there was a specialist nurse with the practice who could give them time and expertise in their condition.

In our stage two interviews, ten patients said they had gone to the doctors and not shown the diary, only five patients said they had shown the diary to their GP. Many had not yet been to the doctor, or had forgotten to take it. Eight patients in our stage two interviews said they had taken their diary to a GP practice or to rehab sessions and all bar one had some conversation.

"I'm not a bleater, I can handle it but my local doctor, he's not very sensitive about my situation". When prompted this was about not being given time to talk and not feeling supported. *"The nurse however is brilliant".* (Case D36 male age 71)

The diary would appear to make the request easier for some patients because there is an official looking piece of paper to put the readings in and in some cases, the need to "fill in the diary", reminds the patients to ask for the blood pressure readings. As well as encouraging patients to ask for their readings, it could encourage health professionals to give the patients responsibility for this.

There was a group of patients that felt it was up to the doctor or nurse to ask about the diary and did not have the confidence to bring it up in the discussion or felt they could not take up the doctor's time. At the other end of the spectrum, there were patients who were very assertive with their GP. One patient spoke of his frustration with not understanding what the doctor was saying with regards to cholesterol and so got him to write it down in the diary in an attempt to find some one later to explain it.

In the second stage patients' survey, 77% of patients felt they would be more motivated by the interest of a health professional and use the diary more.

There were a minority of patients interviewed that were having difficulties with the hospital or their GP. This was around late diagnosis of their condition, or their condition initially not being diagnosed correctly or patients who had alternative views about treatment and this experience had left them very unconfident about being supported.

Research²⁴ has indicated that emotional and social agendas are likely to be downplayed in communication with the doctor and with the increasing awareness of patients that their time with the GP is limited as seen in our interviews, this situation may get worse.

²⁴ Barry CA, Bradley CP et al. Patients' unvoiced agendas in general practice consultations. BMJ 2000 320:1246-50

Examples of patients showing their diary to health professionals

One patient (A42) felt that his doctor has given him a blood pressure monitoring machine because he had shown him the diary and had somewhere to record the readings.

Another (A70) handed over his diary to a consultant at Papworth Hospital when asked about what medication he was taking. The consultant said that he had seen quite a few diaries coming through but had not shown any wish to discuss it.

"When I showed it (the diary) to her, she thought it was wonderful and when I go there for a check up, she insists on filling it in for me" (D16 Age 62)

P74 age 67, took the diary only because of the research. He doesn't think he would have taken it otherwise. He keeps track of his blood pressure readings. He feels that he can see more progress when he can see how the numbers have changed. He's taken it to the rehab class and made the nurses laugh about what he has written about his exercise records. "It's been brilliant for me." He has lost half a stone, and that is recorded too. He sees it as a record of progress. Once he feels better he doesn't expect to use it much.

Getting information in hospital

Focus groups and telephone interviews asked patients about how appropriate it had been to receive the diary in hospital and most felt strongly that this had been the best time. They had some space to read things, contact with the nurses to ask questions and their initial health readings could be entered.

"Last day, Shirley (the nurse) spoke to me, I learnt more from her than the cardiologist. Explained it all...my older son came in and he was speaking with Shirley more than he was speaking to me, he found it (the diary) really useful" Patient age 62 (case D16)

However, in the previous section looking at non use of the diary, there were 24 patients (25%) who declined taking part in the research because they felt too busy, had too much to do or had health problems. In our telephone interviews, there were some patients who had accepted the diary that also felt it had been difficult to deal with diary while in hospital because of the trauma of the event, the distractions, effect of drugs etc .This led to considering whether for those who did not take the diary in hospital, GP surgeries or rehabilitation sessions after discharge might be an alternative.

However, most patients asked in telephone interviews about this felt that the hospital was a better place to receive the diary as they were more motivated at this stage, they had more time to ask questions, and it could be some time before they were seeing a doctor.

The hospitals when informing patients about their first rehabilitation session via a letter, would ask patients to bring the diary along. Hospital nurses interviewed felt that they had not seen many diaries appearing at their rehabilitation clinics, but the pool of patients using diaries is quite small. Patients spoke of taking the diaries along to rehabilitation exercise sessions and recording changes in health readings, some fed back what had taken place since they last saw the nurse. There were various comments from patients about how recording in the diary had helped in their conversations with nurses.

"Without the diary I would forget all the things that have happened, so it helps me talk to the nurses" (Case P75, age 57)

Patients who had an expectation that health professionals would support them and take an interest in the diary.

At both stages of the evaluation, there were patients who suggested that they would be more motivated to use the diary if health professionals took an interest. Patients were asked if they had taken their diary to the GP or to a rehabilitation class. Many had taken it along because they thought they would get asked about the diary, but when not asked, they did not bring it up in the conversation.

Example of patients waiting for the doctor to make the first move

George, age 67 has poor health. He had angioplasty 5 weeks ago. He is diabetic and taking medication for another condition. He took his diary to his rehab appointment, but was not asked about it, so did not mention it. He took the diary to his GP appointment and put the diary on his lap on display but again when the doctor did not asked about it, he did not mention it. He said he felt disappointed. (Case A82)

The stage 2 survey asked the question whether health professional interest would make a difference to their use of the diary. As seen in table 15 below, 85% of our 34 respondents felt that it would.

Table 15 Responses to the Question: Do you think people would use the diary more if health professionals take an interest in the diary?

| Response | Frequency | Percent |
|------------|-----------|---------|
| Yes | 29 | 85.3 |
| Don't know | 3 | 8.8 |
| Total | 32 | 94.1 |
| Missing | 2 | 5.9 |
| | 34 | 100.0 |

Views of health professionals about the diary and how it can be used with patients

GPs, practice nurses and phase IV instructors were sent letters and copies of the diary in stage 2 of the evaluation with a request for an interview. 1 GP responded. 5 Phase IV instructors responded and 1 cardiac rehabilitation nurse. Some of the phase IV instructors showed the diary to their clients.

They were all enthusiastic about the diary. Most comments about the content and layout were very positive and they all felt they would use it in their sessions with clients, mainly to record information and progress. They felt that the diary should be given out to patients before they were seen at stage IV because it was information needed early on and really too late by the time the patient came to them.

One instructor felt patients who came to her sessions with a diary with the basic information completed would be able to get started quicker at her session because she would not need to check information with the hospital or doctor when they do not know their drugs and blood pressure etc. She also felt the diary would work with a range of patients that she sees. She often sets goals with patients and putting this in the diary would be helpful. She thought its main strength was having all the information in one place.

Another instructor showed the diary to five of her clients who all felt that it would be useful for them to record in and wished they had something similar when they had left hospital. She spoke of her clients feeling they had been left on their own once they were out of hospital. They know they should do exercise but are fearful of doing too much, or are uncertain about what is

appropriate. They also need to be supported and motivated and although they receive lots of leaflets and information, the diary brings it all together.

She felt the diary was a good tool to keep track of progress; it helped the instructor have an easily accessible record of their clients' health readings and what tablets were being taken, and that this form of seeing progress could contribute to motivating and supporting people. She felt it was a very valuable tool for the patient and health professionals dealing with them.

