

Disseminating information about healthcare effectiveness: a survey of consumer health information services

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Abstract

Background—In 1997 a research based information leaflet designed for men considering being screened for prostate cancer was distributed to general practitioners (GPs) and consumer health information services.

Objectives—To investigate consumer health information service staff opinions of the leaflet and the use they made of it. To find out whether such staff would find similar leaflets on other topics useful.

Design—A postal questionnaire survey sent to United Kingdom consumer health information services.

Results—Consumer health information service staff were enthusiastic about the content and presentation of the leaflet and gave it to many enquirers, including some who had not been given information by their GPs. Respondents were keen to be supplied with similar leaflets about different topics. Some respondents were reluctant to give the leaflet to people enquiring about screening for prostate cancer, for example, because they thought that the leaflet would cause anxiety, or because prostate cancer screening was not freely available locally.

Conclusion—Consumer health information services can complement information provided by health professionals and make good use of research based information for consumers. However, they may withhold information from some people who might benefit from it and are not well placed to advise people about healthcare options. Strategic thinking is needed to encourage a more integrated approach to giving information and support for patients in making decisions.

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It is increasingly accepted that people facing decisions about their health care need good quality information about the relevant options and their outcomes. Timely provision of such information during the course of care is still the exception rather than the norm, however, and strategies are needed to support and complement provision of information by health professionals if the quality of this important aspect of health care is to be improved. Many organisations now produce information materials (leaflets, videos, etc) for patients and the public,¹ and there is growing interest in improving the

quality of these products.^{2,3} Even the best materials are of little use, however, unless people receive them when they need them.

Consumer health information services which respond to enquiries from members of the public (box), have an important part to play. A survey conducted in 1994 found that such services were indeed receiving enquiries about healthcare outcomes. The information sources they

Consumer health information services

Consumer health information services provide information about health conditions and healthcare services to patients and members of the public. They developed in various ways: hospital medical libraries extended their services to patients; public libraries strengthened their ability to provide health related information; various collaborations set up health information shops and specialist services developed out of self help groups focused on particular conditions.¹³ The diverse services have different strengths and weaknesses.

The United Kingdom has had a national freephone Health Information Service since 1993. Health authorities run or contract with consumer health information services to provide an enquiry service for their local population and members of the public who dial the freephone number are routed through to the nearest service that is part of the system. All consumer health information services that are part of the national network are supposed to achieve certain minimum standards and since April 1996 they have been required to provide information about the effectiveness of healthcare interventions.¹⁴ A limited amount of funding and training support has been provided to promote uniformly high standards of providing information across the national service. This work is not helped by the fact that reorganisations within the NHS and devolution of responsibility for providing the freephone Health Information Service from regional to local level have led to many changes in the groupings of consumer health information services that operate the national service.

A voluntary umbrella organisation, the Consumer Health Information Consortium, provides a forum for discussion among all consumer health information services, regardless of whether they operate the national freephone service. It too aims to promote high standards among its members.

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used to respond to these enquiries, however, were often not reliably research based, and staff often gave verbal rather than written responses.⁴ The information services had neither the resources nor the skills needed to identify and appraise research based information about healthcare effectiveness, and to present it in appropriate written forms to their enquirers.⁵

The recent proliferation of research based sources of information for health professionals has made searching for information about healthcare effectiveness easier and reduced the burden of methodological assessment which falls on the reader. However, sources such as the *Cochrane Database of Systematic Reviews* are still difficult for many information services staff (and more so for their enquirers) to use. Even the *Effective Health Care* bulletins which are produced by the NHS Centre for Reviews and Dissemination and aim to summarise research findings about healthcare effectiveness for decision makers (including non-specialist managers) in the United Kingdom National Health Service (NHS)⁶ contain technical details and language which render them difficult for information service to use. Some information services staff have benefited from training courses on critical appraisal skills.⁷ For most, however, carrying out a literature search and critically appraising research reports remains an impractical way of responding to many enquiries. The ability of the consumer health information services to provide satisfactory responses to enquiries about healthcare outcomes remains unproved.

There is little doubt that good quality research based information leaflets specifically prepared for people facing decisions about their own care would be useful for the consumer health information services. The availability of such materials is improving but is still limited.⁸ Even when good examples are available, many factors affect their use. We report here on a small study that examined some of these issues in the context of an initiative to disseminate research based information about the effectiveness of screening for prostate cancer.

