

King's Fund

The POPPi Guide

Practicalities of producing patient information

Mark Duman and Christine Farrell



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Glossary

Who is a 'patient'?

The term 'patient' is in common use in the NHS and, while we understand that not everyone approves of the passive concept associated with this word, we have used it throughout in the knowledge that it is widely understood. We use it in this guide to refer to all health service users, including individuals with specific disease states, their carers, and people seeking information on health promotion and disease prevention.

Case studies

Many of the illustrative examples in the text are drawn from the development sites that were part of the King's Fund *Promoting Patient Choice* (PPC) programme. Further information about the programme is given in *Appendix 4*. The following abbreviations are used to refer to the development sites:

PPC Bristol: <i>Urge incontinence</i>	Bristol Urological Institute multimedia package on urge incontinence
PPC Hull: <i>Colorectal cancer</i>	Hull University/Castle Hill Hospital multimedia package on colorectal cancer
PPC Manchester: <i>Ulcerative colitis</i>	Manchester University/Hope Hospital personal organiser on ulcerative colitis
PPC Nottingham: <i>Bedwetting</i>	Nottingham University/Nottingham City Hospital multimedia package for children on bedwetting.
PPC Oxford: <i>HRT</i>	Beaumont Street Practice, Oxford, interactive video disk on Hormone Replacement Therapy
PPC Nottingham: <i>Pain relief</i>	Queen's Medical Centre, Nottingham, booklet on post-operative pain relief
PPC Redbridge and Waltham Forest: <i>Anxiety</i>	Redbridge and Waltham Forest Health Authority project to provide information materials for Asian women on anxiety.

Abbreviations

BMA	British Medical Association
BMJ	British Medical Journal
BNF	British National Formulary
BSL	British Sign Language
CaF	Contact a Family
Cancer BACUP	British Association of Cancer United Patients
CHC	Community Health Council
CHiQ	Centre for Health information Quality
CNST	Clinical Negligence Scheme for Trusts
DDA	Disability Discrimination Act 1995
DISCERN	Developing an Assessment Instrument for the Clinical Appraisal of Written Consumer Health Information
HEA	Health Education Authority
HEBS	Health Education Board for Scotland
HIS	NHS Health Information Service
HPIC	Health Promotion Information Centre
HQS	Health Quality Service
HTA	Health Technology Assessment
LMCA	Long-Term Medical Conditions Alliance
NHS	National Health Service
PACE	Promoting Action for Clinical Effectiveness
PCGs	Primary Care Groups
pecmi	Promoting Excellence in Consumer Medicines Information
PiF	Patient information Forum
POPPI	Practicalities of Producing Patient information
PPC	Promoting Patient Choice
RCT	Randomised Controlled Trial
RNIB	Royal National Institute for the Blind
RNID	Royal National Institute for Deaf People
VHOs	Voluntary Health Organisations

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Introduction

The POPPi Guide: Practicalities Of Producing Patient information is for people who want to produce health information packages. It is intended primarily for people working in the NHS – in primary care, community health or hospital settings – but it may also be useful for voluntary organisations specialising in health, to patient and carer groups, and for pharmaceutical companies that wish to make their medicines information more accessible. It aims for excellence in the production of health information materials. We know that it may not always be possible to achieve this ‘gold standard’, but working towards high standards is an important part of the process.

The guide is based on the evaluation of, and the lessons learned through, the work done at the King’s Fund under the title *Promoting Patient Choice*. This programme funded and supported seven projects that met specific criteria in the production of good quality, evidence-based patient information. Details of the work are given in *Appendix 4*. The unpublished report of the detailed external evaluation of the programme, carried out by Bec Hanley in 1997, concluded that patients had been enthusiastic about the materials produced through the *Promoting Patient Choice* programme, and that their knowledge both of their conditions and of their options for treatment had increased.

We want to share what we learned from *Promoting Patient Choice* so that others can continue and improve upon this work.

The POPPi Guide aims to provide basic information and will be a useful starting point and a hands-on resource. It includes:



Action points, which sum up each section at a glance.



Case studies and *illustrations* from information packages which offer an opportunity to learn from other people’s experience.



Further information about books, articles, web sites and other sources for each topic.

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This guide cannot answer every question about producing patient information. The appendices contain sources of specialist information for people who need more technical help, including:

- contact details for all organisations mentioned in the guide
- information about funding sources
- references for further reading
- details of the *Promoting Patient Choice* programme
- electronic sources of patient information
- feedback form.

The following literature reviews provide useful background to the topics of informed choice and consumer health information:

- *Well read* (MacDougall 1998) considers the fast-growing area of consumer health information and makes a number of recommendations.
- *Putting people in the picture* (Olszewski and Jones 1998) reviews the literature on information for patients and the public about illness and treatment.
- The 18 September 1999 issue of the *British Medical Journal* provides an excellent overview of this area.

A guide to producing health information (Entwistle and O'Donnell 1999), available only on a web site, includes an excellent section on information needs and gaps in research evidence. Internet: www.abdn.ac.uk/public-health/hsru/guide/index.htm

Although not the focus of POPPi, it is important to mention that producing and providing good quality, evidence-based patient information must complement – not replace – communication with health care professionals. Two publications aim to help patients obtain a better understanding of the system in which health care is delivered.

- *Patient Power: Getting the best from your healthcare* (Harvey and Wylie 1999).
- *Trust Me I'm a Doctor* (Hammond and Mosley 1999) gives patients encouragement and information to move from blind trust to informed scepticism. Examines health issues from a consumer's perspective, exposing myths and highlighting the gap between scientific evidence and treatment.

I The right to information

Statutory requirements

The Health Act 1999 puts information for patients, and for the public generally, high on the NHS agenda. One of the major strands in its policy is to set national standards and define service models through a series of National Service Frameworks. The first of these – *A National Service Framework for Mental Health: Modern Standards & Service Models* (DoH 1999) – was published in October 1999. Other frameworks will be published throughout the year 2000. Each framework will include statements about seeking information from patients and carers to ensure that the NHS is sensitive to individual needs. Standards will be set and monitored in every NHS trust, including primary care, for the way in which patients and their carers view the quality of the treatment and care they receive. These standards will include information and choice.

The introduction of clinical governance requires all NHS organisations to involve users and carers within an organisation-wide strategy; this must include strategic plans for communicating with them. These new requirements mean that every trust should develop an information strategy and policy, with agreed standards.

The Patient's Charter

The Patient's Charter lists certain 'rights' to information for patients, and the standards expected from those who provide the information. These include the right to:

- be given a clear explanation of any proposed treatment, including any risks involved and any alternatives, before being asked to agree to it
- have access to health records, and know that everyone working for the NHS is under a legal duty to keep those records confidential
- be given detailed information on local health services, including information on the standards of services that can be expected, waiting times, and on local GP services
- have any complaint about NHS services investigated and receive a quick and full reply from the chief executive or manager
- choose whether or not to take part in medical research or medical student training
- be offered appropriate arrangements for informing relatives and friends about the progress of a patient's treatment, subject to the patient's wishes.

There are also specific charters for maternity services, services for children and young people, and mental health services. Few of the 'rights' in *The Patient's Charter* are legal entitlements. These charters are currently subject to review and a consultation paper on a new NHS Charter will be published imminently. The existing charters will continue to operate until the new Charter is issued.

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Other policy initiatives

Patient information may be linked to national and local policy initiatives such as patient partnership, *Information for Health* or public health agendas.

Patient Partnership Strategy

This UK NHS initiative was launched in 1996. The aims of the strategy included:

- users of NHS services, and their carers, having a greater voice and influence as active partners with professionals
- patients becoming informed about their treatment and care, and being able to make informed decisions and choices about it if they wish.

A revised version of the 1996 strategy, *Patient and public involvement in the new NHS* (DoH 1999) was launched in the autumn of 1999. It restates the importance of partnerships between the NHS and the public, gives examples of national and local initiatives in partnership developments, and identifies future actions to be taken.

Information for Health

Information for Health, issued in September 1998, outlines an information strategy for the modern NHS from 1998 to 2005. It aims to ensure that NHS professionals have the information they need to provide care and to play their part in improving the public's health. The strategy also aims to ensure that patients, carers and the public have the information they need to make decisions about their own treatment and care, and to influence the shape of health services generally.

Chapter 5 of the strategy focuses on meeting public and patient needs and supports the concept of shared decision-making, by aiming to:

- eliminate unnecessary travel and delay for patients by providing remote online access to services, specialists and care, wherever practicable
- provide access for NHS patients to accredited, independent, multimedia background information and advice about their condition
- provide fast, convenient access for the public to accredited multimedia advice on lifestyle and health, and information to support public involvement in, and understanding of, local and National Health Service policy development.

Public health strategy

The Government's public health strategy was launched in July 1999 in a White Paper, *Saving Lives: Our Healthier Nation*. The strategy aims to improve standards of health for everyone in England, and the worst off in particular, with specific targets for improvements in the areas that account for most deaths in those under the age of 75.

The strategy is based on the belief that people can make individual decisions about their own and their family's health that can make a difference – and those individuals and their families need to be properly informed to make decisions.

The Carers Act

The Carers (Recognition and Services) Act 1995, which came into effect in 1996, contains two main elements:

- the right of carers who regularly provide a substantial amount of care to ask for an assessment of their ability to care
- the duty of the local authority to take account of the carer's assessment along with those of the person being cared for.

Carers already had the right to be involved in the assessment of the person they are caring for under the NHS Act 1977 and other legislation.

Caring about carers: A national strategy for carers (DoH 1999) sets out in more detail the ways in which carers can be properly informed so that they can contribute discussions about care needs and solutions (the needs of the person they care for and their own needs). The strategy includes lists the kinds of information carers need (including health information), statements about the need for carers to be involved in planning and providing services, and ways in which their views can be collected.

The King's Fund Carers Project has produced a useful list of information sources for carers in its publication *Information for carers* (Banks 1997).



Action points

- To get copies of all the government policy publications, call the NHS Responseline. Tel: 0541 555 455.

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2 Developing an information policy

Developing an information policy will involve many people and should certainly involve patients and their carers. Meeting their needs, as well as the organisation's need for information, should have a high priority. The production of specific information for patients will then fit into this policy.

To develop an information policy, an agency or department needs to ask some questions:

- Is there, or should there be, a general corporate policy on information for patients?
- Who is responsible for policy, planning, providing information and setting priorities?
- Does the information policy cover the full range of topics and issues that concern patients and carers, and departments?
- Will there be a clear boundary between information and advice? All information services have to make this distinction, and it is important to be clear at the outset exactly what is the purpose of all the information provided.
- Does the policy make it possible to meet new needs as they emerge?
- Does the policy allow for the use of all existing media and new media as they are developed?
- What resources are available for implementing the policy and who will be responsible for allocating and managing them?
- Who will have overall management responsibility for implementing, monitoring and reviewing the policy?

Corporate strategy and policy guidelines should include the roles and responsibilities for staff in charge of patient information. These responsibilities should include:

- deciding how patients are told about their rights
- access to records
- confidentiality
- procedures for patients and carers who want to make positive comments or register complaints.

The corporate information policy should also include issues such as the use of 'house style' to ensure that the presentation of printed material and the use of corporate logos are consistent.



Further information

- The Patient information Forum is developing a generic policy, *Provision of Information for Patients*, which can be adopted by a wide range of organisations.
- The Consumer Health Information Consortium (CHIC) is a support organisation for those interested in improving health information to the public. It encourages good practice and promotes free and open access for all to health information.

Guidelines for patient information

If you work for an NHS trust or in primary care where the production of patient information is well established, you may feel it worthwhile to produce guidelines for use throughout the organisation. Ideally, a patient information officer or someone in the quality assurance department should take responsibility for producing guidelines and for making sure that they are used wherever information is produced. Once they have been agreed, such guidelines should be audited and updated regularly. The drive to improve patient information within NHS trusts can be linked with quality standards schemes (see p.11).