Patients may have a few different providers of care. Each provider may have different packages to offer. To avoid confusion it is important that health professionals are aware of any new tools being provided and respect the patients need to avoid duplication. As one patient said "I can't spend all day filling in forms about my health".

There are many other bits of paper in competition with the diary. Naturally, patients do not want to have to fill in similar information on different bits of paper and they don't want a lot of paperwork. They may get exercise sheets from Papworth and Peterborough. One of the hospitals is piloting a diabetic diary. Their drugs come with sheets that can be used to keep track of dosage.

The diary was sent to Papworth Hospital cardiac rehabilitation department for their views because many patients from the three hospitals piloting the diary are sent on to this hospital. Papworth has its own package of care that includes an information book that has been provided to patients over the past nine years. The current version provides a lot of detailed information for heart patients. It is about to be updated and will be known as the Road to Recovery. It has areas for patients to record in, and the latest version has taken some aspects of the BHF diary on board. However, Papworth is unlikely to move to the BHF diary given the investment in its own publication and the hospital's surgery specialism means that patients who go through this hospital will have additional needs to be met. After surgery patients may be more concerned with wounds and healing in the immediate future than keeping a record of progress.

However, awareness of the BHF diary may mean that staff at the hospital will be primed to ask patients if they are recording elsewhere and not expect the patient to start a new book of recording. For example, Papworth already asks patients what British Heart Foundation leaflets have been provided at other hospitals to avoid providing yet more duplicated information.

The diary's impact on health behaviour

Patients were using the diary to record their health readings and this may contribute to a better awareness of what the figures mean. However, there were instances of patients having the numbers but not knowing what they mean. In such circumstances, the patient is keeping the record for others rather than for themselves. Having an "official" place to record may help patients overcome their reluctance to take up the doctor's time or act as a prompt for the GP to give the readings. Many patients in this study have spoken about requesting readings from their GP or the GP offering to put them in the diary. All such transactions give the patient more involvement in and knowledge of their condition.

Four patients found that recording their progress had benefits in terms of helping combat depression and building confidence and well being because they could see how much had changed since the heart attack. One patient was able to articulate his feelings of anger in a more precise way to the nurses and see what was triggering it. The emotional upheaval of the condition is well documented and this use of the diary may be particularly beneficial for patients coping with the emotional ups and downs.

It is not just health professionals that may use the diary to support patients. We have reported the views of some spouses of patients in our interviews. The diary helps them focus on supporting their partner make changes. One wife was the main user of the diary as her husband had a poor memory; another was helping his wife give up smoking. Many patients have reported support by wives, who are reminded them about keeping the diary up to date, and who are being involved in supporting changes particularly around diet.

The diary provides a useful tool for those who want to use it. The diary on its own is not going to change behaviour, but it may provide a mechanism to remind both patient and health professional about keeping a record. Those that are not interested in their blood pressure numbers are unlikely to change, but may record them for their health professional if asked. A doctor may simply tell his patient that their blood pressure is fine, but the diary provides the reminder to the patient to record the detail.

2.6 Research Question: How well does the diary work as a learning resource

Although the diary does provide information about CHD, it is not a repository of information but aims to signpost its reader to where they can find information. It is provided as one of many items that are given out to the patient in the hospital. It complements the BHF leaflets and other information sheets provided that give the detail of advice and is not a substitute for any of them. As well as a signpost to where the information can be located, its other major role is that of a record of health and progress.

Patients in our second stage survey were asked if they had used the diary to look for information. Of the 34 patients who had used the diary, 20 (59%) said they had used the diary in this way. When we asked them whether the diary should be made available nationally and some comment on their response, comments from five patients were around the fact that the diary improves awareness, knowledge and was a source of information for patients.

In telephone interviews we asked patients whether they felt they had enough information when they left hospital and what were the gaps. Most felt they had sufficient information and their needs were often not about more information, but how it applies to their circumstances and sometimes reassurance about what they could do.

Examples of needing to know how information applies to the patient

"We all want to know how much he can do and what it is safe for him to do" (wife of patient D47)

(Patient P21 age 67) He explained he was fine in hospital, he felt safe, but when he came out, he was a bit frightened about what he could do without a nurse around.

The rehabilitation nurses either in the hospital or in the community were the main source of how patients found out about how the information applied to them. The diary cannot provide this individualised information, but it can help as a prompt to ask questions about how the information relates to the individual and in the previous section, we have learnt that the diary was mainly being used in discussions with rehabilitation nurses.

Information needs expressed by patients in interviews were:

- Better signposting to ideas about diet.
- There was less knowledge about cholesterol and how to have an effect on it without drugs
- More help about tackling stress
- Reassurance by a health professional about when they could go on holiday, mow the lawn, drive etc

The first three information needs could be better signposted in the diary. Discussion at a BHF steering group on this raised the point, that these three areas currently get a lot of coverage in the media and it was not surprising that the patients felt confused with all the different views being expressed on these areas.

In the stage 2 survey, patients were asked to rate the usefulness of the diary on a scale from not useful to very useful. 35% of the 43 patients who responded rated the diary very useful and 33% rated it fairly useful.

2.7 Issues around the management of the diary

Before any roll out of the diary, those using the diary will need to consider the management of the diary and include plans for:

- Updating the diary and providing additional pages
- Electronic versions on web sites
- Consideration of a paper version compared to the current more robust version.
- How the diary complements / competes with other systems likely to be used by the patients
- Raising awareness and marketing the diary to health professionals in the area where the diary is to be used.

The way the diary is delivered to patients is likely to help them take control of the diary. It is suggested that patients should be encouraged from the time they are given the diary, to take out what is not needed, particularly if they feel the dividers make it more complicated, perceived messages about life style blaming or lack of risk should be explored in order to make patients more comfortable with the diary.

3 Conclusion and Recommendations on the BHF Diary "Your Heart Matters"

3.1 Use of the diary by patients

The majority of patients (85% in the second stage survey) had made some use of the diary. Our first stage survey that had respondents in possession of the diary between 5 and 11 months found that although 31% of patients had stopped using the diary within the first four months, 25% were still using it from time to time at eight months.

Most frequent responses in the stage two survey about what patients were using the diary for were:

- A record of health and activities (65%)
- To record information and progress (59%)
- To discuss something with a GP or nurse (56%)

Our patients were a mixture of people who found the diary useful for managing their condition and keeping a record of events and health readings and those who did not feel the need to use a diary for this, as they were able to keep in their heads or had other systems of keeping a record.

Those who are tackling particular risk factors find it useful to chart their progress and find that seeing the record or history of that progress gives them confidence and hope at times when they are feeling low. Some patients find the keeping of a diary at a time of emotional upheaval a helpful experience that can be used in their conversations with health professionals.

Non use of the diary (15% in our second stage survey) was around not needing to manage their condition by writing and recording. The patients often felt well and were ready to get back to work. A few did not want to use the diary because it was a reminder of their illness.

