King's Fund

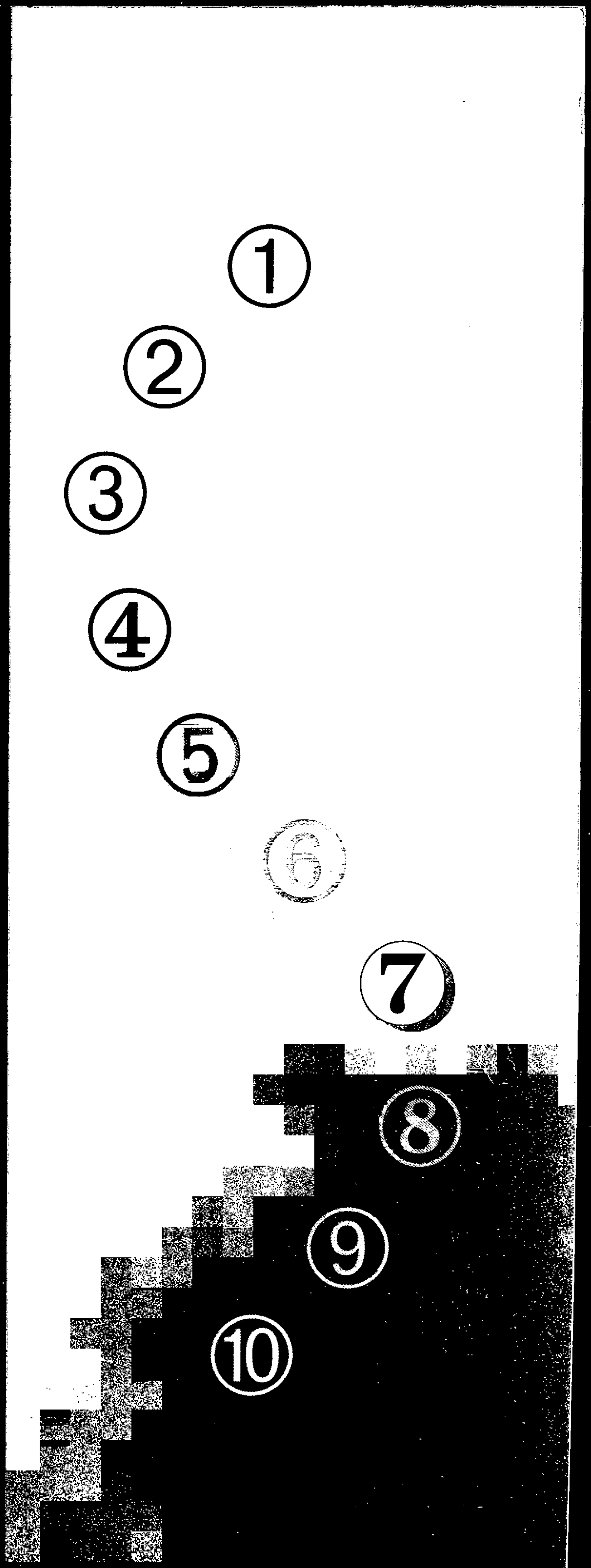
Disseminating Treatment Outcomes Information to Consumers

Evaluation of five pilot projects

Sarah Buckland
Bob Gann

100
YEARS
SUPPORTING
PEOPLE'S
HEALTH
1897~1997

Promoting
Patient
Choice



King's Fund
Publishing
h Square
AN

Disseminating Treatment Outcomes Information to Consumers

Evaluation of five pilot projects

Sarah Buckland & Bob Gann

King's Fund

Published by
King's Fund Publishing
11–13 Cavendish Square
London W1M 0AN

First published 1997

ISBN 1 85717 132 2

A CIP catalogue record for this book is available from the British Library

Distributed by Grantham Book Services Limited
Isaac Newton Way
Alma Park Industrial Estate
GRANTHAM
Lincolnshire
NG31 9SD

Tel: 01476 541 080
Fax: 01476 541 061

Printed and bound in Great Britain by
Biddles Short Run Books, King's Lynn.

Contents

Appendices

Acknowledgements

We are grateful to the following without whom the project would not have been possible:

- Jackie Chapman, Sarah Clark, Vikki Entwistle, Sue Gauge, James Herring, Ruairidh Milne, Mig Muller, Mary Newburn, Sandy Oliver, Helen Thompson and Ian Watt for their contributions and assistance with the evaluation;
- the participants of the workshops who completed the questionnaires;
- Sarah Farthing for her invaluable assistance in the analysis of the data as well as for providing administrative support.

The Help for Health Trust is grateful to the King's Fund for providing the grant to fund this research.

NB: Any views expressed are those of the authors and not necessarily those of the King's Fund or any of the five pilot projects.

Executive summary

- In January 1995, the King's Fund commissioned five pilot projects to improve the delivery of treatment outcomes information to the public. At the same time The Help for Health Trust was asked to carry out an overview evaluation of these pilot projects. These projects sought to identify and develop the skills and knowledge needed by providers of treatment-choice information to consumers. The projects were carried out between February and October 1995 by the following organisations:

  The National Childbirth Trust, London (NCT)
  The NHS Centre for Reviews and Dissemination (NHS CRD) York, and Queen Margaret College, Edinburgh
  Critical Appraisal Skills Programme (CASP), The Institute of Health Sciences, Oxford
  Trent Healthline, Nottingham
  Health Matters, Milton Keynes

- The projects addressed different stages in the provision of information on outcomes and effectiveness to the public. The four main stages are outlined below. Each of the projects overlapped to some extent in their aims and the areas they covered, but can be loosely placed into one of the four stages in terms of outcomes. For example, the NCT project produced a booklet explaining to readers where they could go to find out about different sources of treatment outcomes information (searching for information). Whereas the Trent Healthline Project went further by searching out and selecting the information for readers and then providing an interpretation of that information on one specific area (providing interpretation of information).

  - searching for information (NCT)
  - developing skills to select appropriate information (NHS CRD & CASP)
  - providing interpretation of information (Trent)
  - consumer evaluation and action (Health Matters).

- Three projects with a training focus lent themselves to consistent external evaluation (NCT, NHS CRD and CASP)

- The Trent Healthline project was a pilot study in dissemination of treatment outcomes information to users of mental health services and their advocates. The lack of adequate evidence-based information produced in a format that was clear and accessible to service users led Trent Healthline to develop their own information pack. A more detailed evaluation is necessary to explore possible methods of dissemination and to evaluate the impact of the information pack.

- Health Matters was in a different category since it was itself a research project. The Health Matters study provided some insight into the expectations and information needs of callers to a Consumer Health Information Service (CHIS). Many respondents were found to be unclear about their information needs, but most reported that they would have liked more information than they received, and still had unanswered questions. The project received fewer treatment outcomes enquiries than expected during the study period. No enquiries about treatment outcomes were received from self-help groups and few enquiries were about drug treatments.

- All of the projects were concerned with the accuracy and currency of information. It is important then that provision is made for updating the products – particularly the NCT and Trent Healthline publications. The NHS CRD readings stand alone and would merit wider distribution.

- It was much easier for organisations working within established networks to establish contacts, but this could also lead to those outside the networks being excluded. For example the NCT project was readily able to work with maternity organisations but had difficulty in accessing other consumer health information services.

- It takes time to build up awareness and enthusiasm for clinical effectiveness and outcomes. This work was new to many CHIS whereas NCT had had previous critical appraisal training and were keen to repeat and extend it.

- There were some interesting differences between questionnaires completed by those attending workshops and those completed by consumer health information services in 1994. The level of information provision about treatment outcomes was about the same (we might have expected it to have increased). In both surveys self-help groups remain a major source of treatment information but there appears to be a growing awareness of the deficiencies of medical textbooks.

- We do not yet know whether consumer health information services have become any more effective in dealing with treatment-outcome enquiries as a result of the projects. A follow-up study using Phase One as a baseline to measure change would be worthwhile for the CASP, NHS CRD and NCT projects. The Help for Health Trust has recently received a grant from the NHS Research & Development Programme on Implementation of Research to work with patient organisations to evaluate improvements in consumer health information services since the original 1994 study.

- The projects facilitated a wider understanding amongst CHIS workers of the issues around evidence-based health care and treatment outcomes, but they also enabled different methods for disseminating information to be explored, which could in the future be further adapted and developed.

- The projects highlighted both the importance and the difficulties of providing quality information for consumers in an accessible format.

- The projects were constrained by the lack of resources in both consumer health information services and self-help groups. Consumer health information services found it difficult to release staff from helpline duties to attend workshops. Workshops were constrained by time and organisers needing to keep costs to a minimum.

- These projects assisted in giving CHIS workers a wider understanding of the issues around providing information on evidence-based health care and treatment outcomes, as well as providing further insight into the information needs of consumers. Further resources are needed to take forward some of these initiatives and enable consumer health information services to continue to improve their delivery of treatment outcomes information to the public.

PART 1

EVALUATION

Chapter 1

Introduction

In 1994, the King's Fund commissioned The Help for Health Trust to assess the extent and nature of the dissemination of information about treatment outcomes by Consumer Health Information Services (CHIS) in the UK (Gann & Buckland, 1994). (By treatment outcomes we mean information about the risks and benefits of treatments as well as information to help people choose between different treatment options.) The study found that nearly half (42 per cent) of the 73 services contacted reported dealing with treatment outcomes enquiries frequently, and a further third (38 per cent) occasionally. However, over a quarter of enquiries (29 per cent) were answered by the provision of only verbal information, and the study found low usage of research-based evidence. Over two thirds (69 per cent) of Regional Health Information Services (RHIS) and a half (52 per cent) of local consumer health information services did not feel able to answer enquiries about treatments satisfactorily with the information available to them. The findings from this study illustrated the need for a greater awareness and access to treatment outcomes information for CHIS staff, and the need for more evidence based information aimed at consumers.

In January 1995, the King's Fund subsequently commissioned five pilot projects to improve the delivery of treatment outcomes information to the public. These projects sought to identify and develop the ability and knowledge needed by providers of treatment choice information to consumers. The projects were carried out between February and October 1995 by the following organisations:

The National Childbirth Trust, London (NCT)
The NHS Centre for Reviews and Dissemination, York (NHS CRD), and Queen Margaret College, Edinburgh
Critical Appraisal Skills Programme (CASP), The Institute of Health Sciences, Oxford
Trent Healthline, Nottingham
Health Matters, Milton Keynes

The five pilot projects were selected by the Patient Information Advisory Group (PIAG) at the King's Fund. Each addressed, in different ways, the issues of how to provide research-based evidence to consumers. Three of the five projects were concerned with training health information providers in various aspects of awareness and interpretation of research-based evidence (NHS CRD, NCT & CASP). The Trent Healthline project was concerned with providing mental health services users, and their advocates, with research-based evidence for treatments. The fifth project was carried out by Health Matters, a local CHIS. This was a research project evaluating consumers views of the treatment choices information they had received from the service. Three of the pilot projects were carried out by organisations that were directly involved in providing health information to the public, Trent Healthline, Health Matters and the NCT.

The projects were required to build internal evaluations into their proposals, but the King's Fund also commissioned The Help for Health Trust to carry out an overview evaluation of these pilot projects. This report provides a brief explanation of the pilot projects, describes the evaluation that was carried out by Help for Health and provides a critical overview of the projects and the successes and lessons learnt from the projects.

---

* Throughout this report the project involving The Centre for Reviews and Dissemination, York, and Queen Margaret College, Edinburgh is referred to as the NHS CRD project.

Chapter 2

Background

The process of dissemination

The process of providing treatment outcomes information to consumers involves agencies in:

- eliciting the type and level of information needed;
- searching for relevant information;
- selecting appropriate and accurate information;
- where necessary, providing an interpretation of that information.

The provision of such information helps the consumer to decide whether or not to act on the information provided.

The following factors may influence the quality of information provided by Consumer Health Information Services (CHIS) to consumers:

- the existence of good quality, accessible and understandable evidence based information;
- awareness of the availability of the information;
- knowledge of how to access such information;
- the ability to select, from the information available, information that is appropriate and reliable;
- where necessary, the ability to interpret the information for the consumer.

Diagram 1 illustrates the different stages involved in providing treatment choice information to consumers.

Provision of information by HIS to the consumer

The role of Health Information Services staff in listening to their clients and finding out the sort of information that they would like is crucial. The public are becoming more active in seeking complex information (Buckland, 1994), and in particular, treatment choice enquiries which are often more detailed and complicated. The Health Service Guidelines (HSG (95) 44), which, from April 1996, required CHIS in England and Wales to provide such information, places further demands on CHIS to respond to such requests.

Having established the information needs of the consumer, information services need to know where and how to access the most relevant sources. Many agencies are limited in the sources of information used or available to them (Gann & Buckland, 1994).