Patient information Forum (PiF)

Some NHS trust hospitals have developed standards for producing patient information. These range from guidelines suggesting how material should be developed, through to protocols that require all patient information materials to adhere to internal standards. Members of the Patient information Forum have developed their own in-house guidance and are willing to share their experiences (see *Further information*, p.8).



Action points

- If your organisation needs guidelines for producing patient information, contact someone in your audit or quality assurance departments to discuss the best way to proceed.
- Get in touch with people in other trusts who have produced guidelines, to share experiences.
- Guidelines will need to be regularly reviewed and audited.

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The process...has been lengthy but has resulted in a cohesive and controlled approach to the production of patient information. Directorates still 'own' the process but are given support and assistance which was previously lacking. We are currently at the stage where the first leaflets are being produced which adhere to the standards. It will be necessary to evaluate the leaflets and standards, a process involving patients.

Richardson and Moran (1995)



Further information

Some examples include:

- *Checklist of Trust principles for producing written information.* Stockport Healthcare NHS Trust, 1999.
(Contact Paula Jackson. Tel: 0161 456 0119.)
- *Good practice guidelines for staff.* Worthing and Southlands Hospitals NHS Trust, 1997.
(Contact Pam Lelliot. Tel: 01273 455 622 x 3978.)
- *Guidelines for producing written information for patients.* Royal Berkshire & Battle Hospitals NHS Trust, 1996.
(Contact Carole Arnold. Tel: 01734 878 592.)
- *Patient Information: Standards and Process.* Derbyshire Royal Infirmary NHS Trust, 1997.
(Contact Helen Watson. Tel: 01332 347 141.)
- *Producing written information for patients: staff guidelines.* Nottingham City Hospital NHS Trust, 1997.
(Contact Uta Khendek. Tel: 0115 969 1169 x 45664.)
- *Step by Step Procedure for Developing a new Patient Information Leaflet.* Leicestershire & Rutland Healthcare NHS Trust, 1999.
(Contact Sally Sanger. Tel: 0116 258 8856.)

Aim of the information policy

An organisation's information policy will be based on a general aim, which applies to all the information provided. The aim could, for instance, be:

To ensure that patients receive consistently high quality information which:

- *reflects what they want to know and how they want to use it*
- *helps them to receive the services to which they are entitled*
- *helps them to understand their condition*

- enables them to choose the treatment appropriate to their condition, if they wish.

Legal liability

Information providers may be liable in law for the consequences of their information. If you are providing information for patients and members of the public, you need clear and detailed guidance about legal liability. The degree to which you (or your organisation) are liable depends on the aim of your information. Is the user going to rely solely on your information to make a treatment decision, for example?

Methods you can use to protect against negligence claims include:

- using and quoting the source of good practice clinical guidelines
- making it clear what the information does and does not do
- checking your organisation's insurance cover
- if you are thinking of using recognisable photographs or pictures of real people, make sure that they sign a disclaimer in which they agree not to have any ownership of your material. Model release forms can be obtained from the British Association of Picture Libraries and Agencies (see Appendix 1).

Clinical Negligence Scheme for Trusts

The Clinical Negligence Scheme for Trusts (CNST), which is administered by the NHS Litigation Authority, reviews insurance cover for NHS establishments. Ten core standards are benchmarked and scored by a visiting assessor. Discounts on premiums can be given, subject to the score and level achieved.

Risk Management Standard 7 states that:

Appropriate information is provided to patients on the risks and benefits of the proposed treatment or investigation, and the alternatives available, before a signature on a Consent Form is sought.

To achieve the minimum level (level one), CNST assesses whether such patient information is available for ten common elective treatments.



Action points

- Find out whether your organisation has medical negligence cover, and whether it covers your project.
- Consider whether the information will comply with CNST's guidelines.

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Security and use of patient information

Two health and local authority circulars, HSG(96)18 and LASSL(96)5 give guidance on:

- the circumstances in which information may be passed on
- keeping patients informed about the use made of information about them
- patients' right to access their own records
- information about children and young people
- security measures and the retention of records
- dealing with patients who are offenders
- specific restrictions on passing on information.

The Data Protection Act applies if you will be storing personal information in electronic or paper formats. The Data Protection Act 1998 brings together the individual's right of access to information held about them, including their own health records. The Data Protection Registrar issues guidance notes and an introduction to the Data Protection Act 1998, both of which are available on the Data Protection Registrar's web site or from the Registrar's office (*address in Appendix 1*).



Action points

- Make sure that everyone involved in producing patient information knows all the rules for using patient information and accepts responsibility for complying with them.
- Seek expert advice on the Data Protection Act in advance if you want to set up any systems for collecting and storing information about named individuals.



Further information

- *Information about health care effectiveness* (Entwistle et al. 1996).
- *The therapeutic partnership* (Gann 1995).

Quality standards for patient information

The following criteria were devised and evaluated during the *Promoting Patient Choice* programme at the King's Fund. Good quality patient information:

- informs patients about their clinical condition and includes information about all available treatments or management options, including non-interventions
- provides comprehensive and unbiased information about outcomes (risks and benefits) based on systematic reviews of research evidence
- outlines uncertainties and gaps in scientific knowledge
- involves users and professionals in developing and evaluating the materials
- caters for people from a variety of ethnic and cultural backgrounds and for people with learning difficulties
- is regularly reviewed and updated
- is integrated into a planned programme for shared clinical decision-making
- has language and design that are simple and easily understood.

These standards were found to be difficult to achieve in their entirety, but represented a 'gold standard' to be aimed for. Health Quality Service subsequently adopted similar standards for information quality (*see below*).

Centre for Health information Quality (CHiQ)

Launched in November 1997, the Centre for Health information Quality was established as part of the Patient Partnership Strategy and *Information for Health* (*see p.4*). CHiQ is working to develop high quality patient information about services, treatment options and outcomes and recommends that patient information:

- is clearly communicated
- is evidence-based
- involves patients.

CHiQ acknowledges, accepts and understands the need to put patients first. It works directly with NHS and patient representative groups to raise awareness of key issues in developing consumer health information.

DISCERN

DISCERN is a general set of quality criteria that help consumers and information providers to judge the quality of written consumer health information on treatment

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choices. A handbook has been written to help consumers and producers understand and use DISCERN effectively. It has been written from the patient perspective, but can be used by anyone interested in information about treatment choices (Charnock 1998).

DISCERN has been designed to rate the quality of a publication's content. It examines *what* information a publication is providing, rather than *how* it is providing it; it does not address issues about presentation (e.g. layout, graphics, readability) because a publication may be well presented and readable without being informative and accurate. However, it cannot be used to determine the scientific quality or accuracy of the evidence on which a publication is based.

DISCERN lists 16 questions to help users and producers of health information to think about quality issues in a systematic way.

- Questions 1–8 address the reliability of the information and should help you consider whether it can be trusted as a source of information about treatment choices, e.g. *is it clear what sources of information were used to compile the publication (other than the author or producer)?*
- Questions 9–15 focus on specific details of the information about treatment choices, e.g. *does it describe what would happen if no treatment is used?*
- Question 16 is an 'intuitive summary' of the first 15 questions and provides an overall rating of *high, moderate or low*.

Health Quality Service (HQS)

The Health Quality Service is an independent accreditation programme for the development of standards on the practice, organisation and delivery of health care services. It offers provider organisations an external survey to demonstrate the extent to which they are achieving the standards.

Section three of the HQS programme focuses on the patient's experience. Standard 21.9 states:

Patients/users and carers are provided with condition/treatment/procedure information materials, which:

- *are evidence-based*
- *identify treatment options and possible outcomes*
- *identify treatment risks and side-effects*
- *promote the concept of shared decision-making*
- *are jargon-free*
- *are translated into other languages, where appropriate for the local community.*

The standards go on to state that information may need to be developed in different media and that patients/users should be involved in their preparation.

SPLASH

Survey of Pharmacy Leaflets – A Self-Help guide is a quality assessment tool, developed by Health Promotion Wales in 1996. It was designed as a self-help guide to enable pharmacists to appraise and choose the most helpful information leaflets to use in their pharmacy. The SPLASH test assesses the key points that ensure a leaflet ‘works’, keeps the reader’s attention and is easily understood. It assesses the content of leaflets, how they are written and how well they have been designed and illustrated. A new edition is planned imminently.

Awards

A number of organisations now offer awards in the area of patient information (see Appendix 1 for contact details).

- **BMA Patient Information Award.** Annual prize for the best patient information leaflets and booklets. The judging criteria are similar to those used by DISCERN (see p.11) but also look at presentation issues.
- **BUPA Communications Award.** Annual award for an achievement initiated and carried out by doctors associated with one or more of the Royal Colleges. Often such initiatives include the development of patient information.
- **National Information Forum.** Getting the Message Across calls attention to the information needs of disabled people and recognises initiatives that seek to bridge this gap.
- **Plain English Campaign Awards.** For documents written in plain English that have not previously been awarded a Plain English Campaign Crystal Mark.

Journals and newsletters

- **CHIC Update.** Quarterly newsletter produced by the Consumer Health Information Consortium. Tel: 020 7928 9292 x 2507.
- **Health Expectations.** International journal on public participation in health care and health policy which sometimes features articles on patient information.
Internet: www.blackwell-science.com/online
- **HEALTHinfo.** Bimonthly news publication from the world of consumer health information, available from Health Facts Centre. Tel: 0117 975 3867.
- **Healthlines.** Bimonthly magazine providing information on the work of the Health Education Authority, available on subscription. Tel: 02392 230 900.
- **Hi Quality Matters.** Quarterly publication from CHiQ on a variety of consumer health information topics. Internet: www.hfht.org/chiq/publications.htm
- **Patient i.** Monthly publication for people interested in excellence in consumer health communications. E-mail: david.dickinson@consumation.com
- **Patient information Forum Newsletter.** Available to members of PiF.
E-mail: briang@rfhsm.ac.uk

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Action points

- Assess the quality of patient information – your own or anyone else's that you are considering using. The DISCERN Instrument has been designed specifically to do this job for patient information that offers a range of treatment options.
- Approach patient information officers and/or audit/quality departments in your own and other organisations – they may have developed guidelines for producing patient information.
- Once you have looked at existing standards, decide which are appropriate for your own material and apply accordingly.



Further information

- DISCERN: an instrument for judging the quality of written consumer health information on treatment choices (Charnock *et al.* 1999).
The DISCERN Handbook (Charnock 1998).
Internet: www.discern.org.uk/
 - Patient Information (England 1999) discusses the benefits of providing patients with information, against the background of political history, legal requirements and the element of design, including recommendations for improving quality.
 - *A survey of health information on electronic public information systems* (HEA/SPIN 1999). Internet: www.hea.org.uk/multimedia
 - *Consent to treatment* (Medical Defence Union 1999).
-

3 Planning the work

What information do patients need?

Organisations such as Community Health Councils (CHCs), the NHS Health Information Service (HIS) and local voluntary health organisations (VHOs) can help identify gaps in the current provision of health information. Medical audit and quality departments within NHS trusts and primary care groups (PCGs) may be able to identify information needs through contact with patients and their carers.



Action points

- Listen to what patients, carers and staff say about the kind of information they want – don't just rely on the questions they ask clinicians.
- Ask local audit departments what patients and staff say about patient information.
- Ask local NHS trusts, CHCs and PCGs what kinds of positive comments or complaints they receive from patients and carers relating to any aspect of information.
- Look at annual reports, local research and analyses of health information needs from the health authority.

Aims of your information package

It is important to be clear at the outset about the reasons for producing information for patients. The information itself should include a statement about its aims. The kinds of questions to ask at the planning stage are:

- Who is the package for (the target audience)?
- How can we ensure that it is relevant and useful to them?
- How do we think it will be used?
- What medium will be most attractive to the target audience?
- How do we ensure that the information can be easily understood?
- Does it fit the general aims of the organisation's information policy? (*See Section 2.*)

When you have discussed these questions with the people who will be producing the material, write down your answers and turn them into a statement of aims. These preliminary aims may need to be modified as you go through the planning and piloting stages.