About 27 (40%) of those interviewed in stage one and two felt that they made small use of the diary. Our two largest groups were those who felt well and those were in poor health. Of those patients who feel they are not making a lot of use of the diary, patients of seventy year plus are more likely to feel in poor health, not very good with paperwork and the "younger set" of fifty and sixty year olds are more likely to be feeling well and fully recovered so feel they have nothing to record, or do not want to dwell on their illness.

A significant number of patients coming into the hospital refused the diary (40%). Being too busy and having too much to do was a frequently cited reason for not taking the diary (14%) followed by health reasons (11%). These two reasons are subject to change, and it may be that some patients will change their mind about using the diary later. Most patients felt that the hospital was the best place to receive the diary despite its problems of distractions and for some patients the difficulty of taking in all the information at that particular traumatic period in time. Their view was that they were more motivated at this stage and had the expertise of nurses to call upon. A high proportion of patients had misgivings about whether being given the diary in doctor's surgeries would be timely enough and many patients felt that unless there was a specialist nurse at the practice, they would not get sufficient expertise at a surgery compared to the rehabilitation nurses.

Patients' conditions can improve quickly and so from a health viewpoint, they may difficulty realising the importance of continuing to manage their own care. Similarly, those in poor health may recover and have a different attitude to the diary at a later stage. Some method to give patients another opportunity to have the diary when less traumatised or beginning to recover would benefit these patients. Phase 2 rehabilitation sessions would be an alternative opportunity

It should be accepted that there comes a time when there is less need to record once a routine has been established and that patients can self care without resorting to a written record.

The role of carers using the diary should not be overlooked. Eighteen to twenty one percent of patients in the survey reported that the diary was shown to family and interviews revealed that spouses or partner were supporting them in some way to keep track of their progress and or make changes. In one of our focus groups, the spouse was the diary holder. If patients have a particular problem such as a poor memory, or are unwell, it may be appropriate to ask if the partner or a carer would want to use the diary.

Patients who do not feel they have risk factors or feel they are being blamed for their illness may feel put off by the messages in the diary. The delivery of the diary to this group of patients needs to tackle this. Patients talked about the good practice of the hospitals going through each piece of paper in their information pack with them. Some discussion about how an individual can adapt and use the diary for their own purposes would be useful. Should there be an emphasis that can be put on keeping fit after a heart attack rather than risk factors?

Sixty two percent of patients in the stage two survey felt the diary should be rolled out nationally to benefit other patients. Ten per cent did not feel this should happen, or did not know and 17% did not respond to this question.

The diary was designed to be a tool to help patients increase their self management of their condition and increase their involvement in their care and treatment. Most patients report that they have found the diary useful, even those not using it for recording purposes. 37% rated it as very useful. 35 % rated it useful. Only 7% said not useful.

3.2 The diary as a learning resource

The diary incorporates many of the good practices identified in “Health Literacy”¹⁰ and the CHD collaborative publication on patient records¹⁵. Health professionals at stage two of the study have been complimentary about its content and design. Although there have been mixed responses from patients about the way they want to interact with the diary, there has been little negative comment about the content and it is more around tweaking for improvements rather than major change in terms of the content. The major design amendments are around how much information to signpost and balance this against a product that is not too bulky.

The diary has been designed to signpost patients to information rather than being a new source of information. Fifty nine percent of the 34 patients who had used the diary and responded in the survey said they used the diary to look for information and comments from five patients around why the diary should be introduced nationally were around their view that the diary improves awareness, knowledge and was a source of information for patients.

Our patients in stage two of the evaluation felt they had been given sufficient information in hospital and what they needed was to find out how the information applied to their individual circumstances.

3.3 The impact of the diary on interactions with health professionals and health behaviour

There was little evidence from patients that the risk factor section made much difference to their attitudes towards risk factors and that it changed behaviour patterns. No patient in focus groups or interviews suggested that the diary motivated them to change their lifestyle. Those that had decided to make a change found the diary useful as a place to keep track and particularly as a record of their progress, which in itself gave them confidence and hope. It also gave some preciseness to discussions with health professionals about symptoms and emotions. Two

patients in the stage two survey when asked what the main use of the diary was for them had written that it helped them focus on what they had to do to make changes. Most patients felt they were aware of the risk factors of a heart attack through the leaflets and discussions but the diary was a good general source of information.

The diary on its own is not going to change behaviour, but it may provide a mechanism to remind patients to keep their own record of health, and its “sanctioned” presence may help the communication between patient and health professionals. It will help health professionals in the community have quicker access to the basic medical details they require from patients. It may remind them to give patients their figures on blood pressure and glucose readings.

The general impression in the mixture of accounts about their presentations of the diary was that if requested there was no problem in getting nurses and doctors to provide blood pressure readings for their diary. Patients gave accounts about their doctors were very positive about having something to record blood pressure figures.

The diary is already being used in conversations with health professionals, mainly with rehabilitation nurses. 56% in our stage 2 survey reported using the diary to discuss something with a GP or nurse. Generally patients have more confidence in the nurses to provide time and support than GPs or consultants in terms of dealing with the management of their condition rather than the medication. However, not every patient goes to rehabilitation classes. It would be helpful to patients for the diary to be brought to the attention of local GP practices because unless there is a proactive approach from the GP, many patients have the perception that their concerns cannot be dealt within the time restricted GP visit. Some patients also felt that their GP did not have the expertise in their condition.

Health professionals have welcomed the diary because it provides them with the baseline information they need from their clients, it helps carry the information from the hospital to the community based rehabilitation and exercise sessions. Those nurses that designed the diary felt the diary could be a tool to promote self management and empowerment of patients. It could be used in hospital, at home and with health professionals in the community and so carries information from primary to secondary care. This is a strength that appealed to many of the phase IV instructors. There was a suggestion that the diary could be used at the annual check up with the GP as a tool to look back on progress and re motivated patients to keep up with the changes to their diets, exercise regimes etc. Such long term use is not usual in our current patient population although some have been recorded as using the diary between eight months and ten months. Input from health professionals is needed to motivate patients to use the diary in this way.

Patients, like the health professionals find it useful to have information in one place. Patients did not want to be filling in paperwork, and often there was a decision to be made between the diary and other systems such as other rehabilitation exercise sheets, and other drug recording sheets. For this reason, it is recommended that any area taking on the diary should consider how the diary compliments and competes with other systems and raise the awareness of health professionals in contact with the patients about where the diary can be used with the patient and to avoid duplication of recording health readings and exercise in different places where possible.

There was often disappointment expressed by patients if their health professional did not take an interest. In the survey 85% of those using the diary felt that interest by health professionals would motivate them to make more use of the diary.