A range of information is available to consumer health information services on treatment choices, but the quality and scope of such information varies. In addition, the source, reliability and accuracy of some information is not always apparent. Thus consumer

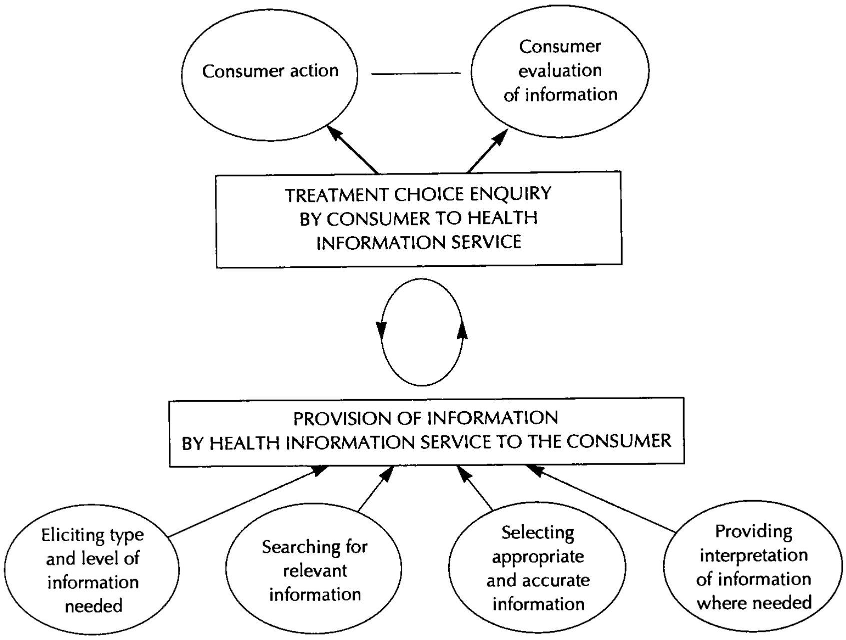


Diagram 1: The process of dissemination

health information services need to be aware not only of the sources and range of information available, but also how to select from these sources information that is appropriate and reliable.

There is an increasing body of evidence-based information being produced, but this does not yet cover all the areas of health on which people need information. In addition, such information has mainly been written for health care professionals and purchasers rather than consumers, and is not always appropriate for consumers.

Searches of databases and other information sources may produce a range of articles on a subject, but it is often difficult for both health information providers and consumers to interpret such information and assess its quality. The language and format in which evidence-based information is produced is often not accessible to consumers. Health information services may be asked to translate and interpret the findings from research studies. The extent to which agencies can and should interpret such information is a current issue of concern amongst consumer health information services.

Consumer evaluation of information and action

Consumers calling CHIS need to evaluate the relevance and usefulness of the information they receive. Factors such as their knowledge, previous experience, and the perceived credibility of the information source will influence whether callers act on the information. However, given the difficulties of interpreting treatment outcomes information, and the lack of consensus on the effectiveness of certain treatments, it is unlikely that many callers will be able to judge for themselves the reliability and accuracy of the information they receive.

Chapter 3

Methodology

Several visits were made to all of the projects as well as, where possible, attending some of the workshops and advisory group meetings that the projects arranged (see Appendix 1 for a full list of the meetings and involvement by Help for Health with the projects). The meetings involved discussions of plans and progress as well as assisting with evaluation plans where appropriate.

Originally the projects seemed very different but as they developed there were many similarities in method and content. Similarities that were emerging between three of the projects (NHS CRD, NCT, and CASP were all training initiatives) enabled us to provide some consistency between these projects. We decided to carry out a limited evaluation by developing and administering a questionnaire. Tight time scales and limited resources meant that a questionnaire was the most appropriate method. The questionnaire included a range of open and closed questions, and was distributed at the end of the workshops for people to complete at home and return directly to Help for Health. This evaluation was carried out in addition to evaluations carried out by some of the projects themselves. The questionnaires covered the following topics: previous experience in providing treatment choice information; reasons for attending the workshop; views on the workshop; and general comments.

In the case of the Trent Healthline and Health Matters projects, such an evaluation was not appropriate. Although there were similarities between Trent Healthline and the other three projects, the nature of the work (disseminating treatment outcomes information to mental health service users and advocacy workers) would have meant that substantial differences in wording and approach would have been needed, and thus comparison would not have been possible. The work being carried out by Health Matters was a research project in itself.

Chapter 4

Aims and objectives

The five pilot projects addressed different stages in the provision of information on outcomes and effectiveness to the public. The aims and objectives of the projects can be usefully placed into the different stages of providing health information identified in Diagram 1 (see page 10). Each of the pilot projects overlapped to some extent in their aims and the areas they covered, but they can be loosely placed into one of four stages in terms of the outcomes of each of the projects. For example, the NCT project produced a booklet explaining to readers where they could go to find out about different sources of treatment outcomes information (searching for relevant information). Whereas the Trent Healthline Project went further by searching out and selecting the information for readers and then providing an interpretation of that information on one specific area (providing interpretation of information). The following is a brief summary of the projects and their aims and objectives.

Searching for relevant information

National Childbirth Trust (NCT)

Aim: To raise awareness of treatment outcomes information in the area of maternity care.

The NCT produced a booklet called *Through The Maze*. This booklet aimed to raise awareness of outcomes research among information services and self-help groups. The booklet provided details of sources of outcomes information on pregnancy, birth and post natal care. Workshops were arranged throughout the UK to introduce maternity and other community groups to outcomes resources, and to disseminate the booklet. In addition, 3,000 booklets were distributed to a range of individuals within organisations including the NCT, CHIS, Community Health Councils, Maternity Alliance member organisations and other maternity related self-help organisations.

Selecting appropriate and accurate information

NHS CRD and Queen Margaret College

Aim: To develop pilot training materials which may enhance the ability of information professionals to provide information about the effectiveness of health care interventions to consumers.

The NHS CRD project developed a training pack to enhance information professionals' ability to provide information about health care effectiveness and outcomes. The training pack introduces the concepts of evidence-based health care, considers the usefulness of specific information sources which aim to present good evidence-based information in a relatively accessible form, and explores issues relating to the provision of information about the effectiveness of health care options to consumers in response to enquiries.

As part of this work the project organised a two-day workshop in Edinburgh to pilot the pack.

Critical Appraisal Skills Programme (CASP)

Aim: To help people in CHIS and self-help groups develop the skills they need to make sense of evidence about clinical effectiveness.

The CASP project went one step further in showing people how to appraise research articles. The project was designed to help people assess systematically the reliability, relevance and results of published materials. The workshops were adapted for consumer health information services. Three pairs of workshops were run for staff from consumer health information services, and one pair for maternity self-help groups.

Providing interpretation of information

Trent Healthline: Dissemination of Mental Health Outcomes Information by Consumer Health Information Services

Aim: To investigate the dissemination of outcome information to users of mental health services and their advocates. To build a model for good practice for the dissemination of such information in this field.

The lack of adequate evidence-based information produced in a format that was clear and accessible to mental health service users led Trent Healthline to develop their own information pack. They have produced a pack on depression, which explains how to interpret and understand treatment outcomes information and provides summaries and explanations of relevant studies.

Consumer evaluation of information and action

Health Matters: Access to Information on Treatment Outcomes

Aim: To gain information about factors affecting consumers' access to outcomes information through CHIS, and the relevance of outcomes information supplied through CHIS to consumers' needs.

This project was a research study looking at: how and why people seek information from a consumer health information service; how staff can effect access to information; and how people use treatment outcomes information to access services, make decisions and participate in their own care. Semi-structured interviews were carried out with 40 people who had called Health Matters (a local consumer health information service) with treatment outcomes enquiries. Respondents were asked about their experiences of contacting Health Matters, their views on the information they received and whether the information they received influenced their decisions on treatment.

The Health Matters project was very different from the other four projects funded by the King's Fund. This project was a research project exploring largely from the consumers' perspective the experience of receiving information from a CHIS on treatment outcomes information; whereas the other projects, to a greater or lesser extent, were involved in educating and training intermediaries in issues around the provision of treatment choice information. It is for this reason that the Health Matters project will be described separately after the other four projects. However, in the final section on general issues, many of the topics raised are relevant to all of the projects.

Chapter 5

Identifying target audiences

Networking/establishing contacts

Table 1

	Networks used	*Difficulties*
NCT	NCT members CHIS members	CHIS Other maternity services
NHS CRD	–	Identifying CHIS providers in Scotland
CASP	NCT members CHIC members	CHIS
TRENT Healthline	Advocacy group CHIS networks	Consultants

A common theme amongst the four projects was the importance of being familiar with the networks that they were trying to access. For example the NCT and CASP projects, through their connections, were able to easily target NCT members. This helped both in terms of identifying people to contact, as well as in physically having access to mailing lists etc. For these two organisations, accessing the more generalist consumer health information services was far more difficult and time consuming. The CASP project set this as an early objective, and invested a lot of time making contact with Consumer Health Information Consortium members (a network of local consumer health information services) and other individuals, trying to enlist their support. By contrast the NCT project concentrated mainly on NCT members and other maternity and childbirth organisations, not being able to make contact with any consumer information services until the latter half of the project. As a result, little CHIS involvement in the workshops was achieved.

For the CASP project, being able to announce the project at the AGM of CHIC assisted in this work, but other factors such as advertising in the CHIC newsletter were not possible within the time scale. For the CASP project, as will be explained later, involving local organisers in the planning and publicity of the workshops was an integral part of the project, and one which placed a reliance on those organisers to assist in identifying and encouraging people to attend the workshops.

The Trent project from the outset worked with the Nottingham advocacy group in the development of the project. The advocacy group assisted in arranging their meetings with self-help groups, apart from Depressives Anonymous who were contacted directly.

Trent Healthline did not however succeed in eliciting the views of consultants. The original contact they had at the hospital left, and as a result of a prolonged correspondence, they ran out of time. This was not a serious concern as their primary contacts were consumers rather than health care professionals, and they gained valuable input from other health care professionals.

The NHS CRD project spent considerable time identifying general health enquiry services in Scotland. This may in part have been because the original project leaders were not based within consumer health information services in Scotland, but there were other contributing factors. This project made various attempts to involve CHIS in the design and development of the project, but in practice the bulk of the contribution came from the core workers based at NHS CRD and Queen Margaret College. Questionnaires were distributed to various organisations in Scotland in an attempt to identify consumer health information providers and establish the extent to which they provided outcomes information and their likely interest in workshops on different topics. They found few services that were actively providing treatment choice information, and little contact between the different organisations. Thus there did not appear to be the same network of organisations as there is in England and Wales.

The CASP and NHS CRD projects commented on how much longer than planned this initial stage took, but also how essential it was to ensure the success of the rest of the project, both in enabling them to ensure interest in the workshops and also to see that the contents of the workshops were appropriate to their target audiences.

Issues Raised

- It was easier for organisations to enlist the support of target audiences already within their active network than those beyond it
- Considerable time is needed to develop links and establish contacts, particularly when relevant networks do not exist

Chapter 6

Organising workshops/group sessions

Table 2

	Type of workshop / session	*Number and Location*
CASP	Training workshop in critical appraisal skills	Four pairs of half-day workshops: Birmingham Bristol and London.
NHS CRD	Training workshop	One Two-day workshop Edinburgh
NCT	Workshops to raise awareness of outcomes information.	27 workshops One to two hour sessions Throughout the UK
TRENT Healthline	Consultation prior to production of information pack	6 user groups 2 staff groups Various individuals Nottingham area

Three of the projects were involved in organising training and/or awareness raising workshops (NHS CRD, CASP and NCT). The Trent Healthline project organised less formal sessions with various staff and user groups to discuss the problems and benefits of users having treatment outcomes information, and ways to improve this provision. This included discussions of the type and style of information that they would find useful from an information pack. The Trent Healthline project was different from the others in that initial consultations were held, followed by production of the information pack. The pack was subsequently evaluated through group discussion sessions.

As can be seen in Table 2, there was considerable variation in the length and number of workshops held, ranging from the NCT project which held 27 workshops, to the NHS CRD project which organised one 2-day workshop. This difference is a reflection of the varying nature of the projects and the other activities they were involved in. For the NCT and CASP projects, the organisation of the workshops appeared to be greater than for the other projects. For the NCT, this was mainly because of the logistics of organising a large number of workshops throughout the UK. For the CASP project, this was because of the need to make contact with people in the areas, enlist their support and arrange venues.

The organisers of the workshops/meetings

The NCT and Trent Healthline projects took advantage of opportunities in some instances to piggy back their agenda onto existing meetings. In the case of the CASP project, they worked with local CHIS and NCT members to plan and organise the workshops, although the workshops were organised as separate events. Piggy backing onto other meetings had both advantages and disadvantages for the projects. Such a method made the organisation of the workshops or group sessions easier, as well as minimising the costs involved. This was particularly true for the NCT project where meetings were arranged throughout the UK and the local organisers took responsibility for providing venues and publicising the meetings. For the CASP project, where the involvement with local services was slightly different, their approach enabled CHIS to share the ownership of the events which helped in encouraging commitment and attendance, as well as assisting with the practical aspects of organising the events. The CASP project felt however, that they would have liked more time to support those helping with the workshops to do more themselves, and thus it was not as empowering as they would have liked.