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Action points

- Talk to people who are involved with public relations and communications locally or at the health authority.
- Draft a plan for publicity and distribution of the finished material.
- Take account of distribution when you are deciding how many copies of your materials to produce.
- Include the cost of publicity and distribution in your budget.



The profile of the project has been raised in the public and academic domains through several channels. Thanks to the efforts of press officers of both the King's Fund and the University of Nottingham, there were several media reports about the developing project.

The national charity, ERIC, has been kept informed about the development of the project and even used the forthcoming education package to strengthen a bid for funds to the National Lottery.

Overall interest in the project is high. Approximately 80 leaflets about the project were picked up by delegates at the European Health Psychology Conference. Several clinicians involved in the care of children with Nocturnal Enuresis have made contact with members of the team to enquire about the availability of the package. Three paediatric consultants in the Nottingham area have approached the team with requests to put in for funding to develop and evaluate interactive multimedia patient information packages for the children in their care. Interest in funding for such a package is being shown by pharmaceutical and commercial publishing companies.

PPC Nottingham: *Bedwetting*

Paying for the work

It is easy to underestimate the amount of time and money it will take to develop a health information package. Some people may give their services free of charge; others will need to be paid. Even if your own organisation will pay for the production, distribution and publicity, it is worth working out a budget to make sure you have thought of everything. If you do this now, you shouldn't be taken by surprise later on.

Costs might include:

- paid project worker
- fees for design, editing and illustrations
- translation
- collecting the views of patients and professionals
- piloting, external reviewing and media expertise
- production, including printing and reproduction
- publicity, dissemination, distribution
- support
- evaluation.

People sometimes forget to budget for hidden costs and overheads, such as stationery, photocopying, writing applications for money, advertising for posts, servicing the steering group, databases searches and buying in other expertise, such as information technology (IT).

Finding money to support your project will vary according to where you work. It is important to identify where the funding came from to make it clear that the cost of production has not been met at the expense of core services and that it has not come from sources not 'approved' by NHS trusts or health authorities. Some NHS organisations have policies that exclude accepting money from pharmaceutical companies.

Within NHS trusts, you could approach your manager for information about endowment funds and whether your project could be eligible to apply for any.

Funding may be available through local policy initiatives such as public health or patient partnership.

Appendix 2 lists some funding bodies and reference sources. Contact possible agencies before you start to write the application. Writing a proposal for financial support takes time and you should make sure that you know what each funding agency requires from an application. Many funding bodies now encourage open dialogue to assist potential applicants in their submissions, and produce written guidance about their funding priorities and application procedures.

Colleagues who have already made applications for research grants or sponsorship may be willing to share information about the agencies they have approached and offer advice about writing applications.

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Sponsorship

Your project may be eligible for sponsorship from a pharmaceutical company. English health authorities have recently redrawn their guidelines about dealing with this industry and you should check what your organisation's attitude is before you decide to approach, or accept sponsorship from, any pharmaceutical company. It is also advisable to gain consent from the chief executive (or equivalent) before pursuing arrangements with commercial organisations. These publications offer guidelines:

- *Working with the Pharmaceutical Industry* (Long-Term Medical Conditions Alliance 1998). Guidelines on working with the industry and acknowledging their help, for patient organisations that are considering whether to approach pharmaceutical companies for financial help.
- *Making Partnerships Work* (Pharmaceutical Partners 1998). The pharmaceutical industry's own recommendations on such relationships (see the Health Coalition Initiative for contact details).
- *The Ties That Bind: Weighing the risks and benefits of pharmaceutical industry sponsorship* (Health Action International 1999).



Action points

- Make a list of all the things you will need to do to develop your material.
- Estimate how much they will cost. If necessary, get help from a financial manager or someone else in your organisation who has experience of doing similar work.
- Consider and approach external sources for funding (see Appendix 2).
- Check guidelines before agreeing to a sponsorship deal with a commercial company.



One of the King's Fund *Promoting Patient Choice* projects aimed to promote the mental health of Asian women in Redbridge. To do this, they planned to adapt and translate two existing English booklets – one on depression, the other on anxiety – into four Asian languages.

However, when initial guesstimates for the cost of translation were compared with real quotes, it was realised that insufficient funds were available to allow both booklets to be developed. This resulted in the project team re-appraising their overall project aims and deciding to deliver only one adapted and translated resource – on anxiety.

PPC Redbridge and Waltham Forest Health Authority: *Anxiety*

Support and training

It is always worth looking round for other people who may have experience, in your own organisation and in other local trusts or voluntary organisations. Nurses and people who work in quality departments can be helpful as they often have experience of putting information together. Some trusts now have patient information officers you can contact for advice.

If you can't find anyone locally, you can always contact the Patient information Forum or the Centre for Health information Quality (see Appendix 1). Sharing experience with other producers usually gives you lots of tips and ideas and can help you solve some of the problems you may be having. Help is only a phone call (or e-mail) away. If you would like to learn more about producing patient information, there are organisations that run training courses.

- Fife Healthcare NHS Trust Health Promotion Department and Health Education Board for Scotland offers a two-day course, *Getting your message across*, for people who wish to gain more detailed knowledge and hands-on practice in producing patient information, and a one-day course on developing leaflets and posters.
- Patient information Forum (PiF) has information about training courses on patient information developed by members for personnel within their own NHS trust.
- Centre for Health information Quality (CHiQ) runs courses on the practicalities of producing patient information for health information service workers, NHS trust workers and people who work in voluntary organisations.

Implications and consequences

Think about the knock-on effect that informing patients will have on services. Will patients expect a choice of treatments where only one was offered previously? It is worth discussing these possibilities with senior members of your organisation and, where appropriate, the local health authority.

Support

Think how you will support the package once it has been distributed. Will you need to designate a contact point for people who want to ask questions after they have received the information? Suppose people find it difficult to load your CD-ROM onto their computer? How will you make sure that people who have received the information also receive updated versions as you produce them?

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- Will you need to use sampling methods? If so, which tools are most appropriate? For example, a questionnaire, a topic guide or a series of open-ended questions.
- What form of analysis will you use once you have collected the views of patients? Will you need help with the analysis? Will you use existing computer software for the analysis and, if so, what is the most appropriate software and is it easily available to you?

If you do not have experience of research and sampling methods and analyses, ask for advice. Local academic or audit departments may be helpful.

Before you make any final decisions, check with your Local Research Ethics Committee to see if you need their approval for this kind of research. In some cases you may do, and this involves writing and submitting an application to the committee. Find out what their timetables are. Sometimes this process can take a long time – as much as six months – and can hold up the development process.

Contacts

Contact a range of organisations to collect information on:

- local needs, whether they are currently being met and, if so, how and by whom
- local self-help groups and organisations representing people with particular health needs
- patient information that has been produced by other agencies relating to your area of concern.

The following sources will be useful. (*For contact details, see Appendix 1.*)

General information

- Local trusts, PCGs, health education/promotion departments and CHCs.
- Health Information Service on 0800 66 55 44 or 0800 22 44 88 in Scotland.
- Specialist information centres (e.g. Centre for Health information Quality, CHiQ) and voluntary health organisations (VHOs) (e.g. Cancer BACUP).
- Pharmaceutical companies.
- Computerised databases of health information materials.
- Internet.

Health promotion

- Health Promotion Information Centre (HPIC) – part of the Health Education Authority. Internet: www.hea.org.uk/hpic/index.html
- Health Education Board for Scotland (HEBS). Internet: www.hebs.scot.nhs.uk/datasets
- Health Promotion Agency for Northern Ireland.
- Health Promotion Wales is now part of the Welsh Assembly.

Voluntary Health Organisations (VHOs)

(Contact details in Appendix 1.)

- *CaF Directory of Specific Conditions and Rare Syndromes*, Contact a Family. Free on the Internet, and updated monthly, including details of available support groups for over 800 conditions affecting children. CaF also has local and national support networks.
- *Health Address Book*, Patients' Association.
- *Helpbox*, Help for Health Trust.
- Patient Information Publications. Details of self-help health organisations on the Internet. Database of Patient Information Leaflets (PILs) available to subscribers through software packages and on CD-ROM.
- The SHARE Database has a list of ethnic health projects throughout the UK.
- *Your Health*, Healthwise. Directory of national health organisations, and those serving the north west, available to subscribers and updated monthly.

Medicines information

If you are preparing information on medicines you should ask the legal department of the Royal Pharmaceutical Society for advice.

The British National Formulary (BNF) is a useful resource to determine medicines-related information and to identify the pharmaceutical companies that already produce Patient Information Leaflets (PILs) and package inserts that accompany their products.

A number of groups specialise in the production of medicines information. For example, the Association of Information Officers in the Pharmaceutical Industry (AIOPI) is the professional organisation for individuals in the pharmaceutical industry who are involved in the provision and management of information. *pecmi* (see Appendix 4) looks to improve information for consumers around the supply of medicines in the UK, both prescription and self-medication.

Many voluntary health groups produce medicines-related information, as do other organisations. For example, the Royal College of Psychiatrists produces a number of drug fact sheets under the *Defeat Depression* banner including alcohol, antidepressants, depot medication, lithium therapy, and tranquillisers and sleeping tablets.

Methods for collecting the views of patients and carers

Focus groups

Focus groups involve selecting up to ten people from the groups who will be using the information. They are useful because:

It is useful to have support from senior management and clinicians (depending on your organisational structure). If you have received a grant from another agency, it will be important to keep them in touch with the work.

It can also be useful to link the project to policy initiatives, such as the Patient Partnership Strategy, *Information for Health* or public health strategy agendas (see p.4). These links can raise the profile of the project and may help if you need to apply for money.



Action points

- Get advice from previous information projects. Contact the Centre for Health information Quality or the Patient information Forum for advice from developers of patient information in NHS trusts.
- Contact staff who have corporate responsibility for patient information.
- Make sure that you have copies of all guidelines produced by your organisation that relate to any aspect of patient information.
- Link with current policy initiatives.
- Seek Board and clinical support; consider the need for an advisory group.
- Draft a realistic timetable, with milestones for each stage of the process.
- Identify the need for paid workers.
- Consider your budget and whether there is money to commission outside professionals for any parts of the work.
- Define the roles of all team members.



The multidisciplinary team that carried out the project involved academics and clinicians. A multimedia developer and a research assistant were both employed half-time for the 12 months of the project. The research assistant had a vital role in liaising between the two centres.

To establish and maintain good teamwork and effective communication, monthly meetings were held at either the City Hospital or the Queen's Medical Centre throughout the project to exchange information and express concerns (or congratulations) regarding the progress of the work. Minutes and agendas were circulated.

The nurse in charge of the clinic where the programme was being implemented was invited to all meetings, but was only able to

attend a few. Involving the clinic staff in the development of the programme, as well its implementation, seems to have been appreciated and probably assisted with the acceptance of the computer in the clinic.

The console was designed so that clinic staff could move the computer equipment easily with minimal 'setting up' required, and there was little to be lost, damaged or stolen. It was decorated in an informal style so that children could recognise that the computer was there for them.

PPC Nottingham: *Bedwetting*

A forward look at dissemination

A common mistake people make at this stage is not to think about how they will disseminate the material once it is produced. Planning a distribution and publicity strategy at the beginning of the work saves a lot of time and trouble at the end. It is also essential for budgeting: for example, you cannot budget for printing unless you know how many copies can be distributed and, therefore, how long your print-run needs to be.

Think about all the people who will be involved with the patient information package once it is produced and invite them to comment on your project and to give you ideas for publicity now. As well as helping you think through your plans, the people you talk to will be more prepared to help at the end because they will feel more involved with the work and the final product (even if they never actually took up your initial invitation to contribute).

Publicity

Work out how much publicity might cost and include a heading for it in your budget. Review all the different methods of publicising the material, including local radio, local newspapers, NHS journals, academic conferences, and the newsletters and other publications of national and local voluntary health organisations. Consider what you will be able to afford and which sources of publicity are free. For example, do you want to produce flyers to tell conference delegates about your information package?