3.4 Recommendations on the design and delivery of the diary

The findings of the design stage of the evaluation did appear to remedy many of the problems being experienced by patients but some of the elements were not full incorporated and

reoccurred at stage two. The areas below could do with some more work but do not stop the diary from being currently used and valued by patients:

- Overall floppiness of the diary so that it can be folded up and the pages remain open
- Title of being overweight to be amended to more friendly terminology
- Improved signposting to tackling diet
- Improved signposting to tackling stress
- More information in the diabetic area for newly diagnosed patients
- Change of sub title to include Personal and progress record on the front cover is suggested
- Consideration be given whether a picture on the symptoms page as recommended at stage one to remind patients about recording symptoms would make the section more patient friendly?
- The risk factor tab title is not a term that works well with patients. The pages should be divided up in terms of Giving up smoking, keeping your heart fit, watching your diet and weight

3.5 Management and Delivery of the diary

Before any roll out of the diary, those using the diary will need to consider the management of the diary and include plans for:

- Updating the diary and providing additional pages
- Electronic version on the BHF web site
- Consideration of a paper version compared to the current more robust version.
- How the diary complements / competes with other systems likely to be used by the patients
- Raising awareness and marketing the diary to health professionals in the area where the diary is to be used.

Discussions with patients before giving them the diary should indicate whether they are likely to make use of the diary. The way it is delivered to patients will help them take control of the diary. They should be encouraged to take out what is not needed, particularly if they feel the dividers make it more complicated, perceived messages about life style blaming or lack of risk should be explored in order to make patients more comfortable with the diary.

An electronic version is an option that should be considered by the BHF and hospitals using the diary. This would help disseminate the work done on the diary to other health colleagues, who may be in the process of producing diaries and notification about updates. Those patients who are computer literate may prefer to have an electronic version available.

To help overcome the perceptions of some patients that the diary is bulky and so complicated, the diary should be simplified further and if time permits, nurses may want to start with a basic minimum of sheets (section one, section three, appendix 1 and 2 and some blank progress sheets) The patient can then be asked if they want to take particular pages from section two on smoking, exercise, symptoms, blood pressure and weight or just record on the blank sheets.

Health professionals in phase IV, exercise on referral, GP surgeries could offer patients extra pages when supporting them to make changes to their routines.

3.6 Conclusion

The views of patients and health professionals about their use of the diary would suggest that this diary is a useful resource for patients on discharge from hospital. In some cases it will aid communication between the patient and their health professionals. Its continuation is recommended with the suggestion that those agencies using the diary take time to raise awareness of its potential to those health professionals in contact with their patients, particularly given the desire of patients to have health professionals take an interest and support them. The diary also needs to be made simpler to reach a wider range of patients.

Appendix 1

Methodology of the Research process

1. The design and scope of the evaluation

The evaluation was designed in two phases. For the first stage, diaries were distributed to 60 new MI patients in three hospitals. The views of 31 patients and carers sought in the course of 4 focus groups and telephone interviews along with 7 practice nurses. Recruitment of patients took place in all three hospitals. Addenbrookes and Peterborough being larger hospitals recruited 20 patients each and Hinchingbrooke recruited 10 patients.

The findings of this stage of the evaluation were reported to a BHF steering group and the diary amended.

In the second stage, the revised diaries were distributed through the same hospitals to a larger number of patients. Although recruitment of 120 patients was originally envisaged in the proposal, only 88 patients were recruited due to some delay in the reprinting of the diary, the Christmas period and obtaining Local Ethics Committee agreement to changes of staff on the research team. These delays meant that the evaluation took 1.5 years by the end of the project rather than the 1 year initially envisaged.

This second stage of the evaluation was an evaluation of the use of the diary, and its impact in relation to the BHF objectives. Interviews with GPs, nurses and phase 1V instructors focused on their perceptions of how the diary would be used with patients and its usefulness to patients and health professionals.

The evaluation of the diary did not directly address health outcomes. In other words it did not attempt to assess whether the PHD has improved people's actual heart-related health. Such a study would require a much larger size and longer duration to produce robust data. Rather, this evaluation assessed *how people value the usefulness of the PHD*. By 'people', we mean three key stakeholder groups: patients, patients' families, and health professionals.

Ethics and Informed consent

The Local research ethics committees in Cambridge, Peterborough and Huntingdon were approached prior to the start of the research study to approve the protocol and methods of the research. Chairs action sought when staff changes took place within the hospital and research team and further committee approval sought when the chief investigator changed. The research and development units of the three hospitals were similarly approached about the research and kept informed of any changes. Honorary contracts were also requested and issued to research staff in contact with patients.

All patients approached by nurses during their stay in hospital were given an explanation of the research, and an information leaflet about the research. Where possible nurses would give the patient time to think about the diary and come back later to see if they had questions and whether they were willing to take part in the research. If the patient agreed to take a diary and take part in the research, a consent form was signed. A copy given to the patient and a copy kept by the hospital which was sent on to the researcher.

Anonymous data on the age, ethnicity and gender of any patients who declined was also recorded along with a brief reason for declining if given.

In the course of the study, a few patients died and a few withdrew because of other personal pressures at home or in one case, where the researcher felt the patient was too confused about the diary to take part.

The GPs of those patients taking part in the research study were sent a letter that gave outline details of the research and offered to send a diary if requested. No GP practice took up this offer.

Data collection methods

Focus groups were conducted with patients and healthcare professionals to explore the overall concept and physical design of the diary, their views on their use of the diary and its usefulness generally.

A scoping review was undertaken of current literature on the policy context, heart health, and heart condition/health education.

The different scenarios and experiences of patients, patients' families and professionals were explored in relation to their heart conditions to ground the study in the current lifeworlds and practices of the stakeholders.

Quantitatively assess the distribution, usage and rating of the diary through two patient surveys

SPSS used to quantitatively record the different profiles of the patients approached as compared to patients recruited and those who responded to surveys.

SPSS to code the characteristics of those patients involved in focus groups and telephone interviews.

Research questions

The evaluation needed to integrate both statistical and qualitative data. Key statistical research questions included were:

- who has received the PHD?
- who has not received it?
- who makes use of it and who does not?

Key qualitative research questions included:

- how do patients assess the PHD's design and overall concept?
- what do say patients about their potential use of the PHD?
- what meanings are given to the PHD by its various stakeholders?
- what role if any does the PHD play in their everyday lives?
- how well does the PHD work as a learning resource?
- how does the PHD affect patients' health-related behaviour?
- how does the PHD improve patients' communications with their families and health professionals?

- how does the PHD improve patients' mental and emotional well-being (their sense of empowerment, involvement, understanding, and control)?

Confidentiality and Information sharing

All data gathered from consenting research participants was treated in confidence and their identities fully protected. Any quotes presented in reports were non-attributable.

The Nurse would forward the following basic information about those patients that had signed a consent form and agreed to participate in the research to the researcher:

Contact details

Name/address of GP,

Date of Birth

Date of MI

Discharge date

Payments

Patients and family attending a focus group were given £20 to cover their expenses. Nurses travelling to a venue to take part in an interview were given £20 to cover their expenses.

Intrusiveness and Vulnerability

The evaluation worked to minimise the disruption, burden and intrusiveness of the research on all participants, including patients, their families and health professionals. The hospitals kept the researchers informed of any deaths of patients recruited to the study.