Some of the disadvantages mentioned by the projects, of not being in control in organising the events, were the lack of control over who attended (mentioned by CASP, NCT and Trent Healthline), and the length and format of the sessions. Thus for example, the NCT project commented that sometimes people at the workshop sessions were there for another reason and had not consciously chosen to attend the NCT project workshop. Also, the projects were dependant on the organisers for the length of time available to them.

Arranging workshops

The NCT were able to use their networks to enable the project worker to stay overnight with NCT people, rather than in hotels and thus reduce costs. Without such support, it would not have been possible to cover such a wide geographical spread. Similarly for the CASP project, there was no funding for the cost of venues or catering and thus the project was dependant on the networks of the local organisers to help in finding free venues.

The location of workshops for the CASP project was restricted to being within driving distance of the project worker's home, again to minimise financial costs. For the NCT project, decisions were made to cover as wide a geographical area as possible including Scotland, although a few offers of venues were turned down for financial reasons. It was felt by the NCT project that some of the visits could have been better co-ordinated so that a group of workshops was run in the same area at one time.

Availability to attend workshops

A problem raised by two of the projects was the difficulty for CHIS staff to send more than one or two people to attend training courses. Thus for example, the NCT project offered to run workshops about the booklet for individual CHIS, but for most it was not possible for sufficient numbers to be able to attend, as they obviously could not close the service and they needed to have enough staff available to answer calls. The NCT project commented that, on reflection, it would have been better for CHIS staff if they had written earlier to them, telling them about workshops that they had planned in their area, so that they might have been able to hook in to workshops already planned by

NCT members. To a lesser extent this was also an issue for the CASP workshops, in that it limited the numbers from any one CHIS being able to attend a particular pair of workshops. However, CHIS providers were able to choose from several dates and venues (although some might not have been nearby), and as a result some CHIS sent staff to different workshops. A difficulty linked to the nature of CHIS was that CASP initially had problems enlisting the support and involvement of CHIS in some of the areas, particularly London. There were various possible reasons for this, but it may in part have been a reflection of the organisational structure of CHIS, which are often small, with only one or two staff and thus unable to commit time to assisting in the training of other CHIS providers.

Attendance at the workshops

Table 3

	Target Audience	*Actual Participants*
NCT	Mix of NCT, other maternity organisations and CHIS	245 NCT members 13 CHIS providers 9 community groups 267 people total
NHS CRD	20 CHIS providers	17
CASP	75 (max.) – at CHIS workshops 25 (max.) – at maternity self-help groups	43 – attended 2nd pair of CHIS workshops 23 – attended 2nd pair of maternity workshops
Trent Healthline	User and staff groups	35 people – user groups plus staff groups

The NCT and Trent projects were less formal sessions, and thus although they set targets in terms of the range of groups they wanted to contact, they did not set targets for the numbers of individuals.

Trent Healthline

Trent contacted a variety of different groups to discuss the provision of treatment outcomes information. These included the Nottingham Advocacy Group, Depressives Anonymous, and patient groups attached to mental health teams as well as the Community Development Worker of the Black Mental Health Organisation. In addition they had meetings with several staff groups and individuals, namely the staff of the Nottingham Healthcare NHS Trust's library services, a Senior Pharmacist, one of the community mental health teams, and the mental health advisor of the DHA. It was decided not to contact GPs in the area because of the lack of time available.

NCT

This project achieved contact with a large number of individuals (267 in total), throughout the UK. Response from NCT members was good, with large numbers wanting to be involved. However, the numbers of non NCT members was particularly small, with only 13 people from CHIS, and 9 people from community groups attending. Those from community groups included people from a linkworker scheme for Asian women, and staff from an advice agency for women. The staff from CHIS were all from three regional consumer health information services. Some of the reasons for the low numbers of CHIS staff have already been highlighted, namely the difficulties of involving whole consumer health information services in a workshop, as well as the late invitation to many individuals.

CASP

As with the NCT project where both maternity self-help groups and more generalist CHIS were invited to attend, there was a far greater enthusiasm and uptake amongst maternity self-help groups, and in particular, NCT members. The maternity self-help group workshop was fully subscribed, with 23 people attending the second pair of workshops, (21 attended both), whereas two of the CHIS workshops were undersubscribed. Only 43 out of a potential maximum of 75 attended the second pair of CHIS workshops (37 attended both), despite extensive work to enlist the support and involvement of CHIS staff. The issue of the differing response between these two groups was discussed at one of the CASP advisory group meetings and various reasons were speculated. For instance, in the previous year, NCT had asked CASP to provide a workshop for their members, which proved to be very successful. Thus when this second workshop was advertised, many had heard about CASP from others and wanted to attend themselves. Other reasons given for the enthusiasm amongst NCT members were the commitment of NCT staff in assisting with the organisation of the workshop, and the advantage of knowing the system and many of the people involved. It was also pointed out that the size of the organisation (400 branches throughout the UK), meant that there was a greater pool of people who might be interested.

Amongst CHIS staff, as has been mentioned before, some of the difficulties arose from the limited time to either gain the commitment and involvement of local organisers, or to publicise through CHIS networks. The last of the three CHIS workshops was the best attended with 25 attending the second of the pair of workshops. It is ironic that in this area it was hardest to obtain a venue and local organisers to assist. The London location of this workshop may have made a difference to the response. It is also possible that by being the last workshop, which was run at the end of the summer in September, there had been time for people to hear about CASP and get feedback from those attending earlier sessions.

NHS CRD

The NHS CRD workshop was oversubscribed, and organisations were limited to only sending one person. Twenty-one were invited to attend; however four did not turn up thus only 17 attended. Approximately 10 were directly involved in providing health information, the rest were interested in the provision of health information for various reasons. They included quality managers, purchasers, and researchers. There appeared to be considerable interest in the provision of research-based evidence to consumers although few in Scotland appeared to be providing it.

Issues Raised

- Practicalities of organising workshops
  - For two of the projects (NCT and CASP) there were hidden costs in terms of venues, accommodation, and travel (for the organisers and/or those attending)
  - Difficulties of organising workshops away from the project leader's work base (CASP, NCT)
  - The value of involving local people in organising workshops (NHS CRD, CASP)
- Availability of CHIS staff
  - The limited numbers of staff in many CHIS made it difficult to arrange training
  - Encouraging commitment and involvement in workshops takes time
- Attendance at workshops

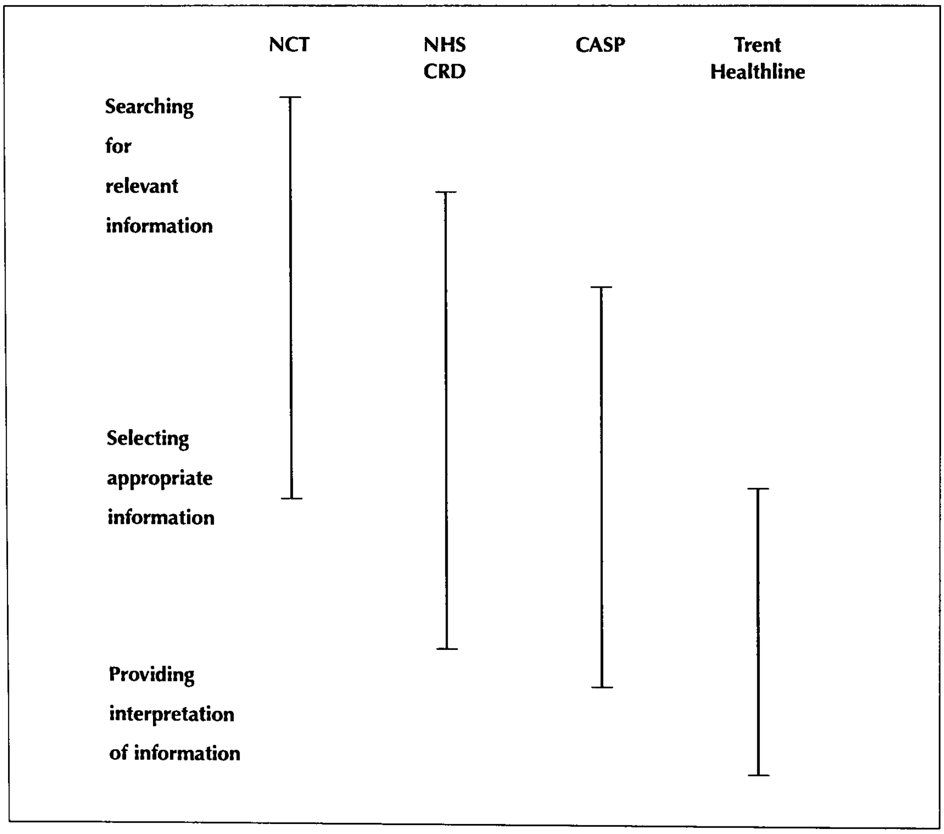
  The numbers of CHIS staff attending the NCT and CASP workshops were smaller than anticipated. It is likely that a combination of the following factors contributed to the comparatively small numbers of CHIS staff attending:

  - small organisations, often difficult to release staff to attend
  - distances to travel to workshops (particularly CASP workshops)
  - unclear of the value / purpose of workshop(s)
  - timing and nature of publicity
  - time of year (Summer)

Chapter 7

Dissemination of information

Different stages of information provision by four of the pilot projects



The NCT project largely aimed to introduce readers to the varying reliability of different sources, whereas the NHS CRD project went further in introducing issues associated with providing research-based evidence. This project concentrated on sources where someone else had appraised the articles or reviews. This was in contrast to the CASP and Trent Projects where the participants were taken back to the original sources, such as particular randomised controlled trials (RCTs) and in the case of CASP, participants were encouraged to appraise articles themselves. For the Trent project, in producing the information pack, the project leader pulled together abstracts of reviews and RCTs and where necessary interpreted them into a format that was accessible to mental health service users and their advocates.

The NHS CRD, CASP and NCT workshops were primarily aimed at dissemination. Although each of these projects produced accompanying materials the workshops themselves also provided awareness training. The Trent project was different in this respect. The consultation sessions were arranged prior to production of the information pack and served a more exploratory role.

Table 4

	Content of workshops/sessions	*Content of information packs/readings/booklets*
NCT	Questions asked by women Sources of information currently used Strengths and weaknesses of sources Using the booklet Discussion of the booklet	Brief introduction to critical appraisal Glossary of terms Sources of systematic reviews of evidence Maternity and parent support organisations Books, journals and other sources
NHS CRD	What kinds of information do consumers need? What is evidence-based health care? Sources of evidence-based information Why is information about outcomes different? Roles of CHIS in information provision Presenting information about outcomes	Introductory case study Evidence-based health care What does an evidence based approach involve Giving research-based information to consumers Useful sources of information about health care effectiveness
CASP	Introduction to key concepts Critical appraisal in small groups: (a RCT and a systematic review) Feedback from groups Evaluation	Pre-workshop pack – materials for workshop 1 Pre-workshop pack – materials for workshop 2 Post workshop pack – reference materials
Trent Healthline	Problems and benefits associated with providing treatment outcomes information How provision could be improved.	Discussion of treatment outcomes Effectiveness of various treatments for depression Treatment comparisons Discussion of talking treatments, drug treatment, ECT, complementary therapies

Chapter 8a

The workshops

Table 5

	Format of workshops or sessions
NCT	– Informal – Varied depending on time available and audience – Content and format designed by project staff
CASP	– Formal – Structured sessions and discussion groups – Content and format adapted from other CASP workshops. Topic areas chosen by planning teams of potential workshop participants
NHS CRD	– Formal – Structured sessions and discussion groups – Content and format designed by project staff
Trent Healthline	– Informal – Depended on audience – Content and format designed by project staff

The format of the workshops and sessions reflected their different objectives. The Trent Healthline project in particular, but also to a certain extent the NCT project, was seeking the views of potential users of the information packs or booklets that they were producing. These sessions were therefore less structured, and whilst both, through the process of discussing the information, were seeking to raise awareness, they were less obviously training sessions than the CASP and NHS CRD projects.

Changes to workshops

All four projects at some stage adapted the workshops to a greater or lesser extent. The NCT project workshops varied depending on the number of people and the time available. In addition, the initial workshops were pilots, which concentrated on seeking people's views on the format and content of the booklet, whereas in the latter half of the project the emphasis shifted towards increasing awareness of sources of research-based evidence. Both the CASP and NHS CRD projects made minor changes to the workshops in the light of comments from people attending. For the NHS CRD workshop, changes were made to the emphasis of the second day to allow greater discussion of the issues around whether CHIS should be providing treatment choice information to the public, as well as generally allowing more discussion time. The CASP project adopted more formal methods for adapting the workshops. Planning teams were invited to identify topics for study. Workshop participants were asked to complete at the end of each workshop an "Improvement Form", allowing them to comment on how the workshop might be improved. These were then used by the project organiser to see if any changes could be made to future workshops. One suggestion, which was acted on, was to make all the sessions interactive. In addition, at the end of each CASP workshop, the participants and facilitators were asked separately to give their views on the session.