In 1997, the NHS Centre for Reviews and Dissemination published two leaflets summarising the available research evidence about the effectiveness of screening for prostate cancer. One was intended primarily for general practitioners (GPs) and other health professionals,⁹ the other for men considering having prostate specific antigen tests.¹⁰ The development of the leaflets has been described elsewhere.¹¹

The men's leaflet aimed to ensure that men asking for prostate specific antigen tests had access to relevant research evidence about them. It was not intended to generate new interest in prostate specific antigen testing so a decision was made to distribute it through GPs and consumer health information services. In January 1997, the services were sent five copies of the health professionals' leaflet and 100 copies of the men's leaflet. They were told in advance about the aim and content of the leaflets, and were forewarned that anticipated

media publicity about the research findings might trigger a spate of enquiries.

In July 1997 we carried out a small survey to inform the future production and dissemination of research based information materials for consumers by the NHS Centre for Reviews and Dissemination. The main objectives of the study were to investigate:

- Consumer health information service staff opinions about the men's leaflet, including features they particularly liked or disliked, any concerns they had about the leaflet, and their perceptions of users' views of the leaflet.
- The use made of the men's leaflet by the information services, including information about the types of enquiries it was used to respond to and any circumstances in which staff were particularly keen or reluctant to give it to enquirers.
- Whether information services staff would find similar leaflets produced by the NHS Centre for Reviews and Dissemination on different topics useful.

Methods

We developed a questionnaire specifically for this study to meet these objectives (appendix). It was not formally piloted among information service staff. The first part of the questionnaire used a combination of fixed response option and open ended questions to ask whether the service had received copies of the men's leaflet and if so: what action had been taken about them within the service; whether staff had any concerns about them; how many leaflets had been given out; the types of enquiry they had been used to respond to; any circumstances in which staff were reluctant to use them; any features of the leaflets that staff had particularly liked or disliked; and any feedback received from people to whom they had given the leaflet. The second part of the questionnaire sought views about the likely usefulness of similar leaflets that might be based on future *Effective Health Care* bulletins and suggestions about how the leaflets, or the way they were distributed to consumer health information services, could be improved.

Fifty nine information services (all those that make up the national Health Information Service and other listed members of the Consumer Health Information Consortium) were sent the five page questionnaire in July 1997. The questionnaire was addressed to named individual contacts (usually the information service manager) and the introductory letter suggested that ideally it should be completed by "someone with a good overview of the types of enquiries received by your service and the way these enquiries are handled by staff". One reminder letter was sent and up to three follow up telephone calls made to non-responders.

Responses to the fixed response option questions were recorded on a Microsoft excel spreadsheet to facilitate the production of descriptive statistics. Responses to open ended questions were transcribed into a Microsoft Word file with all responses to the same question grouped together. Different types of

Table 1 Findings from a fixed response option question about the actions taken by staff when the leaflets were received

	Respondents n (%)
All staff who handle enquiries from the public actively notified	35 (77.8)*
All staff who handle enquiries encouraged to read the leaflet(s)	32 (71.1)*
Leaflets formally discussed among staff	6 (13.3)*
Leaflets informally discussed among staff	17 (37.8)*
Local health professionals consulted about the contents	2 (4.4)

*One consumer health information service had only one staff member, so these questions did not apply.

response (themes) within each question were colour coded and some types of response were counted manually before a narrative summary of these open responses was produced.

Results

Forty five completed questionnaires were returned—a response rate of 76.3%. Forty two respondents worked for general consumer health information services, the others for services specialising in health promotion, information for elderly people, and information about arthritis and related diseases. Reasons for non-response were obtained from eight organisations. Three said that they did not provide information materials to the public, and four said that key staff were away or had left and those currently there were unable to complete the questionnaire. Staff at one large consumer health information service had decided that they did not want to complete the questionnaire and a staff member at one service had completed a questionnaire but it did not reach us. Two non-responding services could not be traced by directory enquiry services and three others did not respond to follow up telephone calls and messages. All 45 respondents had received copies of the men's leaflets in January 1997.

STAFF OPINIONS ABOUT THE LEAFLET

The overall impression created by responses on the returned questionnaire was that service staff were generally enthusiastic about the men's leaflet. Responses to an open question inviting any other comments about the leaflet and its use included: "It was extremely useful to us"; "It has proved a useful resource"; "It is a very useful adjunct to our consumer health information"; and "There is a great lack of consumer health information materials of this type—additional subject areas would be a great help". The only negative comments made in response to this question were in the form of suggestions about how the presentation might be improved (see later).