Certain patients that are deemed vulnerable and too frail by the nursing staff on the ground were not asked to participate in the evaluation. People that would have difficulty engaging with the diary because of illiteracy or if English was a Second Language were excluded although the offer was available for them to have some member of the family with good English skills go through the diary with them. All such events were recorded as part of the record of patients approached.

During the focus group discussions, a qualified BHF nurse was available to act as a first point of contact for any medical emergencies and as a source of advice and information if required. The focus group would take place without the nurse, but she would be available in the building. She would then join the group for refreshments and answer any of their questions. This normally took half an hour to an hour as patients found it very valuable along with being able to talk to others that had been through a similar experience.

2. Details of the research Process

Literature Review

A search was undertaken using the terms Patient diary, Patient record, Personal record. Patient record was more productive. Patient information, cardiac rehabilitation, Chronic Heart disease, rehabilitation were also more general terms used in searches. Searches in specialist libraries such as the Cochrane library also tried combinations of attitude to health, health behaviour, patient compliance, patient education, self management. MI and attitude to health for example resulted in 23 hits. MI and patient education resulted in 64 results. Similar combinations were tried with Google. Medline, Journal of Advance nursing, COPAC

The national research register was productive in giving details of where local research had been undertaken. The term patient record provided 100 hits although not all were relevant. Often patient records and diaries are used to collect data for health professionals and researchers rather than as a tool for the patient. The Research Finding Register did not provide any results of the few relevant hits and so alot of telephoning and emails were used to find out whether any research findings had been written up and unless recent, it was often difficult to find people who had knowledge because the contact had moved on. The National Electronic Library for Health (specialist Library on cardiovascular diseases). The department of Health web site for relevant policies relating to CHD and patient information.

The Cochrane Library Issue 2, 2005 provided 19 hits on patient and record or diary.

The Kings Fund Library provided articles from Journals such as Heart and Lung, the British Medical Journal etc. General reading was also undertaken on the sociology of illness.

Interviews with Community Health Professionals

Telephone and face to face interviews took place with Practice Nurses and CHD Nurses attached to General Practice. Participants who travelled to meet the researcher were given £20 to cover their expenses. It was not possible to get sufficient numbers in focus groups and the response was smaller than expected. 7 nurses took up the offer of looking at the diary at stage one and an interview with a researcher. At stage two, 1 GP, five phase IV instructors gave their views on the revised diary. Discussion with the nurses and phase IV instructors covered the following issues:

- Role and involvement with CHD patients;
- What are the main issues faced in talking with patients who have a heart condition?
- Views on need for patient held resource for CHD patients
- Views on the diary
- Discussion of content, design, format, name
- Views on inclusion of any further information/sections

- Views on likelihood of own (and GP) use of this type of resource and whether they are aware of patients using the diary
- Summing up: suggestions for improvement and views on whether all post-MI patients (and others) should be offered this type of resource

Interviews were undertaken with the cardiac rehabilitation co-ordinators in the hospitals who were distributing the diaries to patients that covered their services, common patient needs and pathways, their views about the role of the diary and the process of handing out diaries and reaction of patients.

Interviews with Patients

The hospitals covered a large rural area and so the numbers attending the focus groups were smaller than expected during stage one with only about four patients attending per group. During stage two with a larger number of patients being recruited, a longer period of time passing before the first focus groups, and selecting local venues with the greatest number of patients living in the area, the number in a focus group rose to six or seven. It was therefore decided to undertake more telephone interviews than originally intended and to cut down on the number of focus groups. This also allowed the researcher to reach the more elderly, non drivers, those who would be at work etc. There was also more opportunity to get the detail of their use of the diary.

Patients seem to get a great deal out of the opportunity at the end of the session to talk to others about the experience and to ask the nurse questions about their condition. The sessions would take about an hour followed by discussion and refreshments with the nurse.

Both telephone interviews and focus groups were written up and response coded on SPSS to provide statistical information about the patients' use of the diary. In the first stage of the evaluation patients were asked about their experience of going into hospital and discharge, how they felt about their health (did they feel well or poorly) and then each section of the diary was explored with them, for whether they used it and their views on the design.

Research questions at stage two included:

- What do patients feel they understood (and needed to understand better) about their condition and treatment before receiving the diary?
- Any contacts with health professionals around their condition or the diary?
- Views about when to be given the diary – hospital , GP, Rehab
- How well the diary was explained when it was given out?
- Why did people agree to take a diary?
- What use was made of the diary including family members?
- What other help, support and information have the patients received about their heart condition, care and treatment?
- How did they rate the usefulness of the diary? Any improvements?

- What were the main benefits of the diary, would they recommend it to others?
- Views on whether it should be rolled out nationally

Surveys

Surveys were sent to all patients recruited at each stage. The survey instrument for stage 2 is attached at appendix 3. The questionnaire was sent to the home address of the patient along with a pre paid envelope. The response rate was 43% at stage one and 45% for stage two.

There were a higher percentage of patients reporting non use of the diary in the interviews compared to the survey. It cannot be known whether this is an effect of the survey being retrospective while the interviews were often held at an earlier stage of the patients' recovery, and so they may have used the diary later. Alternatively, it may be that patients who have used the diary are more likely to return the questionnaire.

The research effect

Interaction with the researcher may have prompted more interest in the diary. Certainly after an interview, one or two patients had ideas about what they would do with the diary in terms of recording or taking it to the doctor. However, it is not expected that this effect would not be that long lasting and the stage 1 survey does show some long term use of the diary. The theme of helping research was explored with the patients in telephone interviews and focus groups to see if they would have taken the diary even if it had not been for research purposes. Most patients felt they would have taken it anyway, some felt they probably were more motivated to fill it in because of the research, only a few felt they only took the diary because of the research aspect.

Appendix 2

Findings from stage one on design improvements

The first stage of the evaluation of the Patient Held Diary (PHD) took place between January and July 2004. 60 patients were recruited from three hospitals of which 31 took part in interviews and focus groups. The stage one survey was sent out to 53 of the patients recruited at the end of the year and 23 responded. (43%).

The nature of undertaking semi structured interview to allow the lifeworld of the respondent to be part of the discussion in order to better understand the reasons behind the responses, meant that stage one of the evaluation did have a wider scope than purely the design of the diary. Discovery interviews that have been highlighted in interviewing techniques with patients are similar in this respect. We encountered a wide range of patients in terms of their stages of recovery. Some patients were still awaiting hospital admissions for angioplasty or bypass surgery. Some patients had not yet had cardiac rehabilitation classes. Some still felt unwell, while others felt very well and were returning to work. The diary is catering for a "moving target" aiming to be appropriate for all the stages that a patient goes through during recovery.

During our interviews with patients, there were several themes identified around the patients' attitude to and use of the diary,

- Patients find the diary useful for its information, signposting and record keeping qualities, particularly the medication and treatment section.
- A minority of our sample were happy to keep a record of their health and use the diary to record progress for themselves on particular risk factors.
- For some patients there was confusion: they did not see themselves as having any of the risk factors, so did not see the relevance of the diary for them, with its emphasis on tackling risk factors.
- Other patients did not feel it was necessary to keep a record of their health even if they acknowledged their risk factors but they found the information in the diary useful and kept some basic information in the diary around medication and appointments.
- Some patients did not want to keep a record for themselves but felt they would be more inclined to keep the diary if requested by the hospital or GP.
- The focus of patients was on the immediate rather than the long term use of the diary.

