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

Vikki A Entwistle, Ian S Watt

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.

Keywords: information; prostate cancer; screening

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, and there is growing interest in improving the quality of these products. 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 health-care 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. 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. 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.
Disseminating information about healthcare effectiveness

used to respond to these enquiries, however, were often not reliably research based, and staff often gave verbal rather than written responses. 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. 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) 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. 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. 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, the other for men considering having prostate specific antigen tests. The development of the leaflets has been described elsewhere. The men’s leaflet aimed to ensure that men 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.

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
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 informa-
tion 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 serv-
ces and three others did not respond to follow
up telephone calls and messages. All 45
respondents had received copies of the men’s

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 fea-
tures of the leaflet that they particularly liked,
13 respondents commented on the compre-
hensiveness 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 spontane-
ously identified as features that were liked.
Fourteen respondents used the words clear or
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 in lay
terms. Six respondents liked the conciseness
of the leaflet, and two combined comments about
the amount and adequacy of information pro-
vided: “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 sug-
gested 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 presenta-
tion. 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 respond-
ents 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 proac-
tively 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>
<thead>
<tr>
<th>Table 1</th>
<th>Findings from a fixed response option question about the actions taken by staff when the leaflets were received</th>
</tr>
</thead>
<tbody>
<tr>
<td>Respondents n (%)</td>
<td></td>
</tr>
<tr>
<td>All staff who handle enquiries from the public actively notified</td>
<td>35 (77.8)*</td>
</tr>
<tr>
<td>All staff who handle enquiries encouraged to read the leaflet(s)</td>
<td>32 (71.1)*</td>
</tr>
<tr>
<td>Leaflets formally discussed among staff</td>
<td>6 (13.5)*</td>
</tr>
<tr>
<td>Leaflets informally discussed among staff</td>
<td>17 (37.8)*</td>
</tr>
<tr>
<td>Local health professionals consulted about the contents</td>
<td>2 (4.4)</td>
</tr>
</tbody>
</table>

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

<table>
<thead>
<tr>
<th>Table 2</th>
<th>Responses to the questionnaire</th>
</tr>
</thead>
<tbody>
<tr>
<td>Leaflets (n)</td>
<td>Services (n)</td>
</tr>
<tr>
<td>&lt;10</td>
<td>11</td>
</tr>
<tr>
<td>11–50</td>
<td>18</td>
</tr>
<tr>
<td>51–100</td>
<td>9</td>
</tr>
<tr>
<td>101–200</td>
<td>4</td>
</tr>
<tr>
<td>&gt;200</td>
<td>1</td>
</tr>
</tbody>
</table>
Diagnosing information about healthcare effectiveness

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

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

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. 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.

We thank the staff of the consumer health information services who participated in our survey and Frances Sharp and Jane Winn for help with the distribution of questionnaires and follow up of responses. The NHS Centre for Reviews and Dissemination is funded by the NHS Executive and the Health Departments of Scotland, Wales, and Northern Ireland. A contribution to the Centre is also made by the University of York. The views expressed in this publication are those of the authors and not necessarily those of the NHS Executive or the Health Departments of Scotland, Wales, or Northern Ireland.

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 ☐

3. 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 ☐
   People wanting information about screening for prostate cancer or PSA testing ☐
   People wanting information about prostate disease ☐
   People contacting the service with other enquiries who said they would like the leaflet when we told them about it ☐

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 ☐

5. Has your service received any feedback from enquirers who were given the leaflet "Screening for prostate cancer: the evidence"?
   Yes ☐ No ☐ Unsure ☐
   If yes, can you briefly explain what these were and what, if anything, you did about them?

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

7. Did you or your staff disagree with or have any concerns about the content of the leaflet?
   Yes ☐ No ☐ Unsure ☐

8. When you received the leaflets, what action (if any) was taken with in your service? (Please tick as many boxes as apply)
   Mainly positive about the leaflet; ☐ Partly positive and partly negative; ☐ Mainly negative about the leaflet ☐

9. Did your consumer health information service receive copies of these leaflets in January 1997?
   Yes ☐ No ☐ Unsure ☐

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 describe the situation and why you were reluctant to provide the leaflet

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

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. Do you think these consumer versions would be useful?
    Yes ☐ No ☐ Unsure ☐
    If yes, what do you think these consumer versions would be useful?

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 services.
    Yes ☐ No ☐ Unsure ☐
    If yes, do you receive these bulletins on a regular basis? (One bulletin is produced every two months)

15. 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 ☐

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

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
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