In responses to an open question about features of the leaflet that they particularly liked, 13 respondents commented on the comprehensiveness or relevance of the information provided, with terms and phrases—such as, informative, thorough, a full picture, salient, and answered questions that callers raised. Four respondents particularly appreciated the provision of information about the advantages and disadvantages of treatment options.

Presentational features were also spontaneously identified as features that were liked. Fourteen respondents used the words clear or

Table 2 Responses to the questionnaire

Leaflets (n)	Services (n)
<10	11
11–50	18
51–100	9
101–200	4
>200	1

clearly in their answers, and a further eight identified the readability and understandability of the leaflet as positive features, with phrases—such as easily readable, all terms explained well, and well written and in lay terms. Six respondents liked the conciseness of the leaflet, and two combined comments about the amount and adequacy of information provided: "enough detail without swamping the reader with too much in-depth medical info"; and "comprehensive without being too long".

Eleven respondents liked the layout of the leaflet (well set out, layout excellent). Three picked out the use of bullet points for particular mention and two particularly appreciated the space to jot down questions to ask the doctor.

Only four people responded to an open question about features of the leaflet they disliked. Two disliked the format, one suggested that there was possibly too much text, and one found the information biased: "The evidence for treatment of prostate cancer is presented in a way that highlights the risks of treatment".

The few that suggested improvements (in response to an open question inviting any other comments and a specific question about how our consumer health information leaflets might be improved) focused on format and presentation. Three respondents said that a smaller sized leaflet would be more convenient, one thought that the title could have been clearer and the front page less old fashioned, and one would have preferred more friendly colours.

Only one respondent answered yes to a question about whether consumer health information service staff had disagreed with or had any concerns about the leaflet. This respondent judged some of the language to be negative and frightening. Five other respondents were unsure whether other staff in their service had any concerns.

USE MADE OF THE LEAFLET

Table 1 summarises the findings from a fixed response option question about the actions taken by staff when the leaflets were received.

Forty three respondents provided estimates of the number of the men's leaflets that had been given to members of the public between January and June 1997. Table 2 summarises the responses.

Responses to a series of fixed response option questions about the types of enquirers who had been given leaflets are summarised in table 3.

Fifteen (33.3%) information services proactively publicised the leaflet in some way.

When asked whether there had been any people enquiring about screening for prostate cancer to whom information services staff had

Table 3 Numbers of consumer health information services giving leaflets in response to different types of enquiry

	People given leaflets			No relevant enquiries	No response
	All	Some	None		
People who specifically asked for it	21	8	1	5	10
People wanting information about screening for prostate cancer or PSA testing	23	11	1	2	8
People wanting information about prostate disease	12	22	3	1	7

been reluctant to give the leaflet, 37 respondents said no, four said yes, and two were unsure. Stated reasons for reluctance were: "Distressed patients, where I felt they would be even more frightened by some of the phrases in the pamphlet"; "some very nervous customers who were unsure about having the test" (for whom the respondent judged the content to be "a little alarming"); and a person with an "incomplete diagnosis" (no further information supplied). One service did not distribute any copies of the leaflet because their main purchasing authority had withdrawn funding for prostate specific antigen testing.

Eleven respondents answered yes to a question about whether they had had any feedback from people to whom they gave the leaflet. Ten said this was mainly positive and one that it was partly positive and partly negative. Few described the feedback, but the mixed feedback was attributed to people who were still unsure about whether or not to have a test after reading the leaflet. One example of positive feedback involved a man who contacted the consumer health information service after his GP refused him a prostate specific antigen test but did not explain why. The man thought the leaflet explained the GP's reasons for the refusal.

Eight respondents answered yes to a question about whether there had been occasions on which people who were given the leaflet contacted the services again. They had received calls from men who, after reading the leaflet, could not decide whether to have a prostate specific antigen test, from a man with a high prostate specific antigen count facing a decision about treatment, and from people wanting more detailed information about treatment procedures. In response to follow up enquiries, four services had given verbal answers to questions, five had provided a copy of *Effectiveness Matters* (the health professionals' leaflet), five had provided other written information (including more information about surgical procedures), and two had suggested that the enquirer discuss the issue with a health professional.

Four consumer health information services mentioned, in response to the question about follow up enquiries, that GPs had contacted them asking for further copies of the men's leaflet. One described how a lay enquirer had requested another copy after giving his first to a friend.