It was suggested that the diary made clearer what the benefits of the diary were for patients, its possible long term use and that at different times, different sections may become more appropriate. Patients should also be encouraged to discard that which is not applicable to them in the diary and customise it for their own purposes. It is also acceptable for patients to be managing their condition without resorting to recording it.

In general, patients who felt unwell, who were awaiting hospital admissions, or who felt that they did not have any of the risk factors associated with MI were not interested in using the diary for more than recording their blood pressure readings and medication. Those at the other end of the spectrum, who felt well or who were thinking about returning to work, also felt they did not have much use for the diary apart from a record of health indicators. It was those patients who were tackling particular health risks, such as giving up smoking or getting a routine of exercise, that used all parts of the diary.

Improvements were suggested to make the diary more accessible for patients, particularly around layout to make it easier for patients to remember what the diary contains.

- Sections two and three to be merged so that all material for each risk factor is contained in the same section. Each risk factor should be given a separate reference tab so that it is easier for patients to see at a glance what is in the diary.
- Some patients felt unless a health professional was interested, their doctor or nurse, there was no incentive to fill in the diary. Therefore the interest of health professionals in the diary has an impact on patient motivation and this should be explored further in stage 2 of the evaluation.
- The diary needs to be part of a package of integrated services for heart patients, so that where it is being used, patients can be supported to manage their health by being referred to other local support services and that these services are aware of the diary as a tool for dialogue with patients. For example, cardiac rehabilitation classes using the diary for recording purposes

The comments of the patients and nurses provided some suggestions for some minor alterations to individual pages in section one, a change of layout and some slimming down of material for sections two and three, some improvement to section four to help patients remember to note symptoms and finally some web site material to be added to the further information section.

The details of the changes to the text of the diary can be found in the Stage One Evaluation Report September 04.

Revision of the stage two evaluation of the diary included:

- More telephone interviews to be undertaken to get the views of the more elderly patients.
- The sample may not include views from black and ethnic minority groups unless researchers try different methods from general focus groups. Agreement to be sought from the Local Ethic Committee to vary the protocol if necessary.
- The second stage of the evaluation would explore the use of the diary with GPs and other health professionals such as phase IV instructors, healthy living centres etc.



Your Heart Matters!

Thank you for taking a 'Your Heart Matters' diary when you left hospital and for agreeing to help The Tavistock Institute¹ by taking part in this research. Whether or not you have used the diary, we would like to know your thoughts and ideas. Your views will help us to decide whether to give the diary to other patients.

This survey has been sent to 90 patients, who agreed to take a diary. The researchers interviewed about 50 people. This is the last stage of the findings will be presented in August. You will not be contacted again by the researchers or need to return the diary. Thank you for taking part.

Your answers to this questionnaire will only be used by the research team. You will not be identified and the information provided by you will be treated as confidential as outlined in the Data Protection Act (1998).

- ❖ This questionnaire should only take a few minutes
- ❖ Please return your questionnaire in the prepaid envelope provided (FREEPOST) or to Tavistock House, 30 Tabernacle St, London EC2A 4UE.
- ❖ If you have any enquiries please contact: Mrs Shirley Russell on 020 7417 0407 ext 226.



¹ The Tavistock Institute is an independent, nationally and internationally recognised social science research, advisory and training organisation. It was established in 1947 and has charitable status (registered charity no. 442517). The Institute's programme of work currently includes projects with government, voluntary organisations and industry in Britain, in Europe and further afield. Its income is entirely derived from its research, consultancy, training and publishing services.

Section 1: Background information about you

Please provide some details about yourself

1. Your current age in years..... Mean age - 64 years

Gender.....Male 85%

.....Female 15%

Employment status when given the diary (Please tick appropriate boxes) 21%

In paid employment..... 9%

About to return to work..... 9%

On sick leave..... 9%

Retired..... 50%

Do not do paid work..... 9%

2. Ethnic origin (Please tick one box)

White British..... 97%

White other (Eastern European)..... 2%

3. Hospitals attended (please tick appropriate boxes)

Addenbrookes 44%

Hinchingbrooke 0%

Papworth..... 41%

Peterborough 15%

Section 2: How you received the diary

4. Which month did you receive the diary?

Month: Feb - June Year 05

5. Were you happy to receive the diary during your first week in hospital? (Please tick one box)

Yes..... 88%

No..... 8%

If you answered 'No', please state why

Example of reason - Couldn't take in what was being said

Section 3: Your use of the Diary

6. Do you or have you used the diary since you received it?

Yes..... 85%

No..... 15%

7. Do you still use it from time to time? (Please tick one box)

Yes..... 67%

No..... 32%

If you answered 'Yes', please go to question 12

8. If you answered 'No', when did you stop using the Diary?

Month: March - July
Year 05

9. What were your reasons for stopping using the Diary (Please state)

Examples - repetition, routine so need for entries
Didn't want to feel like an invalid
Too complicated

The remaining questions are for those who have used the diary in some way. If you have not used the diary at all, please go to the back page.

NB 6 patients did not use the diary (15%) so the results below are based on 34 patients.

10. Please describe how you use the Diary (Please tick one box only)

| | |
|--|-----|
| I use it now and then | 29% |
| I used it a lot at first, but now much less..... | 23% |
| I started using it but then stopped | 23% |

| | |
|---|-----|
| <i>I didn't use it at first, but use it more later on</i> | 3% |
| <i>I have not used it very much at any time</i> | 10% |
| <i>Other- Use it every day</i> | 6% |
| <i>Other – use it just for rehab classes</i> | 6% |

11. Have you used the Diary for any of these reasons?

(Please tick appropriate boxes)

| | |
|--|-----|
| <i>To write down thoughts and questions</i> | 29% |
| <i>To show to family, carers or friends</i> | 18% |
| <i>To discuss something with a health professional such as a doctor or nurse</i> | 56% |
| <i>To record progress</i> | 62% |
| <i>To look for information</i> | 59% |
| <i>To keep a record of your health and activities</i> | 68% |

12. What is the main use of the diary for you?

Examples were mainly around record and progress
.....

13 Please give a "usefulness" rating for the diary.

(Please tick one box only)

| | |
|----------------------|-----|
| <i>Not useful</i> | 9% |
| <i>Fairly useful</i> | 44% |
| <i>Very useful</i> | 47% |

14. Did any health professional (Doctor, Rehabilitation nurse, Health Visitor etc) take an interest in the diary or use the diary with you in any way?

(Please tick one box only).