Distribution

Distribution can be costly, so think about the arrangements for delivering the materials to the distribution outlets. These may include local pharmacies, GP surgeries, libraries, CHCs, out-patient clinics, wards, district nurses and community centres. For example, if you produce a leaflet, how will you supply people outside your local area? Are you going to charge a fee to organisations that request your information in this way?

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- you can quickly collect the views of patients and carers
- they provide an open-ended forum where people can exchange and share their views
- they are a particularly effective method of brainstorming and generating ideas about improvements
- they gather a range of views over a short time, and the breadth of experience of the people involved provides a sound basis on which to build further work.

The discussions need careful planning and a topic guide. This is a prepared list of the topics and questions you need to explore to find out what patients/carers want from the information material. A sample topic guide can be found in the appendix of *Informing Patients* (Coulter *et al.* 1998).

A skilled facilitator is essential for running the group. Discussions should last for about 90 minutes to two hours. The proceedings should be recorded and someone trained in focus group analysis should analyse the transcription. Participants should be offered expenses and must be given feedback on the results of the exercise.

Sometimes patients may not wish to participate despite your good intentions. For example, children (and in some cases their parents) were too embarrassed to join in discussions about the development of a multimedia system on the topic of bedwetting.

Surveys

Surveys are used to gather information about patients' views, usually through a questionnaire. They have the advantage of allowing information to be collected from large numbers of people and, if properly designed to reach a random sample of patients, offers statistical reliability and validity.

Write the questionnaire carefully so that your questions posed in a questionnaire do not bias the responses and are easily understood by the people for whom they are intended. If you have little or no experience of writing questionnaires, ask for help with the preparation.

Once drafted, a questionnaire should be piloted with people who have the same characteristics as the target group to be used in the main sample.

Surveys can be administered using interviewers who ask the questions on a one-to-one basis, or by sending the questionnaire to named individuals by post. The analysis of the data collected is usually done using a computer software package. These packages allow relatively fast descriptive results and statistics.

In-depth interviews

Interviews with individual patients or carers provide a wealth of information about what people want and need from health care information. They are usually carried out by trained interviewers using a checklist of topics, allowing people to give spontaneous replies in their own words, which are tape-recorded. People often feel more comfortable in this situation, but interviews are time-consuming and the analysis of respondents' data is more complex.

Other methods

Other methods of collecting information include:

- the *Delphi technique* (a group of experts gathered together to pool their collected wisdom about specific topics)
- *panels* which involve regular meetings of a selected group of patients to give their views about health care locally and how it can be improved for users
- *observation* of specified processes such as out-patient clinics, or consultations between patients and their doctors.

Each of these methods has advantages and disadvantages, but the important thing is to select one or more methods that are most appropriate for your topic and situation. If you have little or no experience of research, ask for advice. University departments and independent research agencies will often be prepared to help.



Action points

- Decide which groups of patients, users and carers you need to involve and consult.
- Choose the most appropriate methods to collect patient and carer views.
- Check with your Local Research Ethics Committee to find out if you need their approval.
- Collect and analyse data.
- Give feedback on the results to patients/carers and to the professionals involved.
- Use the results to inform the first draft of the material.



For this study, focus groups, an established qualitative technique (also known as group discussions), were used to explore the views of cancer patients. Five such groups took place around Britain. A series of depth interviews (ten in all) were also conducted, over the telephone, to make sure that people unable to attend the focus group had an opportunity to participate in the research.

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Each focus group involved nine or ten people and lasted just over two hours. Respondents were keen to take part in the research, and people who were unable to take part were often disappointed they could not participate.

All the focus groups were audiotaped and transcribed verbatim for subsequent analysis.

All the respondents (with the exception of one which included a carer) were people who had direct experience of cancer at some point in their lives, usually within the previous three years.

Mindful that people from different cultures or backgrounds have different needs with regard to information and how it is delivered, one focus group was held with a group of people from ethnic minorities.

Developing information for *The Cancer Guide*.
BMRB Qualitative for Macmillan Cancer Relief
March 1999

Professional views

Although POPPi is about information for patients, it is important to incorporate and test out the views of professionals. In this context, the term 'professional' includes not only clinicians but also managers and receptionists, for example, who will provide useful views on processes such as in-patient procedures.

In many situations, it is the clinicians who are in a position to give the information to patients and to discuss it with them. Expert knowledge is essential in many cases where up-to-date evidence about clinical conditions needs to be incorporated into the information.

Similar stages of involvement to those already described for patient/carer involvement are necessary. Professional views should be collected at all stages of production – planning, collecting views, and testing out material.

Clinical views are also essential when collecting and producing the scientific evidence. For example, you should have the clinical evidence in your material reviewed by at least two clinicians working in the field. During the production of the incontinence multimedia package at Bristol Urological Institute (see *Appendix 4*), the script was sent to

two urologists and one public health specialist for independent review. Their comments were invaluable in reworking the script. This peer-review process is described in more detail in Chapter 8 of *Informing Patients* (Coulter *et al.* 1998).



Action points

- Collect the relevant professional and clinical views on the material at all stages of production (i.e. planning, involvement, testing and review) in the same way that you have collected the views of patients and carers.
- See *Interpreting the evidence* (p.37) if there are conflicts about how to present the data.



All leaflets were informed by the best available research evidence about the effectiveness of the interventions and by some evidence about the context into which they would be introduced and the information needs of the intended audience.

All leaflets were peer reviewed both by people able to comment on the congruence of the information presented with the best available research evidence and by people able to comment on the likely suitability and usefulness of the information material to their intended users.

Developing information materials to present the findings of technology assessments to consumers (Entwistle *et al.* 1998)



Further information

Patient information

- *Informing Patients* (Coulter *et al.* 1998). As part of this study, focus groups were held with 62 patients to assess the quality of 54 patient information materials (leaflets, videos, and audiotapes).
- *Information about health care effectiveness* (Entwistle *et al.* 1996).
- The Patient Involvement Unit at CHiQ undertook a patient evaluation of breast cancer information materials using focus groups. Internet: www.hfht.org/chiq/publications.htm

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User involvement

- *Reference manual for Public Involvement* (Barker et al. 1999). Guidance on a broad range of issues (from Bromley Health).
- *Positive participation: a planning and training resource* (Health Education Authority 1999). Encouraging more effective involvement of young people in health promotion activities.
- *A guide to developing effective user involvement strategies in the NHS* (Kelson 1997).
- *Partnerships: a training pack* (Kohner and Leftwich 1998). An imaginative, stimulating training pack on skills for partnership with patient and clients.
- *Asking your users: How to improve services through consulting your consumers* (National Consumer Council/Service First Unit 1999). A guide to consulting public service users, including a summary of methods of consultation.
- *Reaching the parts other methods cannot reach: an introduction to qualitative methods in health and health services research* (Pope and Mays 1995). Six articles about qualitative methods in health care.

Clinical evidence

The move towards evidence-based medicine during the past ten years has emphasised the need for information to be based upon sound research findings. It is as important for patients to be aware of this evidence as it is for clinicians. One of the first problems that people experience is how to find the most up-to-date research. The sources list below should get you started, but the task can be daunting if you don't have experience of this kind of work. You may find it helpful to talk to clinical specialists in your locality. Ask them, for example, if you could have a copy of any clinical guidelines that they use and if they would be prepared to explain anything in them that you don't understand.

Because clinicians themselves often find it difficult to keep up to date, you should go to some of the sources listed in the following sections to make sure that what you have is accurate.

Sources of help

Searching for the best quality clinical evidence is a specialised task and unless you have those skills you will need help. Places where you can find this kind of help locally include:

- public health departments, medical schools and some university departments (statistics and psychology, for example)
- audit/quality departments within NHS trusts.

Evidence about conditions and diseases

The School of Health And Related Research (SchHARR) at the University of Sheffield is the best place to start your search for evidence. SchHARR is a health services research department involved in:

- finding the evidence (expertise in literature searching)
- appraising the evidence (critical appraisal training)
- producing the evidence (systematic reviews).

The *SchHARR Guide to Evidence Based Practice* (SchHARR 1997) is a bibliography and resource guide, while *Netting the Evidence* is an Internet resource.

Internet: www.shef.ac.uk/uni/academic/R-Z/scharr/ir/netting.html

SchHARR will point you to numerous sources of information. The following, for which contact details are given in *Appendix 1*, are among the most popular:

- **Bandolier**. Monthly news sheet and web site giving up-to-date information about clinical evidence. Internet: www.jr2.ox.ac.uk/Bandolier
- **Cochrane Database of Systematic Reviews**. Abstracts of reviews and titles of reviews in progress. The database can be searched for specific words and phrases or browsed by Collaborative Review Group. Access to the full reviews and protocols is available only on subscription. Internet: www.cochrane.org/cochrane/revabstr/mainindex.htm
- **NHS Centre for Reviews and Dissemination (CRD)**, York University. Online database search service and structured abstract of good quality systematic reviews of the effectiveness of health care interventions. *Effective Health Care Bulletins* provide up-to-date information about the effectiveness of selected interventions. Internet: www.york.ac.uk/inst/crd/welcome.htm
- **Clinical Evidence 99**, BMJ Publishing. A compendium of the best available research findings on common and important clinical questions, updated and expanded every six months. Internet: www.evidence.org

Evidence-based health care open learning resources. Two products, produced by the Critical Appraisal Skills Programme (CASP) and CASP Finding the evidence Programme (CASPFew), aim to help users find and make sense of evidence: an interactive CD-ROM with workbook and a paper-based resource of five separate units. Further details from CASP.

National Centre for Health Outcomes Development. Produces *Reports on Health Outcome Indicators* on how to assess health outcomes for a number of clinical conditions. Health outcome indicators can be used for clinical audit, reviewing clinical performance and assessing progress towards achieving standards or milestones.

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Research Council for Complementary Medicine (RCCM). Information on the evidence base for complementary medicine based on rigorous research to encourage safe and effective practice and improved patient care.

e.g.

The Guidebook for Ulcerative Colitis, developed by Hope Hospital and Manchester University, has a fully referenced evidence-base for each section, ranging from the general *Introduction*, through *Taking enemas and suppositories*, to *Surgery*.

Evidence-based medical information was obtained through MedLine searches. Information on what patients wanted to know about ulcerative colitis was obtained from a number of sources:

Directly from the patients themselves through interviews and focus groups.

From searching the literature produced by patient support groups such as NACC (National Association for Colitis and Crohn's) and The British Digestive Foundation.

From results of a phone survey conducted by the Medical Advisory Service in 1995.

From papers outlining surveys done to assess the demand for information (Martin *et al.* 1992, Schlomerich *et al.* 1987, Mayberry *et al.* 1989, Din 1996, Ahmed 1997).

From papers written by specialist gastrointestinal nurses outlining the information needs of their patients (Doughty 1994, Phillips 1995, Phillips and Warren 1985).

PPC Manchester: *Ulcerative colitis*

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Further information

- *The SchARR Guide to Evidence-based Practice* (Booth 1997).
- Information about health technology assessment (Booth 1998).
- *Information about health care effectiveness* (Entwistle *et al.* 1996).
- Finding information on clinical effectiveness (Glanville *et al.* 1998).
- *Promoting Action on Clinical Effectiveness* (PACE). A series of projects promoting the uptake of evidence-based practice. Project now completed, but publications are available from the King's Fund library (see Appendix 1).

Interpreting the evidence

When you have collected the clinical evidence, spend some time thinking and talking about the best ways to present it for patients. The language used in the sources of evidence is often technical and not easily understood by lay people – it will therefore need to be rewritten. You should also consider the kinds of references you wish to provide for patients who want to follow up your information package with some further reading.