VIEWS ABOUT THE LIKELY USEFULNESS OF SIMILAR CONSUMER HEALTH INFORMATION MATERIALS

All 45 respondents said that they would wish to be supplied with other consumer information

leaflets about healthcare effectiveness from the NHS Centre for Reviews and Dissemination. Thirty nine received *Effective Health Care* bulletins on a regular basis. Forty four thought that "consumer versions" of *Effective Health Care* bulletins, designed to support people wanting to participate in decisions about their care, would be useful to information service staff and 43 thought that they would be useful to their enquirers. The remaining few respondents were unsure, one noting that "Some consumers of health information are still not happy to make decisions for themselves".

Discussion

We conducted a postal questionnaire survey and relied on one respondent per consumer health information service to present the views and experiences of all relevant staff members. Our attempts to follow up non-respondents suggested that several had moved or closed since our mailing lists were compiled, and that services often have few staff and their performance is limited when these key staff are absent. The use of a postal questionnaire, which was dictated by resource constraints, limited the extent to which we could explore opinions and explanations of behaviour in depth, but none the less yielded useful basic information.

The consumer health information service staff were generally enthusiastic about the content and presentation of the men's leaflet. Efforts to produce good quality consumer health information are welcome, but the ways in which information materials are provided are also important determinants of healthcare quality.

Screening for prostate cancer has been a popular topic recently, and the information services used the leaflet to respond to many enquiries. It is difficult to estimate how many men would have considered or had questions about prostate specific antigen testing during the period of our study, so we cannot tell what proportion of men who might have found the leaflet useful actually obtained it. We did not attempt to estimate how many leaflets were given to such men by GPs. The fact that consumer health information services received requests from GPs for further copies of the men's leaflet confirms that some GPs actively gave the leaflets to their patients (the NHS Centre for Reviews and Dissemination has also been asked for further copies by over 100 GPs). However, the survey also suggests that some GPs do not provide the leaflets (or other information) to men requesting prostate specific antigen tests. The consumer health information services can help fill the gaps when health professionals do not provide information, but only for people who know and are able to contact them.

Although our survey confirms that information services can make good use of research based information leaflets, it also highlights some issues of concern about providing information. The service staff, like other professionals, make decisions that affect the amount and type of information people get. Even a leaflet that was generally deemed to be

of good quality was not given to everyone who requested it, or to everyone enquiring specifically about screening for prostate cancer. Among the reasons respondents gave for this were: concern that the information might make some people anxious; a belief that it was inappropriate to tell people about interventions that are not available locally on the NHS; and a reluctance to provide information to enquirers for whom a complete diagnosis was not known. Opinions will vary about when it is appropriate to withhold information. Health professionals' fears that information about the risks of interventions will make people anxious are not always justified.¹² Also, it may be that a certain amount of anxiety about particular healthcare interventions is actually appropriate. The case of the man who was refused a prostate specific antigen test by his GP showed that the information provided in the men's leaflet might have helped to explain a policy decision not to fund such testing. Even if the leaflet led people to want the test, it could be argued that the information might enable them to seek it elsewhere in the NHS or privately, or to protest about its non-availability in an informed way. The information service staff are often not fully aware of enquirers' diagnoses, and this may indeed hinder their ability to provide relevant information. However, people who are awaiting confirmation of a diagnosis may none the less want information to help them think about treatment options for several eventualities. Thus some of the concerns that led information services staff to withhold the leaflet from certain enquirers may not always be justified.

As well as the potential problem of underuse of the leaflet, the survey suggested that some information services gave the leaflet to everyone who enquired about prostate disease, regardless of the nature of the enquiry. There may be a tendency to provide a leaflet that is judged to be of good quality to people for whom it is not particularly relevant, and again this is a cause for concern.

Organisations that produce and provide information are often asked for more information, clarification, or advice. The ability of information services to respond appropriately to follow up enquiries warrants attention. In this case, some back up material was provided by the producers, but this did not cover all the follow up enquiries made.

The consumer health information services have traditionally been quite good at providing information about treatment processes but still

need further resources and developmental support to improve their ability to provide research based information about treatment outcomes.

As providers of information who are generally not well integrated with other care providers, consumer health information services have the advantage of being able to offer information in confidence, but they have a limited ability to coordinate with clinicians to ensure the relevance and coherence of the information provided. They are not well placed to advise people who are undecided about which option is best for them. A more integrated approach to giving information and supporting decisions of patients would improve the overall quality of health care within the NHS. Some clear strategic thinking is needed about how this might be achieved.