Yes..... 65%
No 35%

15. If you answered yes, please write down who (Doctor, Rehab. Nurse, etc)

59% Rehabilitation nurse. 12% Doctor

16. Do you think people would use the diary more if health professionals take an interest in the diary?

Yes..... 91%
No 0%
Don't Know..... 9%

17. Please tick any of these statements that you agree with.

| | |
|---|-----|
| <i>It would be better if the diary could fit in a pocket or handbag</i> | 70% |
| <i>The diary is the right size</i> | 18% |
| <i>Patient progress record is a better way to describe the booklet than diary</i> | 50% |
| <i>The content of the diary is too complicated</i> | 23% |
| <i>The diary is easy to understand</i> | 47% |

18. Do you think the diary should be introduced nationally for other patients?

Yes..... 73%
No..... 12%
Don't Know..... 12%

19. Can you give us a reason for your answer above?

Examples of reasons were useful resource and source of information. Those not agreeing felt it duplicated information available elsewhere

If you have any other comments about the issues covered by this questionnaire, or any suggestions, please use the space below.

Thank-you for supporting this study by completing this questionnaire.

Your time is much appreciated!

If you would like to receive a copy of the summary of the findings of this study, please write your name and contact details in the space opposite.

Name

Address.....

.....

Postcode

Home  number.....

**The Tavistock Institute
30 Tabernacle Street
London
EC2A 4UE
(0207) 417 0407
Email: s.russell@tavinstitute.org**

Appendix 4

Research articles, evaluations and conference references to patient held records and diaries

| Reference | Aim / Client group | Findings |
|--|--|---|
| Essex B, Doig R, Renshaw J. Pilot study of records of shared care for people with mental illnesses. <i>BMJ</i> . 1990 Jun 2;300(6737):1442-6. | To develop and evaluate a record of shared care to be held by the patient designed to increase the effectiveness of long term care of patients with severe mental illness. | Patients found the shared care records very acceptable and were enthusiastic about their use. They valued being consulted about what was recorded and found the record of their treatment and progress useful. Obstacles to further development of this approach relate to the attitudes, perceptions, and anxieties of the doctors, nurses, and managers |
| Henderson C, Laugharne R. Patient held clinical information for people with psychotic illnesses. <i>The Cochrane Database of Systematic Reviews</i> 1999, Issue 3. Art. No.: CD001711. DOI: 10.1002/14651858.CD001711. http://pb.rcpsych.org/cgi/content/full/28/2/51 | Review of patient held clinical information for those with serious mental illness | Review did not find any completed study that matched all their criteria, particularly that of having a randomised group. So came to no conclusions. |
| Wolfe.R and Stafford.A. (1997) Shared care in mental health. <i>Open Mind</i> 85: 7 | | Results from the pilot study showed that not all patients chose to use the records. Those who did use them valued them. In situations when patients did not understand they would get a professional to write in the record and ask a key worker to explain later. Users tended to show greater satisfaction when staff showed enthusiasm. |
| Lead contact: Dr RN Harrison Respiratory Physician, North Tees and Hartlepool NHS Trust, University Hospital | Lung cancer There have been two reviews of the patient-held record carried out with the views of 80 patients and 130 health | Initial reluctance on the part of health professionals who had concerns about time constraints and an increased workload through duplication of notes. Prior to the |

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| <p>of North Tees. 1999</p> | <p>professionals being canvassed</p> | <p>launch of the record the Lung Cancer Team made joint visits to local practices to speak to general practitioners and district nurses to try to alleviate these concerns. Initial and subsequent reviews carried out with patients and health professionals have been extremely favourable. More health professionals are now writing in the record and recognising its value. The patient-held record has made a major improvement in communication between health professionals, patients and carers. The success of the patient-held record in lung cancer has resulted in it being adapted for use locally in other cancers such as breast and prostate and the initiative is also being considered for use with patients suffering from chronic conditions such as heart failure. The record is only useful if it is kept up to date and this relies on the commitment and ongoing support of both patients and health professionals.</p> |
| <p>Penny L 2002 Health Action fellowship / Luton PCT http://www.harpweb.org.uk/downloads/practical/master.doc</p> | <p>Client held health records for people who are homeless or asylum seekers</p> | <p>Developed a client held record with views of homeless, and health professionals.</p> |
| <p>Warner J. P, King M., Blizard R., <i>et al</i> (2000) Patient-held shared care records for individuals with mental illness: randomised controlled evaluation. <i>British Journal of Psychiatry</i>, 177, 319-324</p> | <p>To evaluate the utility of patient-held shared care records for individuals with long-term mental illness</p> | <p>Patient-held records may not be helpful for patients with long-term mental illness.</p> |
| <p>A. Stafford, R. Laugharne, and K. Gannon Follow-up study of the use of a patient-</p> | <p>This follow-up study aimed to evaluate one pilot project 5 years after the records were introduced. All patients initially</p> | <p>Patient-held records are sustainable in a naturalistic clinical setting over the period of</p> |

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| <p>held record in mental health mentioned above Psychiatr. Bull., March 1, 2002; 26(3): 91 - 92.</p> | <p>interviewed 4 years previously were approached and asked about their use and opinion of the record.</p> | <p>5 years.</p> |
| <p>Williams JG et al Quality in Health Care. 2001 10: 159-65. 2001 http://qhc.bmjournals.com/cgi/content/full/10/3/159</p> | <p>Pragmatic randomised trial to evaluate the use of patient held records for the continuing care of patients with cancer. 344 patients completed study.</p> <p>Health related quality of life (EORTC QLQ-C30) measured at entry into the study and at 6 months; patients' views at 6 months; healthcare professionals' views collected after the completion of patient follow up</p> | <p>The patient held record is valued by some patients and professionals but has no significant impact on the quality of life of patients or NHS resource use. It has a positive impact on quality by helping patients feel more in control and prepare for meetings with healthcare staff. Patients who find it useful tend to be younger and have more professionals involved in their care. It is recommended that it should be made available to patients on request and used by them according to need.</p> |
| <p>Cornfleet M., Campbell P., Murray S., et al (2002) Patient held records in cancer and palliative care: a randomized, prospective trial. <i>Palliative Medicine</i>, 16, 205 -212</p> <p>PMID: 12046996</p> | <p>To evaluate prospectively the introduction of a PHR for patients with advanced cancer and palliative care needs in out patient oncology centres in Glasgow and Scotland and hospice home-care services.</p> | <p>The baseline interview was completed by 231 patients and 117 were randomized to receive the PHR. Between 4 and 6 months later, 80 patients with the PHR and 97 without were interviewed. Of the 83 health professionals caring for patients known to have received the PHR 63 replied to a postal questionnaire. Structured interview at baseline and after 4-6 months. RESULTS: No improvement in the provision of information to patients, or patients' satisfaction with information provided by outpatient doctors, GPs, practice and community nurses and hospice or palliative home care staff. Overall, patients' perception of communication between all staff involved in their care with and without PHRs was excellent in 24% and 21 %, respectively, or very good in 56% and 58%.</p> |