Chapter 8b

Developing content of materials

The focus of the information packs, readings, and booklets produced by the projects were different and took varying amounts of work to produce. The main method of dissemination for the CASP project was the workshops themselves and thus the accompanying written information was brief. Whereas at the other extreme, the main method of dissemination for the Trent Healthline project was the information pack itself and the meetings and group sessions were also used to influence the development of the pack. Further group meetings were subsequently held to evaluate the pack. The focus of the NHS CRD and NCT projects were between these two. Both the NHS CRD readings and the NCT booklet were designed to stand alone, and yet the workshops were themselves seen as also being a part of the dissemination process. The workshops were also used to inform the development of the readings and booklet. For the NHS CRD, and Trent Healthline projects the production of the information packs was on a small scale, whereas for the NCT project 3,000 booklets were distributed to a range of individuals within different organisations including the NCT (over 2,000), CHIS (80), Community Health Councils (207), Maternity Alliance member organisations (64) and other maternity related self-help organisations (73).

Content of written material

NCT

Piloting worked well, and as a result changes were made to the format and content as well as the title of the booklet. The pilot workshops highlighted the importance not only of knowing which sources of information were available and most reliable, but also the need for these sources to be accessible. Concerns were also raised over the need to provide information even where there was no rigorous research available. In discussion with the advisory group, it was decided that the core of the booklet should only include sources of systematic reviews of evidence, but that other organisations and sources would be included at the back of the booklet.

NHS CRD

Originally it was planned that a training pack would be produced to accompany the workshop, which would enable others to carry out similar workshops in the future. However, as the project developed this view changed and the resulting product was a set of readings broadly based around the topics of the workshop, with copies of the exercises used in the workshop, and a glossary of terms. Each chapter begins with a summary and the objectives for the chapter. The readings are a substantial document which is over a hundred pages long and explores a range of issues that were discussed at the workshop. They would not however be enough on their own to equip others to run a similar workshop, and they do not include copies of the overheads used. There were three main reasons why the training pack shifted emphasis. One was a time constraint, as the project took more than the budgeted time, and to produce a training pack it would have been necessary for considerably more work to produce guidance notes etc. The second reason for producing readings rather than a training pack was because they were felt to be of more use to a wider audience. The readings could stand alone and be read without the need to attend a workshop. The third reason was a concern expressed by one of the project leaders that people would need more knowledge than a training pack could provide for them to be able to run a similar workshop. Some of the issues raised at the workshop were difficult for the project leaders to answer, and thus it was felt that those attending would not be suitably equipped to answer such enquiries if they were to run a workshop themselves.

The workshop and readings were almost exclusively about English sources of research-based evidence. The project leaders had made various unsuccessful attempts to include Scottish materials, but it appears that at the time no regularly published evidence-based information sources were produced in Scotland. Attempts to include speakers at the workshop from Network Scotland were also unsuccessful, as they were unable to attend at short notice because of pressures of work. To those attending the workshop therefore, the impression may have been of an almost exclusively English emphasis. The project leaders could maybe have explained the various attempts they had made to include a Scottish input, to prevent those attending feeling that the approach was unnecessarily English biased.

CASP

The workshop packs were similar to those prepared for other CASP workshops, but certain adaptations were made to fit with the needs of CHIS. As a result of discussions with the local planning teams, the materials were refined and circulated for comment before the final version was printed. For the CASP workshop the major work for the packs was in identifying appropriate topics and published papers for study and developing appropriate scenarios to link with the research reports that had been selected. These were different for each of the four workshops and the topics had been chosen by the planning groups. The involvement of the local planning groups at this stage was felt to be important in ensuring that the topics were appropriate to the group. If the topic was wrong, it could distract people from the methods being taught. Sandy Oliver worked with the first group to develop the objectives which would form the basis of the workshops and be included in the information packs. However, because of limited time, the others were sent the objectives to comment on.

Trent Healthline

The development of the information pack for this project was the most complex and inevitably took up the bulk of the project's time. This project differed from the other three in that it went further, by interpreting evidence-based information into a form that could be used by consumers and their advocates, rather than training and educating people in how to understand such information. Thus a lot of time was spent reviewing the literature and summarising it into an accessible format. Various issues arose in the production of the information pack. The project leader found that there was not enough clear, readily available information that they could use without adapting.

The following are some of the major issues that this project had to address:

- dealing with differing medical opinions
- the variable quality of information that was available
- the extent to which the pack should make judgements on the quality of the evidence
- producing an accessible resource which also reflected the complexity of the topic

Time constraints limited them achieving as much as they planned, so that they were unable to include all the information in the guide at the same level of detail.

Issues Raised

- All of the projects adapted and developed their workshops and groups sessions
- For the CASP workshops the main emphasis for dissemination was the workshops themselves, whereas by contrast for the Trent Healthline project the emphasis lay in the production of the information pack
- The level of awareness of participants in the workshops varied and all of the projects discussed the difficulties of deciding at what level to pitch the workshops and/or written materials

Chapter 9

Feedback and evaluation

In the original bids all the projects were required to outline their plans for evaluation. All of the projects sought some feedback throughout the projects, through comments from those involved in the workshops and sessions. In addition, the NHS CRD, Trent and NCT projects sent copies of their written materials to external people for comment, and the CASP and NCT projects discussed the content of the workshops at their advisory groups.

Internal evaluations

Three of the projects carried out their own evaluations (NCT, Trent and CASP). It was agreed that it was not necessary for the NHS CRD project to carry out an evaluation themselves, as the money for an evaluation was removed from their proposal under an understanding that Help for Health would evaluate the project.

CASP

CASP used methods for evaluation that are used in the evaluation of all CASP projects. In addition to discussions at the end of each workshop, participants were asked to complete before and after questionnaires to assess the impact of the workshops on knowledge and practice. Unfortunately the project is dependant on the assistance of an external person in the interpretation of these data, and as a result these questionnaires have yet to be analysed. In addition, the project asked participants to complete an improvement form after each workshop. These were largely used by the organisers to develop the workshops during the lifetime of the project, but some of the data were also analysed for wider application. The majority of participants felt the workshops were a good or excellent use of their time, and all reported enjoying the workshops. For further details of the CASP project and their evaluation, see Oliver & Milne 1995.

NCT

It was agreed that evaluation of the NCT project should be a joint initiative with The Help for Health Trust evaluating the views of those who attended the main workshops, and the NCT distributing briefer questionnaires to a sample of those who were sent the booklets, as well as to those attending the pilot workshops. Thirty pilot forms were analysed by NCT. In addition, evaluation forms were distributed with 786 copies of the guide. Only 12 per cent (95) were returned during the timescale of the project (a further 11 were subsequently returned). This low response rate was in part due to the short deadline to return the questionnaires, and that respondents were not sent stamped addressed envelopes or reminder letters (owing to the limited funding and time available). The main responses came from NCT (29), but 13 forms were returned by CHIS staff, and 28 by Community Health Councils. The majority of those sent booklets who returned the questionnaires (80/106) thought that there was the right amount of detail in the booklets. Half felt that they would definitely use the booklet and a further quarter that they probably would. The booklet was described by respondents as being clearly presented (n=13), compact and comprehensive (n=13) and bringing all the information together (n=20). Few criticisms were given, although the colour of the cover was most often cited (n=12)! Respondents were also asked whether the booklet had informed them of sources that they hadn't heard about before – over half said that it had. Interestingly the main sources identified were also those mentioned by participants to the NCT workshops, namely the NHS Centre for Reviews and Dissemination and the Cochrane Collaboration (see Part 2). For further details of this project and their evaluation, see Gauge and Newburn 1995 (2).

Trent Healthline

The Trent Healthline adopted a more qualitative approach to evaluating their information packs. The project leader described the evaluation as a "pilot formative evaluation", acknowledging the time limitations of the evaluation. The usefulness of the packs was evaluated through contacting two different groups: user groups and advocates, and staff of local consumer health information services. In addition the user and advocacy groups were asked to discuss the appropriateness of the content and format. It was decided that group discussions would be the most appropriate method of evaluation for the target audience, allowing participants to explore their views in a familiar and supportive setting.

The decision that the project leader should, through group discussions, elicit the views of these different groups was pragmatic as there was no-one else available to run the group sessions. However, various attempts were made to encourage negative responses. The information packs were distributed at the workshops to allow for immediate responses to be elicited, although it was hard for individuals to provide detailed comments as the packs were large and complex. The project leader commented that ideally a second evaluation should occur when users have had more time to evaluate the pack. The user groups, advocates, and those CHIS who were consulted, valued the pack and felt that it was useful. Participants at these workshops discussed the ways in which the pack could be further improved. One of the issues raised was the dilemma between "simplifying the material so it is more understandable and giving people enough detail and terminology to effectively make their case" Thompson, p30, 1995(1). For further details of this project and its evaluation see Thompson, 1995(1).

External validation of the information provided

All four projects consulted both the expertise within the organisations where they worked as well as external advisors. Two of the projects (CASP and NCT) established advisory groups to comment on the development of the projects. The NCT advisory group only met once, but they were sent drafts of the information booklet to comment on the content and format. The Trent Healthline and NHS CRD projects sent copies of their information packs/readings to external people for peer review.

Table 6

	External involvement in the projects
NCT	Advisory group of professionals and lay experts in research and consumer health information Copy sent to all entrants in booklet for comment and checking
NHS CRD	Peer reviewed – CHIS staff, Health Information lecturer, Information Manager, Royal College of Surgeons, Sheffield Centre for Health and Related Research (SCHARR)
CASP	Advisory group of professional and lay experts in the field
Trent Healthline	A range of professionals including: psychologist,psychiatrist, psychotherapist, counsellor, pharmacist

Issues Raised

The limited time and resources to carry out proper evaluations was a problem for all of the projects, and thus although they give some indication of the success of the projects, their contribution is inevitably limited. In addition, the effects of these projects on their target audiences need to be assessed over a longer time period, once individuals have had a chance to use and reflect on the value of the resources produced.

Chapter 10

Future

The projects were funded with the aim of developing methods for CHIS to improve the delivery of treatment outcomes information to the public. Each of the four projects described above produced a product or outcome that assisted in this process. All were in many ways just at the beginning, in that time is needed to see the effects that these projects have in the future on the quality of information provided to consumers.

The Trent project pro-actively developed a resource pack on a specific topic and explored the role of CHIS in selecting, presenting and evaluating material for the pack. The complexity of the material led to advocates and certain users being seen as the main audience although the introductory section is accessible to more users. It was felt that it could also be used as a resource by CHIS to answer specific queries, although its major use would be in working face to face with users.

The NHS CRD readings and the NCT booklet, although disseminated initially through workshops, were felt to be documents that could stand alone and be used by a variety of intermediaries to understand the nature of evidence-based medicine and the sources available.

The CASP project, like the NHS CRD project, aimed and succeeded through the workshops in increasing awareness and understanding of research-based evidence amongst a number of providers of health information.

The participants of the workshops were at different stages in their awareness and acceptance to provide treatment outcomes information. Those attending the Edinburgh workshop run by NHS CRD and Queen Margaret College were less ready to provide such information to the public than those attending the CASP workshops.

It was hoped by the CASP project leaders that some of the participants would be able to take the work further and provide training for others in the future. Twenty people who attended the CASP workshops expressed an interest in further involvement in running workshops in the future. However, only NCT members succeeded during the lifetime of the project in planning to organise more workshops themselves. It was felt that the others were new to the concepts and that it would take longer for them to reach that stage. The structure of the NCT also made such progress easier as the networks were in place for further dissemination, whereas amongst CHIS the organisations were smaller and thus less able to pass on the information and skills. The CASP project arranged a "Taking it Forward" event at the end of their project to which participants at all of the CASP workshops were invited. This workshop was used to gain feedback on the workshops as well as discuss views as to how both CASP and CHIS could go forward to improve the provision of treatment outcomes information to the public.

Chapter 11

Health matters

This section provides an overview of the Health Matters project. This project is reported separately as it was a research project in itself, and thus different from the other projects which were concerned with piloting methods to assist in the dissemination of treatment outcomes information to the public. The Health Matters project sought to explore the expectations and information needs of callers to their Consumer Health Information Service.

