KING'S
FUND
CENTRE

INFORMATION ON OBTAINING THE VIEWS OF USERS ABOUT PATIENT INFORMATION

CONSUMER FEEDBACK RESOURCE

INFORMATION ON
OBTAINING THE VIEWS OF
USERS ABOUT PATIENT
INFORMATION

CONTENTS

Introduction

Literature overview

Useful reading references

Current Projects

Organisation Contact List

Questions to ask

INTRODUCTION

These information sheets will be of use to health service staff or Community Health Councils who wish to find out the views of users of patient information.

The purpose of these sheets is:

1 to give some useful reading references for this field or an overview of the literature

2 to give details of some of the current major projects

3 to list some organisations which may be able to carry out research

4 to provide a checklist of what appear to be the most important areas for questions to ask users when asking them for their views on information.

Information on the use of feedback methods is available separately and is also provided in full detail in McIver S. Obtaining the Views of Users of Health Services. London: Kings Fund Centre, 1991.

Details of any type of consumer feedback project using survey or non-survey methods are welcomed by the Consumer Feedback Resource so that we can develop the advice on patient information. Please send the information to:

Shirley McIver
Manager
Consumer Feedback Resource
King's Fund Centre
126 Albert Street
London
NW1 7NF

Tel: 071-267 6111

July 1991

AN OVERVIEW OF THE LITERATURE ON OBTAINING THE VIEWS OF USERS ABOUT PATIENT INFORMATION.

Need for Better Information

The need for better communication with patients is well established as detailed in a recent editorial in the British Medical Journal titled 'Chasms in communication: still occur too often' (1). A recent survey by Which? magazine found one in five patients left the consultation without understanding what was wrong with them and what the treatment was going to be whilst one in four were not given information on their condition unless they asked for it. (2) The report details guidelines to enable patients to get more information from consultations.

A variety of desirable benefits can be identified from the provision of better information. Good quality information is a prerequisite for informed consent and empowered patients. (3) Better information leads to improved patient compliance with treatment, improved patient outcomes and therefore reduced costs (4). Better information leads to increased patient satisfaction. (5,6).

Improved Communication Skills

Improving the information given to patients is not a simple matter as research proves. One response has been the emphasis placed on the need for doctors to improve their communication skills and studies have been undertaken which show that one of the strongest determinants of compliance with treatment is satisfaction with the information given in a consultation. (7) Recent research has also looked at how the communication style of the patient is also an influential faction in the process of information giving. (8,9) Steptoe et al found that patients' tendencies to cope with stress by seeking out or avoiding information affected the amount of information given to them. (10)

Carr suggests the following guidelines for doctors to enable them to increase patient compliance by improving communication with patients: (4)

- Adopt a friendly and informal conversational style which encourages patients to provide information.
- Assess patients' beliefs about the aetiology of their complaints and their expectations concerning treatment.
- Clarify how much information patients would like about their condition.
- Offer an explanation of the patient's condition and the rationale for treatment.
- Present the treatment regimen and the rationale upon which it is based in language that the patients can understand and which allows them to remember what has been said.
- Help the patient appreciate the costs and benefits of compliance and non-compliance.
- Enlist the aid of the patient's family or friends in helping the patient comply with medical advice.
- Review compliance at each follow-up consultation.

Leaflets

Another issue concerns the best format for information provision apart from the skills required in personal interactions. Attempts to improve information provision most often lead to the production of a leaflet. However research findings on the public's preferences for means of getting health information found the following were the typically preferred means: (11)

Means	**% of people favouring**
TV/radio	33
Posters	12
General practitioner	7
Press	6
TV advert	6
Leaflet	4

Little comparative evaluation has been done on the relative effectiveness of disseminating information using leaflets, videos or audiotapes. (12)

Research has been undertaken to evaluate the usefulness of specific initiatives and this research underlines the value of piloting and evaluating developments in communication. Bhopal et al evaluated a practice information leaflet and judged the leaflet to be useful (13). Self referral to nurses increased and the timing of incoming telephone calls was more in line with practice policy. However another study which involved the development and randomized controlled trial of a booklet of advice for parents found that had all households in the practice been sent a copy of the booklet it would have resulted in 28 per cent fewer home visits but 173 per cent more out of hours consultations. (20)

Attention has also been paid to the administrative and technical points of producing patient literature. Brighton Health Authority have undertaken a review of all information provided for patients in their authority in order to produce guidelines which include the following: (see Current Project List)

- A department heading, the date and the Health Authority logo should be on the front or top of all literature.
- A list of contents and an introduction are essential if the length exceeds four pages.
- All should be short avoiding jargon and medical terms. Abbreviations should be avoided.
- If possible, material should be professionally printed or at least produced on a word processor if the quantities required are not sufficient to justify printing.
- Whenever patients are sent photocopies they should be taken from the original material. Recommendations on standards of photocopying have been produced by the Health Authority and need to be implemented. It does not cost any extra to photocopy careful and accurately.
- Literature should be reduced in size by careful cutting, not tearing.
- The material should be assessed by as many medical and non-medical people as possible, for approval and/or criticism before reproduction.