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| | | The PHR made no difference to information passing between health professionals, or to the degree of family involvement. 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 PHRs, although local projects with committed clinicians and patients may well prove popular and effective. |
| <p>Dr Lindsay Crack, Consultant in Palliative Medicine, Marie Curie Centre, Newcastle</p> <p>Dr Kathryn Mannix, Consultant in Palliative Medicine, Marie Curie Centre, Newcastle</p> <p>From Conference papers held in October 1998 on patient held records.¹³</p> <p>See also below</p> <p>Lecouturier, J., Crack, L., Mannix, K., Hall, R. R. and Bond, S. (1999) <i>Care to Communicate? Evaluating a patient held record for patients with cancer.</i> 102, Newcastle upon Tyne: Centre for Health Services Research, University of Newcastle.</p> | <p>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.</p> | <p>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.</p> <p>Conference speaker emphasised the need for extensive consultation to ensure that the professionals who will use the record are involved in generating it.</p> |
| <p><u>Lecouturier et al, 2002</u></p> <p>PMID: 12099947</p> | <p>To evaluate a PHR for patients with cancer. A randomized controlled trial with patients newly diagnosed with lung or colorectal cancer in Newcastle together with surveys of health professionals to</p> | <p>The only significant difference was 86% of control compared with 58% of intervention patients were very satisfied with information received at the end of treatment Fifty-three per cent of intervention respondents found</p> |

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| | <p>gauge views on PHR. Main outcome measures were patient satisfaction with information and communication, and patient and healthcare professionals' views of PHR.</p> | <p>the PHR helpful and 69% felt that it would be useful to them in the future. Primary healthcare (PHC) professionals found the PHR of more benefit than those working in hospitals. The PHR did not improve measures of patient satisfaction with information or communication. Despite its limited use by many health professionals, the PHR was well received by recently diagnosed patients.</p> |
| <p>Dr Mark Drury and Oxford Working Group</p> <p>From Conference papers held in October 1998 on patient held records¹³</p> | <p>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.</p> | <p>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.</p> <p>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.</p> |
| <p>DRURY, M., YUDKIN, P., HARCOURT, J., <i>et al</i> (2002) Patients with cancer holding their own records: a randomized controlled trial. <i>British Journal of General Practice</i>, 50, 105 -110.</p> <p>See also:</p> | <p>AIM: To evaluate the use of a supplementary patient-held record in cancer care</p> | <p>650 radiotherapy outpatients with any form of cancer were randomised either to hold a supplementary record or to receive normal care. After three months, patients' satisfaction with communication and with participation in their own care was assessed.</p> |

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|--|---|---|
| <p>Mark Drury, Jean Harcourt and Michael Minton. Acceptability of Patients with Cancer holding their own Shared-Care Record. <i>Psycho-Oncology</i>, Vol 5: 119-125 (1996)</p> | | <p>There were no significant differences 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.</p> <p>CONCLUSION: A supplementary patient-held record for radiotherapy outpatients appears to have no effect on satisfaction with communication, participation in care, or quality of life. PMID: 10750206</p> |
| <p>Professor Ilora Finlay, Professor of Palliative Medicine and Medical Director, Marie Curie Centre, Penarth</p> <p>From Conference papers held in October 1998 on patient held record¹³</p> <p>see also</p> <p>Ilora Finlay, Nicola Jones, Penny Wyatt and Judy Neil. Use of an Unstructured Patient held Record in Palliative Care. <i>Palliative Medicine</i>, Vol 12: No.5 1998</p> | <p>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. 37 patients recruited.</p> | <p>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.</p> <p>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. 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. Almost half of the patients forgot to write in the record and about a third felt unable to request entries,</p> |

| | | |
|---|--|--|
| | | <p>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.</p> <p>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.</p> |
| <p>Quinn M, Davies MJ, Needles L <i>et al.</i> Handheld patient monitoring and management plan Filofax for people with diabetes. <i>Diabetic Med</i> 2001; 18 (Suppl 2): Abstract A11.</p> | <p>To ascertain whether knowledge of diabetes control and other treatment targets could be improved by the use of a 'Filofax' system.</p> <p>To provide a central record and source of communication to enable seamless care of diabetes between primary and secondary care.</p> | <p>A questionnaire was devised to assess patients' knowledge regarding treatment aims and targets as set out by the Leicestershire Evidence Based Guidelines.¹⁷</p> <p>Three hundred patients were selected at random in the diabetes outpatient department and given the questionnaire to complete as a baseline for the study. Of these, 150 were randomly given the 'Filofax' and 150 were not.</p> <p>After 6 months, a second identical questionnaire was sent out to all patients in both groups.</p> <p>The pilot study showed that patients who received the 'Filofax' showed a greater</p> |

| | | |
|---|---|--|
| | | <p>percentage improvement in:</p> <ul style="list-style-type: none"> • Blood sugar level aimed for • Knowledge of last HbA_{1c} • Knowledge of target blood pressure • Knowledge of name of their DNS • Knowledge of contact number for advice. <p>Knowledge of target HbA_{1c} was good in all patients throughout the study.</p> |
| <p>Managed Clinical Network Team Dumfries and Galloway</p> <p>www.show.scot.nhs.uk/mcn/html/patient_info.html (accessed June 05)</p> | Cardiac patients | Evaluation found PHR was popular with patients and a useful tool but while nurses were good at completing the record, doctors were less so and keeping the record maintained needed further work |
| <p>Cardiac Networks Co-ordinating Group Annual Report 2003/04</p> <p>http://howis.wales.nhs.uk/cardiacNetworks</p> | A patient Held Record has been developed in conjunction with the North Wales Cardiac Network and is currently being piloted throughout North Wales. | A Patient Held Record pilot ran from February to July 2003 and the University of Wales Bangor submitted their Evaluation Report to the Network in December 2003. As a result of positive feedback from patients and health professionals, a recommendation was made to the Network Board in January 2004 for roll-out of the record across the Region. Subsequently a Patient Held Record Launch was planned for the Spring of 2004. |
| Evaluation of the East Suffolk Patient | CHD patients | Internal evaluation findings were |

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| <p>Record 2003 Julie Collier CHD Network Manager, East Suffolk</p> | | <p>Small pocket size diary wanted Simple format needed Patients can be overwhelmed by information, or in a state of shock and when the record is given out to patients needs to take this into account. Patients found it useful, felt more informed about their condition, and felt that it would help them keep a check on their risk factors.</p> |
| <p>Bennett J. CHD patient education morning proves popular. In Reply. <i>Guidelines in Practice</i> 2000; 3 (December): 20.</p> | <p>Review all our patients on the cardiac register. This included patients with the diagnosis of angina, atrial fibrillation or heart failure, and patients who had undergone heart surgery</p> | <p>Events included: A Saturday morning CHD education day for the public A designated clinic with half an hour's protected time for review of each patient. The introduction of a PHR card, with a contract between the patient and the nurse practitioner to address issues such as lifestyle changes. The diary includes Cardiovascular limitations and symptoms profile (CLASP) scores, documenting frequency of angina pain, ankle swelling and breathlessness. We use the Canadian classification of angina scoring system to assess limitation of activity due to angina. A total of 135 patients were seen. in the designated cardiac clinic. 95 (70%) were randomised to receive evaluation questionnaires by post. Patients' comments were skewed towards excellent and very good.</p> |