Identifying a sample for interview

One of the major problems encountered by this project was in gaining sufficient numbers to interview. The original proposal was to interview thirty people who used the CHIS to enquire about treatment choices. In negotiation with the King's Fund, additional funding was offered for the project to increase the number of interviews to 50 so that some treatment enquiries on drugs, and enquiries from self-help groups could be included. In practice, only 40 people were interviewed. None of those interviewed were from self-help groups and only a small number were specifically about drug treatments. However, the project leaders kept the King's Fund informed throughout the project of the difficulty in recruiting sufficient numbers, and the King's Fund was told from the outset that, although if possible they would be included, enquiries were rarely received from self-help groups.

In an attempt to increase the numbers of respondents, it was agreed that interviews would be carried out both with people who had recently contacted the service as well as those who had used the service over the previous five months. Originally there had been some concerns that the quality of information from the latter group of people would be reduced because of difficulties of recall. However, such interviews did enable more people to be interviewed and provided some insight into the use made of information provided by consumer health information services in the longer term.

Nature of enquiries

There is no mention made in their final report of the types of enquires received from the public and so it is not clear how many of the enquiries related to drug treatments, although we were informed that the numbers were low. In addition, during the study period there were no enquiries from self-help groups about treatment choices. Some self-help groups have excellent information themselves, but others do not. The lack of self-help group enquiries raises worrying implications for the quality of information provided by some of these organisations.

Number of enquiries

The number of requests for treatment choice information was smaller than anticipated. The report comments that only one person phoned specifically requesting treatment choice information and that most didn't have specific requests, although all interviewed had been given treatment choice information. This appears to contradict earlier findings by the authors (Gann & Buckland, 1994) where agencies reported a higher proportion of such enquiries. However, in this earlier study, no distinction was made between calls which were specific about treatment outcomes and those where treatment outcomes issues were discussed as part of the telephone conversation.

The method adopted for recruiting people for interview who had recently contacted the service was for staff to explain to callers about the study and to send them a letter and form asking them to return it if they were willing to be interviewed. This method was not possible for those who had used the service over the previous five months, and so Health Matters used their enquiry records to identify and contact these individuals. This method achieved a low response rate despite follow-up letters being sent to those who did not respond. Forty-four per cent (31) of those who had recently contacted the service, and 47 per cent (26) of those who had contacted the service over 5 months previously replied to the request to be interviewed. However, 2 of the former and 5 of the latter group refused to be interviewed. (A further 10 were excluded from the sample because they were found not to meet the criteria for interview.) Such a low response rate raises questions over the validity of some of the findings.

The project leader identified two possible ways in which, on reflection, the response rate might have been improved: remembering to ask all callers, and the way in which callers were asked, may have influenced the response. The staff were given written explanations of what they should ask callers but it was felt that a brief discussion of how best to explain the study might have improved the response.

One further method commonly adopted by researchers, but one that Health Matters did not wish to adopt for fear of pressurising clients, was to write to everybody explaining that they would be telephoned to request their participation in the study unless they contacted the service to say they did not want to be contacted.

Interviews

Piloting of the interviews was successful, and it was not found to be necessary to make any major changes to the interview schedule. Interviews were successfully arranged and completed with 40 respondents. It was felt that using a qualitative approach was more informative than a structured questionnaire. The interviews were, however, fairly structured but were not tape recorded, thus the level of information obtained could not be very detailed. The researcher commented that the interviews started by covering relatively safe or impersonal issues about what they thought of Health Matters, and although this made the introduction easier, she felt that in some cases, it made it difficult to shift and discuss respondents information needs in greater detail. It was also felt that the introductory letter focused on seeking callers' views of the service provided, rather than the value of the information received, which encouraged an overly positive response from callers, who felt the service was at risk of closure.

Main findings

The project provided some insights into the expectations and information needs of callers to a CHIS. The study found that many respondents were unclear about their information needs and were dependant on the staff at Health Matters to interpret their needs. The information provided was however well received and nearly half felt more confident having received information from Health Matters. The staff at Health Matters provided information to respondents in a variety of formats which was appreciated. The research found that a substantial proportion welcomed the technical information that was provided (although many could not understand all of it). In addition, the project found that most respondents reported that they would have liked more information than they received and that they still had unanswered questions. Such responses leave questions about the reasons why respondents did not receive all the information they wanted. Was it because such information was not available, that the staff did not have access to such information, or that the callers did not clearly express the type of additional information they wanted? It would have been interesting to look in greater detail at the types of questions that remained unanswered. On the issue of people wanting technical information, but not being able to understand it, it would have been useful to look at the type of information they received that they felt was difficult to understand.

General issues

Independence of researcher

The researcher was independent of Health Matters, although based within the organisation for much of the project. This independence was stressed to the respondents in encouraging them to participate and speak openly. Working closely with the organisation, while maintaining some independence, allowed the researcher the familiarity with the subject matter, while at the same time being detached from the work. The extent to which respondents were aware of this independence is less clear, given that some appeared to agree to be interviewed because they were concerned that the service was at risk.

Timing

Health Matters experienced similar difficulties to the other four projects in terms of getting the project started quickly and carrying out the bulk of the interviewing over the summer holidays. The project leader did not cost her own time into the project and this proved to be more time consuming than anticipated.

Issues Raised

- The project highlighted consumers' desire for more information, coupled with a lack of awareness of the range of information available
- The project experienced less treatment outcomes enquiries than expected during the study period
- No enquiries about treatment outcomes were received from self-help groups, and few enquiries were about drug treatments

PART 2

QUESTIONNAIRES TO CASP, NHS CRD AND NCT WORKSHOP PARTICIPANTS

Chapter 12

Introduction

Questionnaires were sent to people attending the CASP and NHS CRD workshops as well as the main NCT workshops (i.e. not the pilots). Questionnaires were distributed by the project organisers at the end of the workshops. For the CASP and NHS CRD workshops, where the names of participants were known, reminder letters were sent a couple of weeks after the workshops. This was not possible for the NCT workshops as the organisers did not have the names and addresses of the people who attended.

Response rate

Table 7

CASP	*NHS*	*CRD NCT*
82% (54/66)	88% (15/17)	31% (47/153) approx

The response rate from the CASP and NHS CRD workshops was excellent. The response rate from the NCT workshops is an estimate as it was not clear exactly how many questionnaires were given out. The response rate from those attending the NCT workshops appears to be much lower, mainly because it was not possible to send reminder letters, but also possibly because not all of those attending were interested in the project. This was because some of the workshops were arranged as a session within an existing meeting, and several commented that they did not realise that there was to be a presentation about the booklet. Thus, some may not have been interested in the project.

Role of people attending workshops

Table 8

	CASP	*NHS CRD*	*NCT*
Helpline worker	33	9	23
Researcher	10	5	1
Trainer / teacher	7	1	11
Librarian	10	1	2
Health Service Manager	5	2	1
Policy maker	2	0	0
Other	5	3	15
	n= 54	n= 15	n= 47

NB: Some people gave more than one response in describing their role

At all three types of workshops, a large proportion of those attending described their role as providing health information or being a helpline worker. CASP workshops had a greater proportion of librarians (10/54), 5 of whom also described themselves as helpline workers. Many of the researchers in each of the workshops also described themselves as helpline workers. The higher proportion of librarians at CASP workshops reflects one of the objectives which was to show how CHIS and librarians can share their interests, skills and resources and to find and explain information for the public.

Providing treatment outcomes information

Table 9

	CASP	*NHS CRD*	*NCT*	*TOTAL*
Frequently	39% (21)	7% (1)	42% (20)	36% (42)
Occasionally	31% (17)	40% (6)	21% (10)	28% (33)
Rarely	7% (4)	20% (3)	11% (5)	10% (12)
Always refer on	6% (3)	13% (2)	13% (6)	10% (11)
Didn't get any	4% (2)	0% (0)	9% (4)	5% (6)
Not involved in providing treatment choice information	7% (4)	20% (3)	4% (2)	8% (9)
Other	6% (3)	0% (0)	0% (0)	3% (3)
TOTAL	100% (54)	100% (15)	100% (47)	100% (116)

The majority of those attending all of the workshops were involved to some extent in providing treatment outcomes information to the public. Only 8 per cent overall said that they were not involved in providing such information, and a further 5 per cent said that they had not received any such enquiries in the previous year. However, as can be seen above, there were differences between the different projects in the extent that people attending the workshops reported providing such information. Only one person from the NHS CRD workshop reported answering such enquiries frequently, compared with approximately two-fifths of those attending the other workshops.

In Phase One of the project (Gann and Buckland, 1994) a survey was carried out of Regional Health Information Services (RHIS) and other local CHIS when they were asked the same question as in this survey about how frequently they provided treatment choice information. The responses given by the services in Phase One were similar to those given by the individuals attending the CASP and NCT workshops: 37 per cent reported providing information very frequently, and 41 per cent occasionally. Given that the Phase One survey was carried out 12 months previously in 1994, and there has been an increased awareness of evidence-based medicine, one might have expected those attending the workshops to have reported higher percentages of treatment choice enquiries. The two samples are however different: in Phase One respondents were replying as representatives of CHIS: in Phase Two not all the respondents were directly involved in providing health information to the public; some were policy makers, trainers etc.

Sources of information used

Table 10

	CASP	*NHS CRD*	*NCT*	*TOTAL*
Self-help groups	76% (41)	73% (11)	79% (37)	77%
Prof. Health orgs.	69% (37)	53% (8)	60% (28)	63%
NHS CRD database	11% (6)	13% (2)	4% (2)	10%
Effective Health Care Bulletins	35% (19)	13% (2)	17% (8)	29%
Effectiveness Matters	15% (8)	13% (2)	6% (3)	11%
Cochrane Database of Systematic Reviews	15% (8)	13% (2)	0% (0)	9%
Cochrane Pregnancy and Childbirth Database	15% (8)	7% (1)	0% (0)	8%
Guide to Pregnancy	30% (16)	7% (1)	32% (15)	28%
BMJ	37% (20)	47% (7)	28% (13)	35%
Other journals	54% (29)	40% (6)	45% (21)	48%
Medical textbooks	54% (29)	54% (8)	47% (22)	51%
Own organisation	48% (26)	47% (7)	85% (40)	63%
Medline	35% (19)	47% (7)	6% (3)	25%
Other bibliog. databases	19% (10)	47% (7)	9% (4)	18%
Other	4% (2)	13% (2)	6% (3)	6%

The main sources used by respondents from the three groups were medical textbooks, journals, information produced by their own organisations, self-help groups and professional organisations. Medline was used by a considerable proportion of those attending CASP and NHS CRD workshops but few attending the NCT workshops had used Medline. As with the Phase One survey of Health Information Services, self-help groups and professional health organisations were considered to be the main sources of treatment choice information. A slightly higher proportion than in the Phase One survey reported using information from their own organisation. This is largely explained by the numbers of NCT people attending both the CASP workshops as well as the NCT arranged workshops, as the NCT produce a lot of their own literature. The Cochrane databases were not reported as having been used by any of the participants of the NCT workshop. This is perhaps surprising as one of the databases is devoted specifically to pregnancy and childbirth. It appears that the paper version (*Guide to Pregnancy and Childbirth*) was more likely to be used (32% n=15). It is also likely that those NCT members choosing to attend the CASP workshops were more aware of research-based information than those attending the NCT workshops.

Only just over half (51 per cent) reported using medical textbooks as a reference source for treatment choice information in the previous year. In Phase One of this study, 72 per cent of consumer health information services (excluding the national organisations) reported using medical textbooks. This may in part be the result of an increasing awareness of the problems with medical textbooks (in particular their currency), but may also be partly explained by respondents completing this questionnaire after attending the workshops. At all of the workshops the value of medical textbooks as reliable up-to-date sources were questioned, thus there may have been a reluctance amongst some to admit that they used textbooks.

Expectations of workshop

Table 11

	CASP	*NHS CRD*	*NCT*
To find out about different sources of research-based evidence	58% (32)	80% (12)	80% (37)
To find out about concepts & issues related to evidence-based health care	73% (40)	67% (10)	41% (19)
To understand the different ways that studies can test whether health treatments work	62% (34)	13% (2)	26% (12)
To find out about how to interpret research-based evidence	84% (46)	13% (2)	39% (18)
To find out about sharing information with consumers	73% (40)	73% (11)	57% (26)
To increase confidence in responding to enquiries	49% (27)	40% (6)	52% (24)
Networking	46% (25)	47% (7)	41% (19)

Respondents were asked to tick whether any of the statements (see Table 11) reflected what they hoped to gain by attending the workshop. They were invited to tick more than one if appropriate. The emphases of the three types of workshops were different and thus one might expect the expectations of those attending the three different workshops to vary.

In keeping with the aims of the CASP workshops, the majority of those attending reported that they had hoped to:

- find out about how to interpret research-based evidence (84 per cent)
- find out about concepts and issues related to evidence-based health care (73 per cent)
- find out about sharing information with consumers (73 per cent)

The emphasis of the NCT, and to a certain extent the NHS CRD workshops, was different in that greater emphasis was given to providing information on the different sources available. Thus one would expect those attending these workshops to hope to find out more about different sources of information. Eighty per cent of the NHS CRD and NCT participants ticked this as being important, compared with only 58 per cent of those attending CASP training courses. Increasing confidence in responding to enquiries was most important for some participants of the NCT (52 per cent) and CASP workshops (49 per cent).