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Appendix: Questionnaire**Short survey to inform the production of consumer health information materials by the NHS Centre for Review and Dissemination**

PART 1: "SCREENING FOR PROSTATE CANCER: THE EVIDENCE"

1 Did your consumer health information service receive copies of these leaflets in January 1997?

Yes No (If no, please go to question 12)

2 When you received the leaflets, what action (if any) was taken with in your service? (Please tick as many boxes as apply)

- All staff who handle enquiries from the public were actively notified
- All staff who handle enquiries were encouraged to read the leaflets
- The leaflets were formally discussed among staff
- The leaflets were informally discussed among staff
- Local health professionals were consulted about the contents
- The service advertised the leaflet and/or proactively told people about it
- Other (please specify)

3 Did you or your staff disagree with or have any concerns about the content of the leaflet?

Yes No Unsure

If yes, can you briefly explain what these were and what, if anything, you did about them?

4 Approximately how many copies of "Screening for prostate cancer: the evidence" has your service given to members of the public (from January 1997 until the end of June 1997)? (You were initially sent 100 copies and invited to request more if required)

< 10; 11-50; 51-100; 101-200; >201

(If you feel able to give a more precise estimate, please do so) _____

5 Who has your service given the leaflet "Screening for prostate cancer: the evidence" to? (Please tick one box for each row)

	All of these	Some of these	None of these	There were none of these
People who specifically asked for it	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
People wanting information about screening for prostate cancer or PSA testing	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
People wanting information about prostate disease	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
People contacting the service with other enquiries who said they would like the leaflet when we told them about it	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

6 Have there been any people who have enquired about screening for prostate cancer or PSA testing whom you (or other members of staff) have been reluctant to give the leaflet to?

Yes No Unsure

If yes, please describe the situation and why you were reluctant to provide the leaflet

7 Please identify any features of the leaflet which you or other staff particularly liked

8 Please identify any features of the leaflet which you or other staff particularly disliked

9 Has your service received any feedback from enquirers who were given the leaflet "Screening for prostate cancer: the evidence"?

Yes No Unsure

If yes, was this feedback:

Mainly positive about the leaflet; Partly positive and partly negative; Mainly negative about the leaflet

If there are any particular cases which you would like to describe, please do so

10 Have there been any occasions on which people who were given the leaflet by your service contacted the service again with further enquiries?

Yes No Unsure

If yes, please answer questions 10a and 10b. If no, please go to question 11.

10a If yes, please describe as far as possible the nature of the further enquiries. Please indicate with an asterisk (*) any enquiries which you found difficult to handle

10b What action did you or other staff take on these occasions? (Please tick all that apply)

- Provided verbal answers to questions
- Provided a copy of *Effectiveness Matters: screening for prostate cancer*
- Provided other written information (Please specify)
- Suggested the enquirer discussed the matter with a health professional responsible for their care
- Other (please specify)

11 Are there any other comments you would like to make about the leaflet and its use?

PART 2: OTHER CONSUMER HEALTH INFORMATION MATERIALS FROM THE NHS CENTRE FOR REVIEWS AND DISSEMINATION

12 Would you like your service to be supplied with other consumer information leaflets from the NHS Centre for Reviews and Dissemination about the effectiveness of the health care interventions?

Yes No Unsure

13 Have you any suggestions about how we could improve our consumer health information leaflets, or the way in which they are distributed to you?

14 The NHS Centre for Reviews and Dissemination produces a series of bulletins called *Effective Health Care*. These are written primarily for health care professionals and health service managers. They are also sent to consumer health information services14a Does your service receive *Effective Health Care* on a regular basis? (One bulletin is produced every two months)Yes No Unsure 14b The NHS Centre for Reviews and Dissemination is considering the possibility of producing "consumer versions" of some *Effective Health Care* bulletins. These would focus on information about the effectiveness of the healthcare options and would be designed to support individuals wanting to participate in decisions about their care. They would be written in plain English.

Do you think these consumer versions would be useful?

- (i) to you or other staff Yes No Unsure
- (ii) to your enquirers Yes No Unsure

THANK YOU for completing this questionnaire.

Please return it in the reply-paid envelope to: NHS Centre for Reviews and Dissemination, University of York, York, YO1 5DD