Some of the things you should take into account are:

- the order in which the information is presented
- the way in which the messages are put over – positive, negative, or mixed (*see Section 5*)
- the way in which statistics and probabilities are explained
- the best way to present graphical information
- the way in which all the treatment options (including the option of doing nothing, sometimes called ‘watchful waiting’) are described
- how the gaps and uncertainties in the evidence are presented.

You will find a good source of discussion about these issues in *Developing information materials to present the findings of technology assessments to consumers* (Entwistle *et al.* 1998).

Conflicts of interest

It is important to find out if local practices vary from national standards or guidelines, in case individual patients are not told about the full range of options available or are not advised that local practice conflicts with national practice.

Also think about some of the possible conflicts of views between professionals. There have been examples of good quality patient information being developed where some professional staff disagreed with some of the evidence base and the way this information was presented. In a project about childbirth, for example, a leaflet was produced which contained evidence about statistics for ultrasound in early pregnancy. The ultrasonographers strongly disagreed with the way in which these statistics were presented (Oliver *et al.* 1996).

There may also be differences of views between what patients have told you and what professionals think. In such situations you should inform each party of the other’s views and attempt to reach a compromise. If this doesn’t work, the final decision will have to be made by you or an independent arbiter.

Alternatively the information you produce should make it clear where there are uncertainties, ambiguities and differences between professional views and patient views. If something is not known, say so!

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Action points

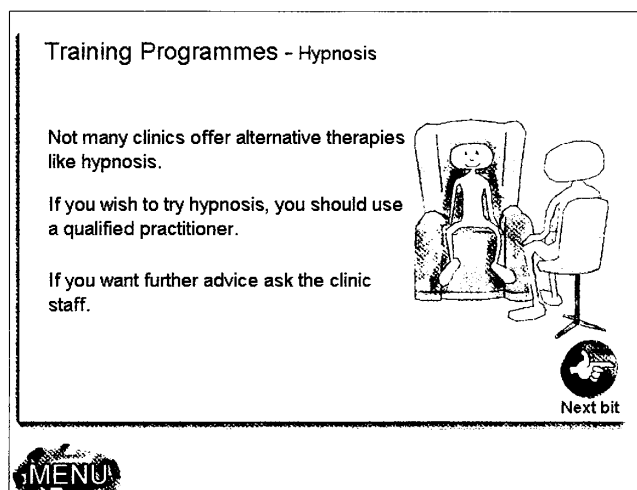
- Discuss ways of searching and finding good quality clinical evidence for your topic with two or more of the following people:
 - clinical colleagues
 - public health specialists
 - academics
 - audit departments
 - research centres.
- Librarians are key sources of help in searching for clinical evidence.
- Talk to local clinicians and people who have skills in making technical language easy for people to read and understand.
- Check local practice and practice guidelines for variations from national standards.
- Offer all treatment options in the material even if local practice does not include some of them. Patients are entitled to know that other options exist including non-intervention, i.e. doing nothing ('watchful waiting').
- Carefully consider how to inform patients of non-evidence-based approaches such as complementary therapies.
- Make it clear where uncertainties and ambiguities exist – say 'we don't yet know'.



Further information

- Developing information materials to present the finding of technology assessments to consumers (Entwistle *et al.* 1998).
 - Informed choice for users of health services (Oliver *et al.* 1996).
-

Figure 2: Interpreting the evidence – alternative therapies



Source: PPC Nottingham: *Bedwetting*

Reviewers

Once a draft has been produced, circulate it for comment. Give clear deadlines. Put a date and version number on each draft and make sure that everyone is working from the same version.

Draft patient information packages should be reviewed by:

- **Patients you have already consulted and some new potential users.** There are several ways to do this. You can bring groups together to discuss the draft material or you can send it to the patients and ask them to let you know what they think about the specific aspects of the material and in general. In both cases, you should ask clear and specific questions and give people the chance to say what they think spontaneously.
- **Clinical staff within the environment in which they will be used**
- **Independent experts.** A minimum of two reviewers with expertise in the topic area, independent of the producers. An independent third party from a voluntary organisation or a professional body may help you to identify suitable people who can be invited to critically appraise the information. Replies from expert reviewers should be anonymous so that they feel free to be honest in their comments (Coulter *et al.* 1998).

You will certainly want to ask senior people in your organisation to comment on the draft. The chief executive or director should usually be given a chance to comment. Many trusts with patient information officers have established editorial panels to approve publications. Use corporate logos where needed.

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External endorsement can be sought from a number of organisations, depending on the nature of the information package. The *Plain English Campaign* charges editing fees for their Crystal Mark (an award that ensures clear writing and meaning).

Royal Colleges and voluntary health organisations may wish to endorse information materials developed around specific conditions. As with copyright (*see p.18*), the use of logos should be agreed well in advance. Take care to determine what users think of such endorsements.



Action points

- Once the first draft is ready, send it to patients and clinical experts for comment.
- Also send it to chief executives and clinical directors (where appropriate) for their comments.
- Seek external endorsement of professional bodies if you think it will help.



Further information

- Developing standards for patient information (Richardson and Moran 1995).

5 Content and presentation

What patients want

Recent research about patient information indicates that they want information about the following issues:

- **Treatment options.** All treatment options, even if a scientific evidence-base does not yet exist. This includes references to lifestyle changes (for example, diet) and alternative and complementary therapies.
- **Cultural sensitivity** to non-European methods of treatment. Different cultural groups may not be familiar with western medical models; ask patients for their own examples during your user involvement exercise.
- **Gaps and uncertainties.** Gaps and uncertainties about the scientific evidence, if there are any. Where science doesn't yet have an answer, say so.
- **Quality of life** is of great importance to patients but not always fully considered by professionals. Patients want to know what it is like to live with a certain condition, not just the medical treatment options. They want to know how their condition or treatment may affect their ability to work, their usual activities, their family relationships and their sex life.
- **In-patient services.** If a hospital stay is required, patients want to know about in-patient services, not just the operation itself. They want to know how to get to the hospital. Do they bring toothpaste? Can they have vegetarian food? Most hospitals now provide this kind of information for in-patients but you may want to include it as part of your package.
- **Discussion with clinicians.** Patients should be encouraged to actively use the information you give them and to feel able to ask questions of their doctors and other clinical staff. Make it clear that the information package will be used to complement discussion with professionals, not as a substitute for it.
- **Personalising the information.** People like spaces where they can enter their own details and make lists of their own questions.



Action points

- Make a list of all the aspects of treatment and care that will be of interest to your group of patients, taking account of the issues highlighted above.
- Use these points to identify the kinds of issues you will raise in your consultation with patients and carers (see *Section 4*).

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e.g.

This extract from the *Promoting Patient Choice* project in Goodmayes Hospital exemplifies why we must gain consumer views in the development of patient information:

Asian women in Redbridge were presented with a booklet outlining western medical treatments that were available for dealing with anxiety. The treatment options included talking therapies and medication. However, no reference was made to spiritual healing through a faith healer – a common treatment for Asian women with this condition.

PPC Redbridge and Waltham
Forest Health Authority: *Anxiety*

Essential information

All the items listed below should be included in your information unless you have a good reason for excluding them.

Clinical information

- Simple description of condition.
- Prognosis and clinical outcomes.
- Brief overview of treatment options, including doing nothing.
- Benefits of the proposed treatment or investigation (impact on quality of life).
- Risks, possible complications and side-effects of treatment (impact on quality of life).
- Clear and unambiguous statements about preparation for specific procedures.
- Why the treatment is needed and how to prepare for it.
- What happens during the treatment and how long it takes.
- Expected pain, discomfort levels and advice about dealing with them.
- Sensory information, description of the range of possible sensations that patients are likely to feel.
- Description of the care required following procedures.
- Dos and don'ts on going home, including advice about rest, time off work, everyday activity, sexual activity, pain relief, alcohol, bowels or using the toilet, driving, lifting, bathing, sickness certification.
- Length of recovery phase and how patients may feel at each stage to full recovery if this is achievable.
- When to seek further professional advice.

Out-patients and day cases

- Full name of consultant and specialist clinics.
- Directions, transport details and whether people can travel home alone, whether they are likely to be fit to return directly to work, school, college, child care, etc.
- The amount of time to allow and what will happen.
- Details of planned investigations, tests and how results are given.
- Whether students are likely to be present.
- Names and numbers to contact to change appointments or get more information.

In-patients

- Name of consultant and named nurse.
- Where to go and who to ask for more information or to answer questions.
- Ward routines, including visiting times, facilities and whether companions and children are welcome.
- What to bring and what not to bring.
- Likely length of stay.
- What happens after discharge.
- Department address, telephone, fax, minicom numbers.
- Who to contact, if worried, for more information or to answer questions.
- Clear directions to the department, including parking and a detailed map of the department and site.

Other information

Information packages should also include details, where applicable, of:

- how to give positive feedback or make a complaint
- details of the local Community Health Council (CHC)
- free phone health information service (0800 66 55 44 in England and Wales; 0800 22 44 88 in Scotland)
- local self-help group details
- relevant health promotion material and sources for further reading
- who provides the information material, where and when (this should include author details and their qualifications)
- who was involved in the development process, e.g. 'This leaflet was tested with 35 patients and reviewed by two specialists in [discipline].'
- reference sources for factual statements
- month and year of publication
- list of key points, contents page, glossary
- stage in NHS journey, i.e. a map of where they are in the health system
- a tear-off slip for comments.

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Action points

- Clearly state who your information is for, the scope and the aim of the information package, as outlined in *Section 2*.
- Make a list of all the points you think should be included in the 'ideal' information package.
- Check out ideas informally with other colleagues and some patients/carers to get a better idea of the important items you should include and how much support there is for your plan.
- Weigh up the amount of support there is from staff and patients. No one information package can meet everybody's needs.
- Depending upon this, and on the findings of your user involvement exercise, list the topics on clinical issues and/or services your information will cover.
- Patients like case studies and other patients' stories. You can gather these from your own or colleagues' experience or from the patients themselves. Remember that you must never name names or include details that will enable people to identify either patients or staff.



Further information

- *Involving consumers in the development and evaluation of health information*. Centre for Health Information Quality (1999). Gives an example (based on low back pain) of the process of developing good quality evidence-based information that meets the needs of the patient.
- *Informing Patients* (Coulter et al. 1998). Reviews of the quality of 54 materials (leaflets, videos, and audiotapes) by groups of patients who had experienced specific health problems and by research specialists with relevant expertise.
- Developing information materials to present the findings of technology assessments to consumers (Entwistle et al. 1998). Page 63 highlights some of the issues of working with different voluntary health organisations and how they may have their own agenda to promote.

Writing style

Your style creates an impression that underlies everything you say – it gives away a lot about how you regard patients. It is really important to make people feel comfortable from the start. Show that you recognise the patient as a whole person who has feelings as well as a medical condition. A few words at the beginning of your introduction will do. If you have difficulty, imagine that you are talking to a friend or sending them a letter.

Keep the following key principles in mind:

- Use **positive images** of minority ethnic groups, older people, women, people with physical and learning difficulties, people with mental illnesses and other groups who may face discrimination and prejudice. You can get advice and examples of positive images from specialist organisations looking after the interests of these groups:
 - Commission for Racial Equality for ethnic groups
 - Council for Disabled Children
 - Equal Opportunities Commission for women
 - Age Concern or Help the Aged for older people
 - MIND for people with mental illnesses
 - Royal National Institute for the Blind (RNIB)
 - Royal National Institute for Deaf People (RNID).Local branches of these organisations are usually listed in the telephone directory and the national offices are listed in *Appendix 1*.
- Use **words and images that won't exclude people** because of literacy levels, gender, socio-economic backgrounds, age, physical or mental ability, race, culture or sexual orientation. Avoid masculine and feminine words.
- **Don't make assumptions.** Avoid words and images that assume that all families have two parents. Don't assume everyone is heterosexual and married – the term partner is more inclusive than husband or wife.
- **Avoid defining groups of people by their illness.** Do not refer to people as manic-depressives, diabetics or epileptics; instead, refer to *people with* manic depression, diabetes or epilepsy.
- **Remember the special needs of people with visual and hearing impairments.** People with these difficulties also have medical conditions that are not related to their impairments (*see Section 6*).
- **Most statements should be in the affirmative.** 'Give only when the patient wheezes' is clearer than 'Do not give unless the patient is wheezing'. Use negative sentences only to emphasise when an action should be avoided.
- **Information about treatment effects can highlight the positive or the negative aspects.** An 85 per cent chance of survival is also a 15 per cent risk of dying; a treatment that relieves symptoms in 90 per cent of cases does not relieve symptoms in

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10 per cent of cases. Think carefully about whether you want to highlight the positive or the negative message, or present both.