All of the workshops were considered to be important to help people find out about sharing information with consumers. Participants at the workshops may have had different levels of experience and involvement in providing information to consumers, but the majority saw the workshops as a means to explore the issues.

New information learnt about

Table 12

	CASP	*NHS CRD*	*NCT*
Sources not heard about	54% (28)	87% (13)	81% (38)
Interpreting research-based evidence	93% (49)	57% (8)	30% (13)

Sources of research-based information

Respondents were asked whether they felt the workshops had resulted in them learning about new sources of information or whether they had learnt anything new about interpreting research-based information. As might be hoped, given the emphasis of the workshops, the vast majority of those attending NHS CRD and NCT workshops, felt that they had learnt about new sources (NHS CRD 87 per cent; NCT 81 per cent).

Interpreting research-based evidence

As has been shown in Table 12, finding out about how to interpret and understand research-based information was considered to be important to the people attending the CASP workshops (84 per cent), but less so to those attending the NHS CRD (13 per cent) and NCT workshops (39 per cent), which was in line with the aims of the different workshops. These expectations appear to be reflected in the extent that respondents felt that they learnt about this area. Nearly all of those who attended the CASP workshops (93 per cent), felt that they had learnt new information about interpreting research-based evidence, whereas only 57 per cent of those attending the NHS CRD workshop felt that they had, and 30 per cent of the NCT participants.

As part of this question, respondents were asked to say what (if anything) new they had found out about interpreting research-based evidence. Apart from specific details, such as what a randomised controlled trial is, or understanding statistical procedures, one of the main recurring themes was gaining an understanding of the unreliability of some research.

New sources of research-based evidence

Table 13

	CASP	*NHS CRD*	*NCT*	*TOTAL*
NHS CRD	6	3	13	22
Effective Health Care Bulletins	6	1	0	7
Effectiveness Matters	7	1	0	8
Cochrane Database of Systematic Reviews	10	4	14	28
Cochrane Pregnancy and Childbirth database	0	0	2	2
Guide to Effective Care	0	0	3	3
ECPC	0	0	1	1
MIDIRS	0	2	6	8
ACP Journal Club	3	1	0	4
Journal of Evidence-Based Medicine	1	1	0	2
Bandolier	0	2	0	2
Drugs and Therapeutics Bulletin	0	1	0	1
Medline	3	0	1	4
BMJ	1	0	0	1
Nearly all	3	4	2	9
Other	4	4	13	21
	n= 55	n=15	n= 47	n = 117

Given the emphasis in the NHS CRD and NCT workshops on sources of research-based evidence it is maybe not surprising that people attending these courses were more likely to have reported finding out about new sources. The people attending were maybe less aware of the range of sources available (hence their reason for attending) and the workshop included a greater coverage of the range of sources available.

The audiences of the CASP and NHS CRD workshops were in theory more similar in terms of the types of information sources one might expect them to be aware of, than those attending the NCT workshops. The majority of people attending these workshops came from generalist consumer health information services (although 13 of the respondents to the CASP workshop were from the NCT or other maternity organisations).

Those attending the NCT workshops were mainly people from the NCT (39/47). Only 7 were from generalist consumer health information services.

Table 13 indicates the new sources of information that the participants reported learning about. For all workshops, the Cochrane Database and NHS CRD database were most often mentioned. In addition Effectiveness Matters was most often mentioned for those attending the CASP workshops; and MIDIRS for those attending the NCT workshops.

Nearly a third of those attending the NHS CRD workshop reported that nearly all the information sources talked about were new to them. As has been demonstrated in their responses to other questions, the people attending this workshop were in many ways less aware of, and involved in, providing treatment outcomes information to the public than the other two groups.

Chapter 13

Views on workshop

Level of detail of workshops

Table 14

	CASP	*NHS CRD*	*NCT*	*TOTAL*
More detailed than wanted	6% (3)	13% (2)	5% (2)	6% (7)
Right amount of detail	78% (43)	80% (12)	63% (27)	73% (82)
Not as detailed as wanted	15% (8)	7% (1)	32% (14)	21% (23)
	(n=54)	(n=15)	(n=43)	(n=112)

Overall, the majority of those attending the workshops (73 per cent) felt that the level of detail provided by the workshops was about right. There was however some variation between the different projects. Fourteen (32 per cent) of those attending the NCT workshops reported that they did not feel that the information provided was as detailed as they would have liked. This may have been a reflection of the way in which people were invited to the different workshops and the information provided in advance. The NCT workshops were advertised through the NCT network as well as via direct mailing to some organisations. However, some of the workshops were arranged as a session within an existing meeting, and several commented that they did not realise that there was to be a presentation about the booklet. Thus, unlike the other two projects, not all of those attending the workshops may have actively chosen to attend a workshop session. Unlike the other projects, the length of the NCT workshops varied depending on the arrangements made by the local organisers. Thus the content had to be reduced for some of the workshops. This may also have affected the level of detail covered in some of these workshops.

Level of detail of readings/booklet

The NHS CRD project produced detailed readings to accompany the workshop, and the NCT project produced a booklet which was distributed as part of the workshop (as well as to a wider audience). The booklet explained different sources of treatment outcomes information. Participants in these workshops were asked their views of the written materials. The majority felt overall (as they did with the workshops) that the level of detail was about right. However there was some variation in the views expressed.

NHS CRD readings

As has been described, the NHS CRD readings were fairly detailed and long, covering a range of issues around providing treatment choice information to the public. Five of the 15 (34 per cent), who replied to the NHS CRD questionnaire, reported that they felt the readings were too detailed compared with only 2 commenting that the workshops were too detailed. Participants at this workshop had expressed concerns over the extent that they should or could provide treatment outcomes information to the public, and thus one might expect them to not feel a need for such detailed information. The lower level of detailed information wanted by this group is also reflected in responses to some of the other questions. For example, a considerable proportion were not currently providing treatment choice information, and mainly reported being interested in a general introduction to the issues rather than wanting information on how to interpret research-based information (see Table 14).

NCT booklet

In contrast with the NHS CRD readings a greater proportion of those attending the NCT workshops felt the booklet and the workshops were pitched at the right level: 71per cent (32) said that the booklet was pitched at the right level; 63 per cent (27) said the workshops were pitched at the right level.

Issues that respondents would have liked to hear more about

Respondents were asked to write down any areas that they would have liked to have known more about. (See Appendix 2 for a full list of the issues raised by respondents.)

CASP

Although only eight people attending the CASP workshop felt they would have liked it to have been more detailed, a larger proportion than at the other two workshops had suggestions as to additional areas they would have liked to have known more about. These can be divided into various headings:

- specific information
- the value of certain aspects of critical appraisal
- alternative methodologies such as qualitative studies
- more explanation of the statistics and definitions
- practical aspects of providing such information to the public

NHS CRD

The main area that respondents attending the NHS CRD workshop reported they would like to know more about was how to provide information on evidence-based medicine to the public. This was a major concern by many at the workshop who for various reasons were reluctant to provide such information to the public.

NCT

The main issue identified by those attending the NCT workshops was that they would have liked to have heard more about the whole area of critical appraisal and how to interpret research. Six respondents specifically said they would have liked to have heard more on this topic. In addition, a couple wanted to know more about the Cochrane

Database. Such requests reflect an interest to go further than the aims of these workshops and find out more about critical appraisal, but may also in part reflect some misunderstanding of the purpose of the NCT workshops (i.e. to discuss sources of research-based evidence). Most of the other comments related to respondents wanting information on particular sources of information, for example preconception care, and drugs in breast milk. Two other issues raised were: how accessible the sources recommended in the booklet would be to "non-members"; and the criteria for including or excluding sources in the booklet.

Relevance of workshops and written materials

Table 15

	CASP	*NHS CRD*	*NCT*
Very relevant	51% (28)	53% (8)	47% (22)
Fairly relevant	42% (23)	33% (5)	38% (18)
Not very relevant	7% (4)	13% (2)	11% (5)
Not at all relevant	0% (0)	0% (0)	4% (2)

The scope and time scale of the evaluation did not allow for an exploration of the practical benefits of the workshops over time, but respondents were asked for their immediate impressions of how relevant they felt the workshops and materials were to their own work. Half of all participants to the workshops felt they were very relevant, and 90 per cent felt they were either very or fairly relevant. There was little variation between the projects in the participants' views on the relevance of the workshops and written materials. Thus it would appear that for most people the workshops were appropriate to the audience they were aimed at.

Reasons why not relevant to current work

As can be seen from Table 15, few felt that the workshops were not relevant to their current work. A small proportion of those attending the NCT workshops commented that they knew much of the information they were told. Of those who felt that the information wasn't relevant, for some this was because they were not information providers, but a few others raised the issue of whether it was appropriate for consumer health information services to provide such information to the public.

Confidence in responding to treatment choice enquiries

Table 16

	CASP	*NHS CRD*	*NCT*
Much more confident	35% (19)	7% (1)	9% (4)
Slightly more confident	47% (26)	43% (6)	61% (28)
No different	7% (4)	14% (2)	26% (12)
Slightly less confident	0% (0)	7% (1)	0% (0)
Much less confident	0% (0)	0% (0)	0% (0)
Not applicable	11% (6)	29% (4)	4% (2)

Not surprisingly a greater proportion of those attending the CASP workshops felt much more confident in responding to treatment choice enquiries than before, compared with the NHS CRD and NCT workshops. The NCT and NHS CRD workshops had a different focus. The NCT workshops were aimed at exploring sources of treatment choice information, but not assisting people directly in interpreting and providing such information to the public. As has been shown, the people attending the NHS CRD workshops were still at the stage of discussing whether or not they should be providing such information to the public. One therefore could not expect the people attending workshops from these two latter projects to feel considerably more confident. Indeed one might have expected some to feel less confident, as the issue of whether to provide such information to the public was a major concern, and one that some had not considered before. Nevertheless, only 7 per cent of those attending the NHS CRD workshops said they felt slightly less confident and none of those attending the NCT workshop felt less confident.

Whether will use the information learnt from the workshops and workshop packs

Table 17

	CASP	*NHS CRD*	*NCT*
Definitely	62% (34)	67% (10)	66% (31)
Probably	33% (18)	33% (5)	21% (10)
Not sure	6% (3)	0% (0)	6% (3)
Probably not	0% (0)	0% (0)	0% (0)
Very unlikely	0% (0)	0% (o)	6% (3)

The majority of those attending the workshops felt they would use the information learnt, with only three people who attended the NCT workshops saying it was very unlikely.

Participants' views of the best and worst features of the workshops and written materials

Participants were asked to record what they felt were the best and worst aspects of the workshops and the written information provided. This question encouraged people to be particularly frank about their views on the workshops.

CASP

As in other areas, the people attending the CASP workshops appeared to be the most vocal and demanding. The main negative comments made about the workshops were about the timing of the workshops and the facilities. Several people commented on the distance they had to travel and that they would have liked the sessions to have been earlier in the day. Others commented on the catering. Some of the negative comments about the workshops themselves were about the knowledge of the facilitators and queries about the statistical information. The message CASP tries to get across in workshops is that if the study design is adequate there is no need to worry about the statistics. Anyone who has the study design right probably has the statistics right too. Thus there was no intention or need to teach detailed statistics. This message, however, did not stop some people worrying about the statistics.

The positive comments however were numerous, with many appreciating the practical group workshops session, the opportunities for discussion and generally the amount of detail covered in the sessions.

NHS CRD

A couple commented that they felt the workshops were too long and others commented that they would have liked some of the sessions to be more focused. Several of the positive comments were about the usefulness of the information presented as well as the presentation of the information.

NCT

The main criticisms of the NCT workshops were that the sessions were too short, and sometimes lacked focus. The people attending the workshops were however very complimentary of the booklet and the opportunity to be able to discuss issues.

Full details of the comments made are included in Appendix 3.

Chapter 14

Summary of questionnaire analysis

The expectations of the participants to the different workshops appeared, on the whole, to be fulfilled. Those attending the CASP workshops wanted to know more about how to interpret research-based evidence (84 per cent), and 93 per cent felt that after attending they had learnt new information about interpreting research-based evidence. Eighty percent of the NHS CRD and NCT participants had hoped to find out more about sources of research-based evidence. Eighty-seven percent (NHS CRD) and 81 per cent (NCT) felt that after attending the workshops they had learnt new information in this area.

The level of awareness of research-based evidence between people attending the different workshops varied. It appears that those attending the CASP workshops were most aware of, and involved in, providing treatment outcomes information, whereas the NHS CRD participants were, on the whole, least aware and involved.