RIPACS have published 'An Evaluation of Patient Literature' which provided guidance to the technical points to be considered such as readability, clear layout, packaging and the need to include information on pensions and other social security benefits whilst in hospital. (14)

Alternatives to Leaflets

Other modes of communicating information to patients are being developed. The usefulness of giving patients tape recordings of consultations is being evaluated by Sussex University (see Current Project List). A further approach to improving information provision has been the setting up of advice centres (15,16,17) or telephone help lines (18). There is a bewildering array of sources providing information to patients but a fairly comprehensive guide can be found in 'The Health Information Handbook' by Robert Gann which also includes a chapter on setting up a health information resource. (19) Gann developed the Help for Health Information Line based at Southampton General Hospital and Help for Health is now selling their database to other organisations (see Organisation Contact List)

Conclusion

In conclusion the following points can be made about research into the provision of good quality patient information:

- The nature of professional and patient interaction is very complex -improved communication skills on the part of the professional and patient can increase the benefits of the exchange.
- Any new developments in information provision are more effective when piloted and evaluated to ensure the following:
    - information is accessible, palatable and available when and where it is needed.
    - information is presented using simple language and format by people who are themselves well informed.
    - information is complete, accurate and up-to-date.
    - patients are not overwhelmed with information.
    - information is provided in a way that it reaches those who may not in the first instance realise they need the information.
    - professionals appreciate the degree to which the public might be uninformed.
- There are various well developed sources of information provision for patients, e.g. help lines, advice centres, the Health Education Authority. These sources should be utilised in new developments.
- More research needs to be done on the relative merits of different modes of communication, e.g. tapes, videos, leaflets, classes and counselling.

REFERENCES

1. Richards T. Chasms in communication: still occur too often. BMJ, 1990 Dec:1407-1408.
2. Mason D. What's up doc. Which? 1991 Feb:94-97.
3. Anonymous. Obtaining patients consent. News NHS Management Executive, 1990 Sep;37:2.
4. Carr A. Compliance with medical advice. British Journal of General Practice, 1990 Sep:358-360.
5. Edwards M. Satisfying patients' needs for surgical information. British Journal of Surgery, 1990 Apr;77,4:463-465.
6. Calnan M, Williams S. Please treat me nicely. The Health Service Journal, 1991 Jan 17:25.
7. Thompson J. Communicating with patients. In: Fitzpatrick R et al (eds). The experience of illness. London: Tavistock, 1984.
8. Tuckett D, Williams A. Approaches to the measurement of explanation and information-giving in medical consultations: a review of empirical studies. Social Science and Medicine, 1984;18,7:571-580.
9. Street R. Information-giving in medical consultations: the influence of patients' communicative styles and personal characteristics. Social, Science and Medicine, 1991;32,5:541-548.
10. Steptoe, A, Sutcliffe I, Allen B, Coombes C. Satisfaction with communication, medical knowledge and coping style in patients with metastatic cancer. Social Science and Medicine, 1991;32,6:627-632.
11. Budd J, McCron R. The role of the mass media in health education, Centre for Mass Communication Research, for the Health Education Council, 1982.
12. Goddard M, Morris J. Putting them in the picture. The Health Service Journal, 1990 Aug 9:1186.
13. Bhopal R, Gilmour W, Fallon C, Bhopal J, Hamilton I. Evaluation of a practice information leaflet. Family Practice, 1990;7,2:132-137.
14. Burnett S. An evaluation of patient information literature. Reading Royal Institute of Public Administration, 1987.
15. Hicks A. Pick it up with the shopping. The Health Service Journal. 1991 Mar 14:24.
16. Sweetland J. In the know. Nursing Times 1990 Aug 15;86,33:36-38.
17. Robinson S, Roberts M. A women's health shop: a unique experiment. British Medical Journal, 1985 Jul 27;291:255-256.
18. Anonymous. Healthline has confident ring. Managing better health: Quality for Life. East Anglian Regional Health Authority, Birmingham NEC Exhibition, Oct 1990.
19. Gann R. The Health Information Handbook. London: Gower, 1986.
20. Usherwood T. Development and randomized controlled trial of a booklet of advice for parents. British Journal of General Practice, 1991 Feb: 58-62.

USEFUL READING REFERENCES

The texts in this list are chosen because they cover issues that arise in consumer feedback or quality improvement in providing information for patients.

Mason D. What's up doc. Which? 1991 Feb:94-97.

> This article contains useful tips for patients to obtain better information from professionals.

Thompson J. communicating with patients. In: Fitzpatrick R et al (eds). The experience of illness. London: Tavistock, 1984.

> This chapter discusses the problems in communicating with patients and some of the training methods that have been employed as solutions.

Burnett S. An evaluation of patient information literature. Reading: Royal Institute of Public Administration Consultancy Services, 1987.

> This book includes guidelines for the production of literature in health authorities.

Gann R. The Health Information Handbook. London: Gower, 1986.

> Describes the range of sources providing patient information, patients' information needs and includes guidelines on how to set up a health advice resource.