- **Instructions should be specific rather than general.** 'Take one tablet three times a day 20 minutes before meals' rather than 'Take three times a day'.
- **Use familiar words, not jargon.** If you need to use medical terms, explain them when they are first used and provide a glossary of terms.
- **Do not abbreviate or use acronyms.** Using initials or abbreviations may confuse and irritate your audience. If it is unavoidable, explain what they stand for when you first use them, e.g. *Promoting Patient Choice* (PPC).

e.g.

Coming into hospital can seem overwhelming at first, but we would like you to feel welcome and we will do everything we can to make you feel comfortable. We hope that this leaflet will answer some of your questions and help you settle more easily into the ward. And if there is anything else at all that you would like to know, please do ask us!

Al Brookes
former Patient Information Project Worker
Brighton Health Care NHS Trust 1997

Plain English

- **Short words, short sentences, short paragraphs.** *Short words* are more likely to be included in the vocabulary of people with low literacy skills. *Short sentences*, listing the main points using numbers or bullet points, make the information easier to understand. They also increase the chance that people will read on. *Short paragraphs*, expressing a single idea, with sub-headings for each section, enable the reader to concentrate on one message or point at a time.
- **The active voice rather than the passive.** For example, 'you should', rather than 'you are expected to'.
- **Be direct.** 'Do not take this medicine with any other drugs' tells the reader that it is their own responsibility to avoid other drugs. 'This medicine should not be taken with any other drugs' sounds more like a suggestion or advice.
- **A personal approach.** Say 'You will be asked to lie down' (the second person), rather than 'The patient will be asked to lie down' (the third person).

Readability

Consider whether to use published readability tests, such as The Gunning Fog Index, Gobbledygook, Watchword and the Flesch test. Some word processing programmes (Microsoft Word, for example) have readability scores built into their software. However,

they may be of limited value (*see below*).

e.g.

The readability score alone does not indicate the appeal and impact of a leaflet ... In the FOG test the Family Planning Association (FPA) scored well on readability with 10, yet the non-FPA had a lower score of 9.2. (Examples of scores are: news story in tabloid paper 10, broadsheet newspaper 17, an insurance policy 20.) Yet the FPA leaflet was much preferred. It is apparent that a straight readability test does not give the whole picture, as it does not reveal interest, relevance or humour which make young people more inclined to start and continue reading.

Family Planning Association (FPA)
Unpublished results of user testing
for booklets on puberty and contraception

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Further information

- In the clear (Beenstock *et al.* 1998). South Manchester University Hospitals Trust account of providing jargon-free information written in plain English, with a simple questionnaire to ensure patients' views are taken into account.
- *Gobbledygook. Promoting Health: a practical guide* (Ewles and Simnett 1995).
- A new readability yardstick (Flesch 1948).
- Readability formulas: cautions and criteria (Meade and Smith 1991).
- How readable are the hospital information leaflets available to elderly patients? (Pettersen 1994).
- *Writing Leaflets for Patients* (Secker and Pollard 1995).
- *Ensuring the readability and understandability and efficacy of patient information leaflets* (Wilson *et al.* 1998).
- Designing healthcare advice for the public (Wright 1999).
- *The advantages and disadvantages of readability tools* (CHiQ 1998).

Also see Section 2 (p.11) *Quality standards for patient information* and Section 6 (p.59) *Selecting the medium*.

Presentation

Issues such as page size, typeface and typesize, line length, justification and use of colour are not dealt with in *The POPPi Guide*. They are discussed in detail in Chapter 5 of *Writing Leaflets for Patients* (Secker and Pollard 1995), published by the Health Education Board for Scotland.

Telling the story

After listening to patients and collecting the clinical evidence (*see Section 4*), bring together all the topics you have decided to include. Plan how you will communicate this information by designing a 'storyboard'. This arranges the information to tell a 'story' that makes sense to lay people, with a beginning, middle and end.

You can order your topics in many different ways. For instance:

- start with what is most important to the patient
- tell the story in the order that the patient will experience it
- take different themes in turn (e.g. causes of the illness, treatments)
- address the topic from the point of view of different patient characteristics (e.g. young people, older people).

At the end of each section, think about what you want your patients to be able to do. You can use a summary to emphasise the most important issues and help patients to remember key points.

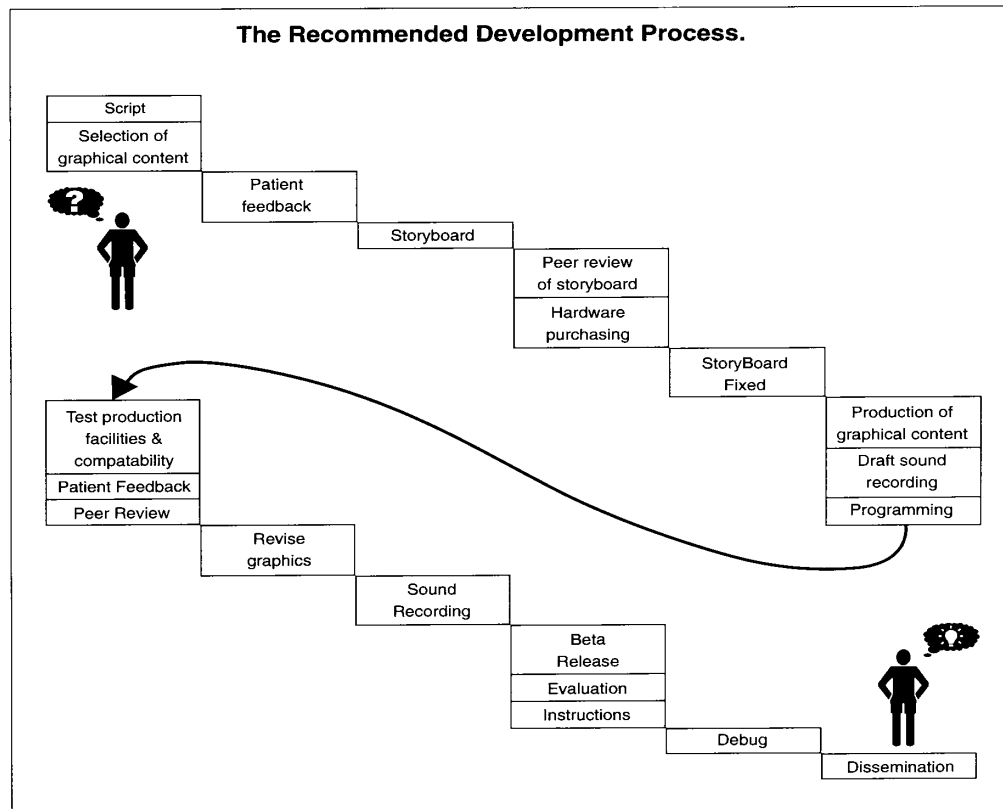


Action points

- Collate the evidence (patient and clinical).
- Before you begin writing your first draft, put yourself in the shoes of one of your patients. Role play that patient and answer the following questions:
 - 1 What am I experiencing physically right now?
 - 2 How long have I been experiencing this?
 - 3 What practical effect has this had on my life in terms of my work, finances and social activities?
 - 4 What effect has it had on me and my relationships with my partner, family and friends?
 - 5 What is my emotional state right now?
- Construct a storyboard.
- Set deadlines.
- Circulate for comment.

Figure 3: An example of a storyboard

The Misbehaving Bladder project at the Bristol Urological Unit in Southmead Hospital developed a useful storyboard technique for keeping track of all the various resources required to develop their multimedia kiosk on urinary urge incontinence. The diagram below, produced for the project by MEDIT Ltd, illustrates how this was incorporated into their Development Process.



Source: PPC Bristol: *Urge Incontinence*

Piloting

It is vital to allow adequate time for consultation and piloting. Rushing the work will ultimately affect the quality and acceptability of the finished article. Any information you want to use with patients – your own and material produced by other agencies – should be piloted to check:

- whether patients find the information easy or difficult to use
- how well patients have understood the key messages.

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Further information

- *Informing Patients* (Coulter et al. 1998). Reviews the quality of 54 materials (leaflets, videos, and audiotapes) by groups of patients who had experienced specific health problems and by research specialists with relevant expertise.
- *A directory of information materials for people with cancer 1999/2000* (Macmillan Cancer Relief/CHiQ 1999). This guide to nationally published leaflets, booklets, books and videos on cancer is an excellent example of how to collate previously published information materials. Many of the resources listed have also been appraised. Internet: www.chiq.org.uk/macmillan/
- *Quality-consumer-health-info*. A forum for stimulating debate about the development and evaluation of good quality evidence-based consumer health information, including issues such as: consumer involvement in development, inclusion of evidence, use of various media, and promoting good patient communication. (Description courtesy of Mailbase.) Internet: www.mailbase.ac.uk/lists/quality-consumer-health-info/

Copyright

Copyright issues must be discussed and agreed before the information is produced. This is especially important if several different agencies are involved and where external funding has been obtained. Borrowing from published sources may involve issues of copyright – always contact the publishers of the material to be used for permission.

Timescales

Decide when you want to complete the work. Base this on a realistic assessment of how long the process will take, bearing in mind the topic itself, the number of people available to help you and the amount of money you have to spend on the project. Experienced patient information officers say that it can take between three months and two years to have a finished product, depending on the complexity of the topic and the medium you have chosen.

Identify clear milestones within the overall timescale so that you can measure your progress throughout the project. For example:

- date for the first draft to be finalised
- date for the second draft to be discussed with patients and staff
- delivery date for produced materials.

e.g.

The authors of this article have recently published an information pack on dysphasia, for patients and carers. Nursing home matrons, patients, carers and local health professionals were canvassed to discover what information was required. The resulting booklet contains fewer than 1,900 words and took about 120 staff hours to write, spread over 14 months.

North, Margrave and Roe (1996)

Teamwork

Think about whether you want to manage the project yourself – and whether you have the time and the relevant skills. Can one person manage the project or do you need to work with other people? It may be worth finding out if you have, or can get, the resources to support a full-time or part-time worker (*see Paying for the work, p.22*).

A number of agencies may be involved in the production of your patient information; let them know well in advance what you plan to do and ask for their help. They can form part of your project team.

Think about what you may need, including:

- qualitative and/or quantitative research skills
- clinical expertise in your chosen topic
- writing skills
- media expertise
- advice about evaluating your information.

Are these skills available locally? Will you be able to afford to pay for them? Is there a local resource that could provide help without payment? For example, art colleges sometimes want local design projects for their students. Is your project suitable?

All the members of the project team, if you have one, must have clearly defined responsibilities and good channels of communication.

You may wish to consider setting up a steering group, or an editorial panel of experienced producers, to provide advice and guidance. The kinds of people you could invite to join the steering group include:

- academics with research experience
- members of the appropriate specialist voluntary health organisations
- representatives of the appropriate minority ethnic communities
- a CHC representative.

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Action points

- Select some of the key messages.
- Devise a set of multiple choice or short answer questions based on them.
- Pilot these with people who were not involved in preparing the information and on a cross-section of the target audience.
- Ideally, you should pilot your information in more detail, using some of the techniques mentioned in *Methods for collecting the views of patients and carers* (p.29).

6 Choosing the medium

Some of the information in this section is reproduced with kind permission of the authors of *Getting it right when you write – the Salford guidelines for written information about health*. Salford Centre for Health Promotion, 1994.