Although obviously there would also be a great deal of variation within any of the groups, it was important that the workshops should attempt to pitch the information they provided at the right level. The majority of those attending the workshops (73 per cent) felt that the level of detail provided at the workshops was about right, although a third (14) of those attending the NCT workshops would have liked more detail. It would appear that for some attending the NHS CRD workshops, the readings appeared too detailed. It is likely, however, that the readings would be invaluable to others with more involvement in providing treatment outcomes information.

Chapter 15

Conclusions

Involvement of CHIS staff

Three of the five projects were carried out by organisations directly involved in providing health information to the public (NCT, Trent Healthline and Health Matters), two of which were generalist consumer health information services. It is likely that without such involvement the projects would have taken much longer to set up and organise. The NHS CRD and CASP projects were not directly involved in health information provision, but both worked hard to recruit others into the organisation and planning of the projects. They did however have difficulties initially in gaining access and involvement, as did the NCT in involving generalist consumer health information services. Identifying and accessing different groups was much easier when agencies were actively involved with those groups.

CHIS involvement in providing treatment choice information

Four of the projects provided varying levels of training and awareness in treatment choice information, ranging from a brief introduction to the reliability of different sources (NCT), through to interpreting treatment choice information for others (Trent). There was concern expressed by some respondents over the extent to which CHIS could or should become involved in providing such information. Even where individuals were taught or developed such skills, it was felt that it was too time-consuming for the services themselves to routinely produce summaries for consumers and there was the need for more readily available information in a language accessible to all. Nevertheless the Health Matters project provided further support for the view that consumers do want this kind of information in more detail than they are currently receiving, and that they are turning to CHIS as a source of such information. The enthusiasm of people attending the workshops run by the pilot projects illustrated the willingness of many CHIS to try and address these issues.

Importance of treatment choice information being kept up to date

All of the projects considered the issue of how to ensure consumers are provided with up-to-date information. The Health Matters project found that clients often would not call back for additional information, assuming that they had been given all that was available. Callers did not consider that the content or range of information available might change over time. The researcher also found that people tended to keep hold of any information they were sent, thus over longer periods there might be the risk of some information becoming out of date. This is an issue for all providers of health information. Two of the projects (CASP and NHS CRD) produced information that was concerned more with the process of understanding treatment choice information than the content itself and thus the importance of updating the information was less critical. However the

NHS CRD project did include sources of research-based evidence. Although most sources were likely to remain static, new sources would emerge in the future and thus the pack would need to be maintained. This was also the case for the NCT project, particularly given its wide circulation (3,000 copies disseminated). In an attempt to prolong the life of the document, the number of self-help groups included was kept to a minimum. The information pack produced by the Trent Healthline project is the most vulnerable to becoming out of date, because it contains summaries of the current literature. This pack was produced in a ring binder so that additions and amendments could be made, but nevertheless this involves a commitment to make those additions and monitor changes, and finances are needed to enable such a pack to remain current. All of the projects dated their publications, enabling others to at least be aware of the age of the document.

Training of others to understand and interpret research-based evidence

The CASP and NHS CRD projects both discussed the potential value of training people to be able to train others. This philosophy is central to the CASP approach, whereby people seeking training themselves are encouraged to participate in planning and facilitating the workshops, with a view to possibly running workshops themselves in the future. The CASP project leaders felt that time and experience were needed before such cascading of training could occur within CHIS, but that it was desirable, achievable and is currently being demonstrated by the NCT delivery of CASP workshops. By contrast the NHS CRD project, although originally seeking to develop a training pack that would enable people attending (and others) to run training themselves, revised this approach after having run their workshop. The NHS CRD project leaders were concerned that many of the issues could not be adequately dealt with by people relatively new to the subject area.

Timing

All of the projects commented on the tight time scale both in terms of the need to start the projects quickly and to complete within nine months. Activities such as organising workshops and involving others in the projects took time to set up. This was made particularly difficult as the main activities had to be organised over the summer, when many of the services they were involving were short staffed. All of the projects felt that they had to a greater or lesser extent underestimated the amount of work involved, and several commented that they had known from the outset that this was the case but had felt the project sufficiently worthwhile that they were committed to carrying out the work regardless.

Evaluation

The evaluation of three of the projects (CASP, NHS CRD and NCT) found that the majority of participants felt that the workshops and written materials had been worthwhile, and would be of use to them in the future in providing treatment outcomes information to the public. However we do not yet know whether consumer health information services have become any more effective in dealing with treatment outcomes enquiries as a result of the projects. A follow-up study using Phase One of the project as a baseline to measure change would be worthwhile for these projects (Gann and Buckland, 1994). The Help for Health Trust has now received a grant from the NHS Research and Development Programme on Implementation of Research to work with patient organisations to evaluate improvements in consumer health information services since the original 1994 study.

The Trent Healthline project was a pilot study in disseminating treatment outcomes information to consumers which produced a detailed and potentially useful document. A more detailed evaluation is necessary to explore possible methods of dissemination and to evaluate the impact of the pack.

References

Gann R. and Buckland S. (1994) *Dissemination of Information on Treatment Outcomes by Consumer Health Information Services: Phase 1*. The Help for Health Trust.

Entwistle V., Herring J. & Watt I. (1995) *Providing information about health care effectiveness to consumers: the development of training materials for information providers* (Report from NHS Centre for Reviews and Dissemination and Queen Margaret College, Edinburgh to the King's Fund) NHS CRD, York.

Entwistle V., Herring J. & Watt I. (1995) *Information about health care effectiveness: readings for consumer health information providers*. NHS CRD, York.

1) Gauge S. & Newburn M. (1995) *Through the Maze*. National Childbirth Trust, London.

2) Gauge S. & Newburn M. (1995) *Through the Maze Final Report* (A King's Fund project on Dissemination of Outcomes Information by Consumer Health Information Services). National Childbirth Trust, London.

Health Matters. (1995) *Access to Information on Treatment Outcomes through a Consumer Health Information Service: A qualitative study*. Health Matters, Milton Keynes.

Oliver S. & Milne R. (1995) *Critical Appraisal Skills Programme*. CASP workshops for Consumer Health Information Services. November, 1995, Institute of Health Sciences, Oxford.

Thompson H. (1995) 1. *Dissemination of Mental Health Outcomes Information by Consumer Health Information Services*. Trent Healthline, Nottingham.

Thompson H. (1995) 2. *Treatment Outcomes in Depression: A guide to sources of information about the effectiveness of treatments for depression*. Trent Healthline, Nottingham.

APPENDICES

Appendix 1 – Help for Health's involvement with projects

Appendix 2 – Issues participants would have liked to have heard more about

Appendix 3 – Best and worst things about the workshops

Appendix 4 – King's Fund evaluation: Evidence-based health care and consumer health information

Appendix 1

Help for Health's involvement with the projects during the evaluation

CASP	Three meetings Attended Birmingham workshops Attended "Taking it Forward" event Attended advisory group meetings Questionnaires to all attending
CRD	Two meetings plus one telephone meeting Attended two-day workshop Questionnaires to all attending
NCT	Three meetings Attended workshop Attended advisory group meetings Questionnaires to all attending
Trent	Three meetings Telephone calls
Health Matters	Three meetings Telephone calls

Appendix 2

Issues participants would have liked to have heard (more) about

CASP

- Statistical analysis argument for and against randomised control trials and evidence-based medicine
- Statistics – full range of issues. Criticisms of meta-analysis
- Should have had a qualified statistician – time was wasted here
- Only attended second workshop and found statistics and graphs on Cochrane difficult
- I think some sceptical discussion of meta-analysis, and tutors should have a greater understanding of presentation of research results, the meaning of confidence limits, standard essays
- Assessing the validity of a paper. Interpreting odds ratios
- Other viewpoints, e.g. qualitative techniques
- Perhaps how doctors/health professionals make their decisions on treatment especially when evidence is not clear
- I'm interested in critical appraisal of qualitative research but I realise that would be a different workshop
- Referral to different methodology (not in detail)
- More about interpretation of research
- Approaches of testing alternative therapies. Also leaders tend to assume I'd heard of Medline – I hadn't
- Perhaps a bit more on how to interpret research
- Would have liked a more detailed glossary – but terms were clearly explained at the workshop

- More explanation of the terms used

- Would have liked a summary of workshop in the pack for workshop, e.g. what things to consider when evaluating an RCT

- Consumer views on successful outcomes

- More discussion on influencing the research agenda

- Powerbase behind who decides what research is going to be published and/or publicised

- A little more background information with definitions of some terms

- I should like to have a copy of the evaluation slips that we completed before and after the course

- How to follow up what we've learnt within our own organisation

- How to pass on CASP

- The dangers and pitfalls for non-medically trained workers in giving information on effectiveness of treatments

- More ideas on how to communicate this information to the public

- More time to see the various databases

- Some of the language was a bit technical for me – but have passed my comments to Sandy Oliver.

- How (as a layperson) to access Information Sources, e.g. it is difficult to gain access to our Medical Library

- I would have liked to study an example of poor research/reviews as a comparison

- Fuller details about the scope of the Cochrane Collaboration

NCT

- More about how to interpret research-based evidence, more about concepts and issues related to evidence-based health care

- Critical appraisal

- Time was short, more information about how to interpret the research

- More about interpreting research – it's very confusing

- This workshop barely covered the area of interest

- It was a one-day workshop, sharing various issues, e.g. pain relief, natural versus managed birth

- How a database works (briefly)

- Surfing the Internet – I find it much easier to find information if given a start address – only the Economic Evaluation Database appears to be on the Internet according to my reading of the booklet. It should be possible to give the Internet address

- Clearer indication about establishing contact with the information sources; how welcoming the sources will be to non-members

- I would have like to have more practical demonstration on how to decide what is good/bad research, and possibly how to use Cochrane Database, but I do realise that time is limited

- A bit more time on the whole

- Background info on organisations and databases presented in booklet criteria for determining which database and organisations were chosen, how search of sources were conducted

- Measures of reliability updates usage by professionals

- I had as a starting point an understanding of double-blind research trials. I wanted to move on from there to specifics

- Workshop was curtailed through lack of time but it did cover a significant amount of detail

- Cochrane database – how well is it being used by health professionals – to what extent

- Is there a direct national contact for drugs in breast-milk enquiries?

- Pre-conception care

- More specific info on pregnancy and childbirth

CRD

- Other examples than the prostate one! Would have been helpful to actually go through the process of following up a query re treatment. Where to start looking for the evidence

- Preparing patients for dealing with information; more about the feasibility of providing this information

- Implementation of evidenced-based health care

- Level and type of info available on Cochrane Database

- Getting evidence into practice

- Not at this workshop but hope we can continue to communicate and develop these ideas in consumer health information field

Appendix 3

CRD: best things about workshop

	Best things
Location	
Timing	• In general the tempo and composition of the two days were well judged
Facilities	
Workshop content	• Raising awareness on how health information services are developing in the UK as a whole • Efforts are being made to make this information available to consumers in a suitable format • Widened my own knowledge – and I hope to obtain some of the materials discussed – very useful for Scotland as networking event • As someone relatively new to information provision, I found it all very useful. Although presenting information on treatments/behaviour choices is not a common question (yet) the workshop and readings have provided a sound base for reference
Workshop presentation	• The presenters were effective in as far as they presented an English picture • Meeting others and hearing their views • I thought the sessions given by individuals were just about the right length, precise and thought provoking
Workshop organisation	
Written materials	• The readings I found clear and precise, presenting interesting angles in a balanced way

CRD: worst things about workshop

	Worst things
Location	
Timing	- Too long - I felt the 2 days were a bit long – began to flag a bit by end of 2nd day! - Finishing time too late for Edinburgh traffic!
Facilities	
Workshop content	- Too detailed, assumed no knowledge base, not Scottish enough - Lack of clear way forward – I don't think some people attending were satisfied that they could/should provide information about treatment outcomes - I felt the small group exercises could have been focused a little better. They tended to drift a little, often going over the same ground of the previous session - Group exercises were made more difficult by the wide range of participants – some of whom seemed to me not keen to give the consumer *any* information
Workshop presentation	
Workshop organisation	- Changing the group composition each time/each day might have been a useful exercise
Written materials	

NCT: best things about workshops

	Best things
Location	
Timing	
Facilities	
Workshop content	• Reminders of places to go for accurate information • Discussion during session • A chance to meet with others and discuss sources • Help people to be more up to date • Three resources were highlighted • Helping us to find sources • Encouragement for those unsure • Brought more information close to us • Made me review what I already knew • Gave me new sources of information • Made aware of publications available • Getting together to think about our roles, and where to get information • Testing out my own prejudices • Finding out where to go • Discussion • Workshop not just a talk • Meeting NCT members • Knowing where to find information
Workshop presentation	• Led through in very systematic easy-to-follow way • Very effective • Good speaker • Practical and well presented • The user-friendly way it was run • The way Sue explained everything • Booklet – locally given rather than sent through post
Workshop organisation	
Written materials	• The book produced will be a handy source of information • Consistent and clear • Receiving a copy of the booklet so we didn't have to take notes • Free, full of useful information, not too long • The booklet • Provides sources and contacts • Easy to read and concise • Getting a list of services and resources • Useful resource list for post natal co-ordinators • Concise information provided in a booklet • Improved the information base of our organisation • Easy to read • Meeting other teachers