Morris J, Goddard M, Roger D. The benefits of providing information to patients. Centre for Health Economics, University of York, 1989.

> This overview of the area includes suggestions for further research.

None of the publications above have been formally evaluated but provide a guide to what is available.

The King's Fund Centre has a reference library which holds many of the publications mentioned. Photocopies of journal articles ONLY (not books or reports) can be supplied at 20 pence a page plus postage and packing. However you are advised to try your local library first.

CURRENT PROJECTS

These projects are ones that are funded to develop good practice in the field of consumer feedback or quality improvement in patient information.

Margaret Morgan-Cooke
Quality Assurance
Research Nurse
Southmead Hospital
Westbury on Trym
Bristol

A survey of patient information about general information and medical information has been undertaken to assess patients' needs.

Pam Lelliott
Public Relations Officer
Brighton Health Authority
Brighton General Hospital
Elm Grove
Brighton
BN2 3EW

Tel: 0203-696011

Have reviewed the presentation of all information for patients to improve the quality of the information.

Jaqui Biggs
Wessex Waiting Line
Public Affairs Department
Wessex Regional Health Authority
Romsey Road
Winchester
Hampshire
SO22 5DH

Tel: 0703-702568

This information service on regionwide waiting times for treatment in Wessex has received funding from the Department of Health to develop its resources further.

Mr Brian Hogbin
Brighton Health Authority
Brighton General Hospital
Elm Grove
Brighton
East Sussex

Tel: 0273-696011

Psychologists from the University of Sussex are assessing the usefulness of tapes in helping families to understand the full implications of the diagnosis and treatment options. They are also studying whether the tape reduces the amount of anxiety and depression experienced by patients between diagnosis and treatment.

Acorn Project

Bob Gann
Health Information Manager
Help for Health
Grant Building
Southampton General Hospital
Southampton
SO9 4XY

Tel: 0703-779091

This is a joint project between the Wessex Help for Health information service and Isle of Wight Health Authority, aimed at improving communication with patients in the new St Mary's Hospital.

Organisation Contact List

This is a list of organisations offering advice and assistance to those seeking to obtain information from users about patient information. This list is not comprehensive and inclusion does not imply endorsement by the King's Fund Centre.

Help for Health
Grant Building
Southampton General Hospital
Southampton
SO9 4XY

Tel: 0703-779091

ACHCEW (Association of Community Health Councils for England and Wales)
30 Drayton Park
London
N5

Tel: 071-609 8405

Research Institute for Consumer Affairs
2 Marylebone Road
London
NW1 4DX

Tel: 071-935 2460

Disabled Living Foundation
380/384 Harrow Road
London
W9 2HU

Tel: 071-289 6111

Department of Community Medicine
Southampton University
Southampton
SO9 5NH

Tel: 0703-593024

AREAS FOR QUESTIONS

Here is a summary of some of the issues relating to patient information around which questions can be constructed:

1. Preferences for the way information is conveyed, e.g. by staff, video, leaflet, etc.
2. Whether enough information is being conveyed.
3. Whether the information conveyed is easy to understand.
4. Whether the information is given at an appropriate time.
5. Whether information is easily accessible to all types of service user, e.g. carers, patients, general practitioners, different black and minority groups.
6. Does the information cover all the issues that users want to know about in an up-to-date and accurate manner.

The type of questions included in a questionnaire will vary greatly according to the circumstances but the questions below are provided as an example of the type that could be used when asking patients for their views on the quality of information.

The questions are taken from 'Obtaining the Views of Outpatients' by Shirley McIver, Kings Fund Centre, 1991.

1. Is this your first visit as a patient to the Clinic/Outpatients?
2. When you arrived here at the clinic today, was it obvious who you should report to?
3. Were you addressed by staff at all times in a friendly and courteous manner?
4. Did all staff address you by your name when they spoke to you?
5. Was it clear to you who each member of staff you saw was (for example, did they introduce themselves, did they wear a name badge)?
6. If you had to wait more than 30 minutes after your appointment time, were you told the reason why and how much longer you might have to wait?
7. Did you know who to ask if you had any queries?
8. Was that person available or easy to contact during the time you were there?
9. Did you see the doctor you were expecting to see?
10. If there were other people present at your consultation, did the doctor explain who they were?
11. Was the consultation interrupted by people coming in or by the telephone ringing?
12. Did the doctor answer your questions in a way you could understand?
13. When you left the consultation were you clear about what was going to happen next? (for example – whether you were going to have another appointment, were being referred back to your general practitioner, or were being admitted.
14. If you thought of more questions after you left the consultation did you know who to ask for further information?
15. Do you have any other comments you would like to make about your experience of either waiting to see the doctor or seeing the doctor?

The King's Fund Centre is a health services development agency which promotes improvements in health and social care. We do this by working with people in health services, in social services, in voluntary agencies, and with the users of their services. We encourage people to try out new ideas, provide financial or practical support to new developments, and enable experiences to be shared through workshops, conferences and publications. Our aim is to ensure that good developments in health and social care are widely taken up.