Your choice of medium will be influenced by:

- who the patients are, their preferences and needs
- the nature of the information and the message to be communicated
- access to technical expertise
- funding and resources.

As new media are developed, the same basic criteria need to be applied in assessing whether they are the most appropriate and effective way to communicate specific information to a specific audience. Does the use of information technology sufficiently enhance the delivery of the message to justify its use over paper?

Who is your audience?

Your information should truly represent and reflect the needs of its intended audience. To choose the most appropriate and effective medium, find out about:

- your target audience: their age, gender, linguistic, educational and cultural background, sensory or other impairments
- the number of people you expect to reach: for example, the cost of producing multimedia materials means that they are not likely to be appropriate unless the information is to reach large numbers of patients
- where the material will be used: by patients on their own at home, or by groups of patients in a clinic or hospital with the support of a facilitator who can respond to questions and concerns
- the context in which the material will be used; material designed for people going into hospital has a different context from that designed to stop people from smoking, or for coping with illness.

Responding to patients' preferences

Include the choice of medium in the discussions during your user involvement exercise (see Section 4). Ask patients to say how they would like the information to be presented and balance this with the resources you have. If possible, give them a choice of formats – do they want to see a video, read a book, or hear a tape? Be honest about what you can provide and willing to change your own ideas about what you think may be best for them.

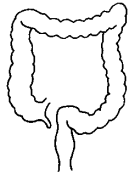
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Think about using more than one medium. When considering resource implications, think about the ways that information prepared for one client group (e.g. large print for people who are visually impaired) may also be useful for others (e.g. people with learning disabilities, people whose first language is not English).

Patients like the opportunity to make a contribution while they use the information package. It is often assumed that only multimedia packages can be interactive. However, paper-based packages can also offer opportunities for patients to add in their own observations. Leaving sections for the patient to fill in with details – such as their own name, their GP's contact details, appointment dates, and a record of their own progress – helps them to feel that they are more involved with the management of their own condition.

Figure 4: Log book clinic results

The section below shows an example of some patient-held record sheets used in the Guidebook for Ulcerative Colitis developed at Hope Hospital and the University of Manchester.

Log book Clinic results	Date / /	
	Test	Result	
	Weight		
	Blood tests	Hb <input type="text"/>	Platelets <input type="text"/>
		WBC <input type="text"/>	Serum Albumin <input type="text"/>
		ESR <input type="text"/>	C-prot <input type="text"/>
			
	Endoscopy		
	Barium enema		
	Assessment	<input type="checkbox"/> In remission	<input type="checkbox"/> Mild flare up
<input type="checkbox"/> Moderate flare up		<input type="checkbox"/> Severe flare up	
Treatment			

Source: PPC Manchester: *Ulcerative colitis*

Minority groups

People whose first language is not English

Written information may not be suitable for ethnic communities who cannot read written English. Depending on the age and gender of the target group, some of them may not necessarily read their own first spoken language, nor can some languages be written down, e.g. Sylheti. Translation is not an add-on. Whether you are producing a leaflet, an audiocassette or a video, it must be considered from the beginning of the project, and taken into account when you decide which medium to use for your information and when you draw up your budget.

Translation is not about taking information produced in English and simply converting it into another language. In some languages, literal translations for English concepts do not exist and translators cannot provide a word-for-word substitution. Sometimes the explanation provided by the translator may distort the meaning, and discrepancies should be discussed fully so that the translator can give an accurate description of a concept for which there is no exact translation.

You must consider cultural differences between western and other models of medicine. For instance, information about diet for Afro-Caribbean people should include foods commonly eaten by people from this community; Muslim women must be consulted about the acceptability of certain kinds of information such as abortion, birth control and other health issues, such as HIV/AIDS or breastfeeding.

The process of developing patient information for minority groups will be greatly helped if your (extended) project team includes someone with previous experience of this work or with knowledge of one or more of the translated languages. Contact the Commission for Racial Equality to identify local groups in your area (*see Appendix 1*).



Action points

- Think about the need to translate information into other languages (even where English is understood) when you start work. Remember to include questionnaires, consent forms, posters and other documentation that you may require later on in the project.
- Find out about and consider any cultural differences that may influence the content of your material.
- Determine which groups you need to cater for and what other materials are already in use. Remember that different needs, levels of literacy and dialects can exist within the same language group. It

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is helpful if the translator speaks the same dialect as the target group and is of the same gender (where appropriate).

- Identify gaps in existing information and areas where certain ethnic and religious groups have different needs from the wider community (e.g. sickle cell anaemia is more prevalent among some Black West Indian and other groups).
- Use appropriate images of people from different ethnic groups in all material.
- Translation can be expensive; get estimates from a number of sources before the work begins. You will also need specialist type-setters for languages that use a different alphabet. Ask translators for samples of previous work and approach people who have previously used these translation services for advice. You may be able to save money by collaborating with other organisations that translate material (for example, health authorities and trusts) and/or by producing multi-lingual literature (that is, one leaflet printed in more than one language).
- The Department of Health recommends that 'back' translation be conducted on all health information materials. This means that a different translator translates the final draft back into English to check that the meaning is correct. Ask an objective third person to proofread translated texts for spelling errors and typing mistakes.

e.g.

Many Asian women in Redbridge were unfamiliar with the term depression to describe their clinical condition. They considered that they were suffering from a thought sickness – *soochnee ke bimaari* – a sorrow in the heart. Faith and spiritual healing is a common treatment option for this condition in their own culture but is not considered by western cultures.

PPC Redbridge and Waltham Forest Health Authority: *Anxiety*

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Further information

- *How to provide information well to Bangladeshi, Chinese, Indian and Pakistani people* (National Information Forum 1998).
- *The Directory* (Institute of Translation and Interpreting). The Institute promotes and develops the science and practice of translation and interpreting and monitors standards of competence, good practice,

conduct and ethics for those engaged (or about to engage) in translation and interpreting. Internet: www.iti.org.uk

- Language Line. Professionally trained interpreters 24 hours a day, 365 days a year. Tel: 0800 78 33 503.

People with disabilities

The Disability Discrimination Act 1995 (DDA) introduced new laws and measures aimed at ending the discrimination that many disabled people face. The Act gives disabled people new rights, such as access to facilities and services that are available to members of the public, including hospitals, clinics, doctors' surgeries and pharmacies. Service providers have a duty not to discriminate against disabled people. The duties are:

- not to refuse service
- not to provide a worse standard of service
- not to offer service on worse terms.

From October 1999, providers of services – whether paid for or free – are required to take *reasonable steps* to:

- change a policy, practice, or procedure which makes it impossible, or unreasonably difficult, for disabled people to make use of the service
- offer an auxiliary aid or service if it would enable (or make it easier for) disabled people to make use of services
- provide a reasonable alternative method of making services available where a physical feature makes it impossible, or unreasonably difficult, for disabled people to make use of them.

Disabled people are a diverse group with different requirements that service providers need to consider. Service providers have a duty to:

- produce information in a format such as Braille or on audiotape, for blind and partially-sighted service users
- provide a sign language interpreter
- take more time to explain to a person with learning difficulties how to take prescribed medicine.

A service provider's duty to make reasonable adjustments is a duty owed to disabled people at large; it is not simply a duty that is weighed up in relation to each individual disabled person who wants to access a service. Service providers should be thinking now about the accessibility of their services to disabled people. They should anticipate the requirements of disabled people and the adjustments that may have to be made for them.

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Defining the target audience

Think through exactly who your target audience is. For example, many voluntary health organisations, such as the National Asthma Campaign, were set up to provide support for people with certain illnesses or conditions and regularly produce information for their users. This kind of organisation knows its target audience, but still needs to consider whether one leaflet is suitable for all asthma sufferers or whether there should be separate materials for children, older people, different ethnic groups, or people affected by different levels of severity of asthma – mild, moderate or severe.

Another target audience could be patients in a group practice who want to know more about treatments for high blood pressure. Again, it is essential to consider the nature of the local population with high blood pressure. The topic you choose and its format should always match the wishes and needs of your target audience and your aims should be directed to their characteristics and needs.



Action points

- Think through the aims of your information, considering the needs of the target audience.
- Take account of the organisation's information policy.
- Write down the aims, but be prepared to modify them in the light of preliminary discussions with patients and professionals (see Section 4).
- Clearly state your final aims in your information package.

Building on existing information

- Seeing what others have done can save you work and give you ideas for improving what has already been developed.
- Ask organisations from the *Contacts* list in Section 4 (p.28) to send information relevant to your topic.
- Search some of the more common computerised databases listed under *Evidence about conditions and diseases* in Section 4 (p.35). If you don't have experience of searching online, most libraries will show you how to begin or may offer to do a search for you.
- If your patient group is likely to use social services or to need benefits, or your topic relates to social services, contact the local social services department to find out what information they produce.
- Ask patients and carers where *they* get information.

When you have collected a range of materials, assess each information package. Always check that:

- the clinical evidence base is accurate and up to date
- patients and/or carers have been involved in the design and content
- the material is relevant to your target audience and meets all their needs
- the information is readable and well presented.

If you identify any information that seems suitable, ask if it is available in languages familiar to your local ethnic communities in your locality and in formats that are accessible for people with physical handicaps (especially those with sight and hearing impairment) and for people with learning difficulties.

If you decide that existing material will meet your patients' needs, and that you won't have to develop your own, you can move on (to Section 7) to consider how you will use and distribute it.



Action points

- Find out if there is an existing information package that appears to meet your patients' needs.
- Use an assessment tool to make sure that it is of good quality, e.g. DISCERN (see p.11).
- Check that any information about clinical conditions and treatments is accurate and up to date.



The Trust's Quality Assurance Steering Group agreed to adopt the audit recommendations and the first stage was a thorough review of all written patient information currently in use within the Trust. This review was undertaken by the nursing development co-ordinator in order to identify gaps, compare leaflets and, importantly, to identify areas of good practice. In addition, details were obtained of when and where information was given to patients.

A very large collection of information leaflets was gathered with some clear outstanding examples of good quality production and content. Other leaflets available were poor quality photocopies of typed pages lacking details, guidance on how to seek further help and contact numbers. Basic information such as identification of the Trust and department were also frequently missing.

Richardson and Moran (1995)

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4 Collecting the evidence

Patient and carer views

When we talk about evidence these days, we usually think the word refers to medical or clinical evidence. And so it does. Increasingly, however, there is acceptance of the position – long held by social scientists – that the views and experiences of patients and carers may accurately reflect what they want to know about their illnesses, conditions and treatment. If collected rigorously, these views are also an essential aspect of evidence.

Genuine involvement or consultation with patients, users and carers will result in a far more useful information package – after all, they are the ones who will be using it.

Involving users from the start of the project is essential and an important criterion for quality. There are five main points where patient and carer input is essential.