NCT: worst things about workshops

	Worst things
Location	• Difficulty finding venue
Timing	• Short time • Limited time, would have liked more detail • Would have liked more time • Full workshop may have been more beneficial • Time of workshop minimal (1 hour) • Workshop being part of a committee meeting • Would have liked more time • More time required
Facilities	• Cold coffee
Workshop content	• Realising the sources are often not guaranteed reliable • Feeling it all takes so much time and effort to do a good job • No mention of Internet • Needed this information 9 months ago • Felt I gained nothing • If I had known more about content could have saved my time
Workshop presentation	• Bit too compressed • Not planned effectively • Trying to cover so many huge issues in a short time • Too many books to look at – not enough time • Presentation quiet and group poorly managed, but adequate • Did not set out aims of workshop
Workshop organisation	• Only 4 participants • Could have been better attended • Trainer arrived very late • Worker one and a half hours late
Written materials	• Appearance and title

CASP: best things about workshops

	Best things
Location	
Timing	• Accessible timing – no frills • I liked the second workshop better than the first which felt rather long
Facilities	
Workshop content	• Valuable information • Mostly easy-to-understand terms • Overviews of research and reviews and the hands-on evaluation tasks • The 10 questions to help make sense • Feeling enabled to use research-based evidence • Looks at research in relation to everyday issues • The new concepts I was made aware of and how to find original papers and reviews • Liked using the desktop computers to access information on database – gave me confidence • Learn and develop skill to systematically assess the evidence step by step • Analysing a paper • The 10 questions • Useful to put theory into practice • Clear framework for analysis • Got more from workshops as a group facilitator • Amount of time to interpret the evidence • Experience at assessing reviews • Clarified a difficult issue • Opportunity to assimilate quite complex concepts • The green checklist • Detailed, factual, focused discussion of examples of research • Breaking down the facts and working through technical jargon • Sharing ideas • Focus on practical examples • Opportunity to work together on actual documents • Clear example to work through • Opportunity to discuss issues • Chance for people to discuss. Putting several heads together • Practical exercises and discussion • Talking to other people in similar situations • Group work is always a good way to learn when facilitated well • Practical examples good, feed-back sessions informative and well handled • Group work, not just lectures • Shared ideas, shared responsibilities • Chance to discuss papers and terms with others • Just to be made aware of the issues • Systematic way of looking at research papers

Workshop presentation	• Friendly trainers • Enthusiasm of tutors • Informality • Very well thought-out and clearly presented • Clear and responsive to our needs • Well-organised material, stimulating format • All excellent
Workshop organisation	• Well organised • Excellent organisation of small group work and feed-back sessions • Very well organised • Well structured, well organised, well conducted • Time for participation and real learning
Written materials	• Design of packs good • Good materials to work with • Having all information together in one pack • Free issues of relevant publications • Very well presented • Good documentation
Other	• Brought together people interested in evaluating research • Time to wade through papers and discuss issues with other professionals

CASP: worst things about workshops

	Worst things
Location	• Long way to travel for a short day • 5.15am start to day to catch train • Travelling to it • Location • Travel to Bristol • Venues and catering – also having to travel a distance on two days difficult • Travelling to the venue • Not enough time
Timing	• Needed longer • Time restriction • Different venues and afternoon timing. A morning meeting starting on time takes up less of the day • Possibly the short time allowed for the workshop • Timing of workshop to end at 5pm in rush-hour away from base • Prefer a morning rather than an afternoon – difficult to maintain concentration post lunch and late afternoon • The course days – Mondays and Fridays and times were appalling
Facilities	• Catering arrangements • Venues and catering • Hard chairs, poor sound proofing, and lack of refreshments (last minute change of venue) • Not enough time, hard chairs second session
Workshop content	• Very NCT based – no acknowledgement of other issues or any interest in non-NCT people • Lack of time for further discussion about meta-analysis and systematic reviews • Sometimes the number crunching jargon was not explained in a very clear concise simple way • Could have been more applicable to actual situations in health information giving • Poor explanation of statistical data. Either simple rules of thinking should be given or proper explanation by an expert • Feeling that the papers we looked at were selected for simplicity and applying the principles may not be so easy with more complex studies • Would have liked a longer demo of the Cochrane
Workshop presentation	• Speaker/organisers unable to answer some of the fundamental questions raised • First speaker at second workshop hadn't attended 1st workshop, resulting in too much repetition • Poor knowledge and understanding of statistics and presentation of results • The small group sessions were a bit sluggish – insufficiently skilled and briefed facilitators (although difficult to avoid in self-help participative training)

Workshop presentation *(cont.)*	• Sometimes felt more specialist expert back-up was required • In each of the group sessions I was in people were floundering around not really knowing what they were doing and I felt there could have been more guidance
Workshop organisation	• Felt tired and disoriented during the feedback session of the first workshop (probably too long) • Time spent collating the small groups' results although I appreciate it was necessary • Smaller groups should have been made up of different people to the second workshop • A four-hour session without a break; not enough time for informal discussion with fellow participants • Not enough time for discussion on the reality of information delivery • Should not be expected to fill in a course assessment there and then as, with hindsight, I missed things • Our group was rather small, needed a few more people to get more ideas
Written materials	• Didn't understand the packs before the workshop • Packs for workshop 2 confusing because of a technical hitch • Not enough put down in condensed form for reference and usefulness
Other	• Persons who were on the course who had too much knowledge – research background took over

Appendix 4

King's Fund evaluation: evidence-based health care and consumer health information

This survey is being carried out to find out your views on the information provided by the workshop you have just attended and the readings you received. We need your views to establish whether and how such information was useful to you. The King's Fund has provided grants to several pilot projects to assist in disseminating information about treatment/behaviour choices. This workshop was funded by one of these grants. The survey is being carried out independently of the workshop organisers, by the Help for Health Trust, on behalf of the King's Fund. Your answers will be treated in the strictest confidence, and no individuals will be identified by name. Please complete and return the questionnaire in the stamped addressed envelope provided. If you have any questions about the survey, please contact Sarah Buckland at the Help for Health Trust, Winchester (01962) 849100.

SECTION A: BACKGROUND

1. **What is the name of the organisation or agency you work for (if applicable)?**

   ....

2. **What is your job title?**

   ....

3. **Which of the following best describes your occupation (please tick more than one if appropriate)**

   ☐ information worker
   ☐ researcher
   ☐ trainer
   ☐ librarian
   ☐ policy maker
   ☐ health service manager
   ☐ other (please specify below)

   ....

4. Prior to attending the workshop, how frequently did you as part of your work provide information about treatment / behaviour choices for health-related issues to the public?

(By this we mean information about the risks and benefits of treatments, care or self help, and information to help people choose between different options)

☐ frequently
☐ occasionally
☐ rarely
☐ always referred such enquiries on
☐ didn't get any such enquiries
☐ not involved in providing treatment/behaviour-choices information
☐ other (please state below)

....

5. Please indicate below the sources of information about treatment/behaviour choices:
a) you have used in the last 12 months prior to attending the workshops and
b) you have had access to (but not used) in the last 12 months prior to attending the workshops

a) Used	b)Access to	Information Sources
☐	☐	Literature produced by self-help groups & voluntary organisations
☐	☐	Literature produced by professional health organisations
☐	☐	Centre for Reviews & Dissemination Database (CRD)
☐	☐	Effective Health Care Bulletins (CRD)
☐	☐	Other NHS CRD Publications (e.g. Effectiveness matters, CRD reports)
☐	☐	Cochrane Database of Systematic Reviews
☐	☐	Cochrane Collaboration Database of Pregnancy & Childbirth
☐	☐	Guide to Effective Care in Pregnancy & Childbirth
☐	☐	British Medical Journal
☐	☐	Other journals
☐	☐	Medical textbooks
☐	☐	Information produced by your own organisation
☐	☐	Medline
☐	☐	Other bibliographic databases *(please give details below)*
		....
☐	☐	Other *(please give details below)*
		....

SECTION B: REASONS FOR ATTENDING THE WORKSHOP

1. **What made you decide to attend this workshop?**

....

....

2. **Did anyone recommend you should attend the workshop?**

☐ Yes ☐ No

If yes, who recommended you should attend?

....

3. **What did you hope to gain from coming to the workshop?**
(please tick more than one if appropriate)

☐ to find out (more) about different *sources* of research-based evidence
☐ to find out (more) about concepts and issues related to evidence-based health care
☐ to understand (more) about the different ways that studies can test whether health treatments work e.g. randomised control trials
☐ to find out (more) about how to *interpret* research-based evidence
☐ to find out (more) about sharing information about health care effectiveness with consumers
☐ to increase my confidence in responding to enquiries about treatment/behaviour choices
☐ networking
☐ other (please state below)

....

SECTION C: VIEWS ON THE WORKSHOP & READINGS

1. **Which of the following best describes your view on the level of detail of the <u>workshop</u>?**

☐ much more detailed than I wanted
☐ a bit more detailed than I wanted
☐ the right amount of detail
☐ not quite as detailed as I wanted
☐ not nearly as detailed as I wanted

2. **Which of the following best describes your view on the level of detail of the <u>readings</u>?**

☐ much more detailed than I wanted
☐ a bit more detailed than I wanted
☐ the right amount of detail
☐ not quite as detailed as I wanted
☐ not nearly as detailed as I wanted

3. **Were there any issues or areas that you would have liked to have heard (more) about ?**

....

....

4. **Overall, how relevant were the workshop and readings to your current work?**

☐ Very relevant
☐ Fairly relevant
☐ Not very relevant
☐ Not at all relevant

If not very or not at all relevant:
In what way were they not relevant to your current work?

....

....

5. Do you think you will use what you have learnt from the workshop and readings?

☐ Definitely
☐ Probably
☐ Not sure
☐ Probably not
☐ Very unlikely

6. Which aspects of the workshop and readings do you think will be most useful to you in the future?

....

....

7. Is there anything that prevents you using what you have learnt from the workshop and readings?

....

....

8. As a result of attending the workshop and receiving the readings that accompanied it:

i. have you found out about any sources of research-based evidence, that you hadn't heard about before?

☐ Yes ☐ No

If yes – please state which

....

....

ii. have you found out anything new about understanding and interpreting research-based evidence that you didn't know before?

☐ Yes ☐ No

If yes – please state what

....

....

iii. do you now feel any more or less confident in responding to enquiries about treatment/behaviour choices

☐ much more confident
☐ slightly more confident
☐ no different
☐ slightly less confident
☐ much less confident
☐ not applicable

Please write down <u>why</u> you feel more or less confident than before you attended the workshop

....

....

iv. is there anything (else) that you feel you've gained from the workshop and readings

....

....

SECTION D: GENERAL COMMENTS

1. **What do you feel was the best thing about the workshop and readings?**

   ....

   ....

2. **What do you feel was the worst thing ?**

   ....

   ....

3. **Do you have anything else you would like to say?**

   ....

   ....

Name and Address
(This information will be kept separate from your responses. Your answers will be treated in the strictest confidence. Individuals will not be identified either to the workshop organisers or in any reports written.)

....

....

....

Thank you for taking the time to complete this questionnaire.
Please return it as soon as possible in the stamped addressed envelope provided.
The Help for Health Trust, Highcroft, Romsey Road, Winchester, SO22 5DH.

Do patients receive sufficient information about their medical treatment? Are they given all the facts to make a choice?

This latest report in the Promoting Patient Choice series from the King's Fund reviews the quality of information patients received in five pilot projects around the country. It looks at the accuracy and currency of the information provided and explores some of the difficulties involved in keeping patients informed.

Disseminating Treatment Outcomes Information to Consumers **highlights many examples of good and bad practice. The authors call for further evaluation of the evidence to determine the full impact of quality information on patient choice.**

Promoting Patient Choice

The publications in the Promoting Patient Choice series are part of a continuing programme of work within the Clinical Change Programme at the King's Fund Development Centre.
For the past five years, the programme has been promoting concepts and materials which help patients and the wider public to become involved in their own treatment and health care decisions. Government initiatives such as *The Patient's Charter* and *Local Voices* have created major changes in patients' rights and responsibilities and have sought to involve the public in decision-making on a wider scale. The Promoting Patient Choice programme has supported a number of projects, including the use of interactive videos for shared clinical decision-making and a survey of consumer health information services.
Each book in the Promoting Patient Choice series tackles a specific set of issues and is intended to help change and develop professional and public attitudes towards patients' involvement in health care.

ISBN 1-85717-132-2
9 781857 171327