- 1 At the preliminary stage of checking your ideas (*see Section 3*).
- 2 After you have decided to go ahead and produce your own information package. At this point you should collect patients' and carers' views about:
 - where they have received previous information and what they thought about it
 - the content of information they would ideally like to have
 - when they would like to have it
 - in what format they would like it to be presented (in writing as a leaflet or visually, as a video for example).
- 3 When you have prepared the first draft of your information package, you should discuss what they think about the material or test it out with them (sometimes called piloting). (*See Section 5, p.49.*)
- 4 Once the material is finalised, when you should again seek their views during the review period.
- 5 After the information has been in use for some time (i.e. after one or two years). (*See Section 8.*)

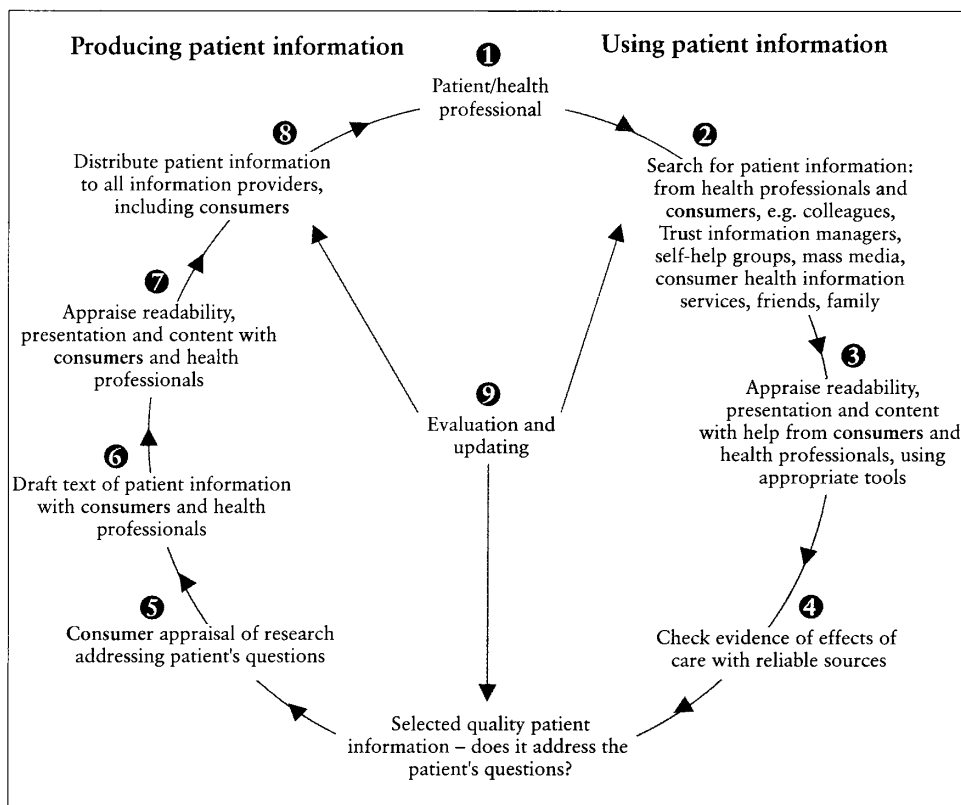
Select a wide enough group of patients from your target audience to encapsulate the appropriate range of views. Patients chosen through a voluntary organisation may not be typical of 'ordinary' users. Consider who you really need to talk to – newly-diagnosed patients, long-established users or people at different stages of treatment. Listen carefully to what people say – don't just look for confirmation of your ideas.

Remember to involve people with sight and hearing impairment, physical disabilities and people with learning difficulties. In areas where there are communities of minority ethnic

groups, recruit members of those communities. In *Section 6* we discuss effective ways of presenting information specifically for each of these groups.

Give feedback to the people you involve. As well as a basic courtesy, it is important for them to know what the findings are. It could affect their lives. Keep the patients informed of progress and provide them with copies of the draft and final packages.

Figure 1: The consumer involvement cycle



Source: CHiQ Topic Bulletin No. 4

Planning your involvement strategy

Before you select a method for consulting with patients and carers, think about these elements of the design.

- What kinds of people do you need to involve? For example, newly-diagnosed patients or existing patients, their families and carers.
- What range of people do you need to involve? For example, older people, younger people, people with disabilities, men or women or both, minority ethnic groups.

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They are expected to consult with disabled users about how to provide services that meet their needs – whether or not they already have disabled users – and should not wait until a disabled person wants to use a service before planning for the reasonable adjustments they need to make.



Further information

A range of information leaflets is available from DDA Information, including:

- *What service providers need to know*
- *Some useful suggestions for when you meet disabled people*
- *Fact sheets*

Publications lists are available online. Internet: www.disability.gov.uk/dda
or from: DDA Information,
FREEPOST MID02164,
Stratford-upon-Avon CV37 9BR

People with visual impairment

Ordinary written information is not suitable for people with visual impairment. The three main ways of communicating information to blind and partially-sighted people are audio-cassette, large print and Braille; all patient information should be offered in these formats. Younger people are much more likely to understand Braille, but only about one in five blind and partially-sighted people can use it. Contact the Royal National Institute for the Blind (RNIB) for advice on producing printed materials for people who are visually impaired and to find out if they already have a Braille transcript of a particular document (see *Appendix 1*).

The DDA Code of Practice gives the following list of auxiliary aids or services which it might be reasonable to provide to ensure that services are accessible to people with visual impairments:

- readers
- documents in large or clear print, Moon (a rarely-used embossed font using the standard alphabet) or Braille
- information on computer diskette
- information on audiotape
- telephone services to supplement other information
- spoken announcements or verbal communication

- accessible web sites
- assistance with guiding
- audio description services
- large print or tactile maps/plans and three-dimensional models
- touch facilities.



Further information

- The RNIB Helpline (0345 66 99 99) can give help on producing information in alternative formats such as Braille and audiotape, as well as details of services available.
- BETSIE – BBC Education Text to Speech Internet Enhancer – is a simple programming language that is intended to alleviate some of the problems experienced by people using text to speech systems for web browsing. Internet: www.bbc.co.uk/education/betsie/

People with hearing impairment

People with hearing impairment may communicate using sign languages, lip-reading, written English or a combination of these. British Sign Language (BSL) is often the first language of people who have been deaf from early in life, with English as their second language. People who have become deaf later in life (often termed deafened) are more likely to lip-read and have a better understanding of English. People who become deaf after middle age may find it difficult to learn BSL. Consider using a sign language video, including subtitles, to translate health information leaflets for deaf people. Contact the Royal National Institute for Deaf People (RNID) for further information (*see Appendix 1*).

The DDA Code of Practice gives the following list of auxiliary aids or services which it might be reasonable to provide to ensure that services are accessible to people with hearing disabilities:

- written information (such as a leaflet or guide)
- a facility for taking and exchanging written notes
- a verbatim speech-to-text transcription service
- non-permanent induction loop systems
- subtitles
- videos with sign language interpretation
- information displayed on a computer screen
- accessible web sites

- textphones, telephone amplifiers and inductive couplers
- teletext displays
- audiovisual telephones
- qualified sign language interpreters or lipspeakers.

People with learning difficulties

Professionals often overlook the particular need of people with learning difficulties for good quality information. People in this group sometimes say that clinical staff do not treat them as ordinary adults and seem to think they are suffering from mental illness. Some of this group are unable to read but do understand clear signs and pictorial information. Try to involve some of them in your consultation exercise, or consult organisations that represent them.

Figure 5: Simple messages

Books *Beyond Words* actively address the problems of understanding that people with learning and communications difficulties experience. The stories are told through colour pictures, helping readers to cope with events such as going to the doctor, bereavement, sexual abuse and depression. The stylised drawings include mime and body language to communicate simple, explicit messages to the reader.



Scenario 2 — The doctor examines Jim Lane's tummy

15. Jim tells the doctor how he is feeling. She asks a lot of questions. Jim answers the best he can. Then he says: "This is George, my supporter. Do you want to ask him anything?"
16. The doctor shows Jim what she wants to do. Jim asks her some questions. "Will it hurt?" "Why do you want to do it?" "Will it help me get better?"
17. Jim thinks about what the doctor has said. "Do I really want to have my tummy examined?"
"Why does the doctor want to do it?" "What will happen if I don't want to have my tummy examined?" He has to decide.
He can say "O.K." to his tummy being examined or "No, thank you."
18. Jim agrees to have his tummy examined. The doctor says: "Please go behind the curtains. Please undo your clothes. George can help you if you want. I will come in when you are ready."
19. Jim undoes his trousers. He lies down on the bed. George helps him cover up with a blanket. Jim is embarrassed. George says the doctor needs to see Jim's tummy to find out what is wrong with him.
20. The doctor looks at Jim's tummy. At first she presses gently, but then she pushes harder. She asks Jim to cough. Jim is still embarrassed. He is glad the doctor is looking at his face most of the time. "Tell me if I'm hurting you," she says. She looks at Jim's face to see.
21. Jim does up his clothes. He is glad he brought George with him.
22. The doctor answers his questions. "I'm glad that's over," he thinks.

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Source: Hollins (1996)



Action points

- Contact specialist organisations for advice about the needs of the groups they represent and about the kind of health information that is already in existence.
- Send for information to find out your duties under the Disability Discrimination Act 1995.
- Include people with disabilities and other special needs, and the groups that support and represent them, in your patient consultation exercises.



Further information

- *Going to the Doctor* (Hollins 1996). *Books Beyond Words* series for people with learning difficulties).

Selecting the medium

(Also see Section 2 (p.11) *Quality standards for patient information.*)

Your choice of medium may be restricted because of limitations in:

- the funding and resources that are available
- the skills and experience that are accessible.

Each medium also has advantages and disadvantages that need to be taken into account in reaching a decision about your information package. Don't use technology unless the benefits outweigh the cost.

The following sections highlight some of the special characteristics of each medium. The *Further information* lists identify specialist sources of advice on detailed technical aspects of production.

Written information

These factors may influence a decision to produce written information:

- it is usually the cheapest medium and requires less specialist technical expertise to produce in the first instance (this does not mean that everyone can write clearly!)
- information can be produced to meet the specific needs of very small or very large numbers of patients
- patients can have their own copy to take away, carry about all the time, and refer to as and when they want
- written information can be readily revised and updated
- published information is easily stored and distributed.

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Written information must be simple and accessible to patients. One secret of good written communication is having a very clear sense of who you are talking to and what you want to say to them. Just as your style of speaking varies according to who you are talking to, your style of writing needs to vary for different audiences. See also Section 5 (p.45) *Writing style*. Design is also of importance:



Action points

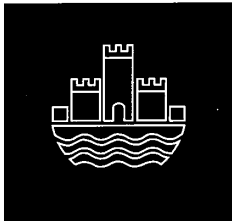
- Decide where you will go for design expertise. It is always worth consulting a professional graphic designer about presentation and layout so that you produce the most effective information package within your budget. Some printers work with graphic designers and you could also consider approaching NHS Supplies, the medical illustrations department, or local arts and technical colleges, if appropriate.
- Check the design and layout with patients and colleagues.
- To find a quality printer, ask colleagues in your own and other local organisations. Get at least two estimates from different printers and ask to see recent examples of their work. Look for quality not just price. Consider using your local medical illustrations department.
- Number of copies. Think about how large your audience is, how you will be able to distribute copies, and when you will next need to update the material. Consider whether it is preferable to produce a large number of cheap copies rather than a small number of a higher quality.
- Ask for advice on the best production method:
 - size and format – an A5 booklet or one-third A4 pamphlet is convenient for patients to carry around and refer to
 - print production process – for 500 or fewer copies it may be cheaper to use ‘docutech’ (a digital printing process straight from a computer disk) where the price per copy is the same however short or long your print-run; for longer print-runs, you can make considerable savings by litho printing (a traditional printing process from film) because the price per copy gets cheaper as more copies are printed
 - the colour and type of paper to be used for inside pages and for the cover (weight, shiny or matt, recycled or newsprint)
 - binding and additional requirements; for example, a pocket for enclosures (having a pocket adds about 30 per cent to the cost)
 - colour of ink (the use of two colours adds about 10 per cent to the cost)


- source and style of illustrations (photos, line drawings, charts and diagrams).
- Avoid flashy fonts, graphics and colours if using desktop publishing (DTP) software.
- If you have to rely on photocopying, ensure that it is always done from a master copy of consistent quality, laminated if necessary, and only use it for leaflets that are used in small numbers (200 – 300 copies).
- Put the month and year of printing, and a review date on all published material.


Figure 6: Briefing a designer – four ways of treating the same design


Briefing The designer, assuming you decide to use one, will visit you to discuss your needs. He will want to know:

- who will be reading the booklet – in this case, patients and their relatives or friends;
- what size and how long you want the booklet to be;
- whether you want it to be printed in one colour or more (black counts as a colour);
- whether you want illustrations;
- whether your hospital has any logostyle, symbol or 'house' colours such as the castle in the Castleport booklet;
- the dates when you want the booklet to be completed and delivered.









Four ways of treating the same piece of graphic design, all in one colour.

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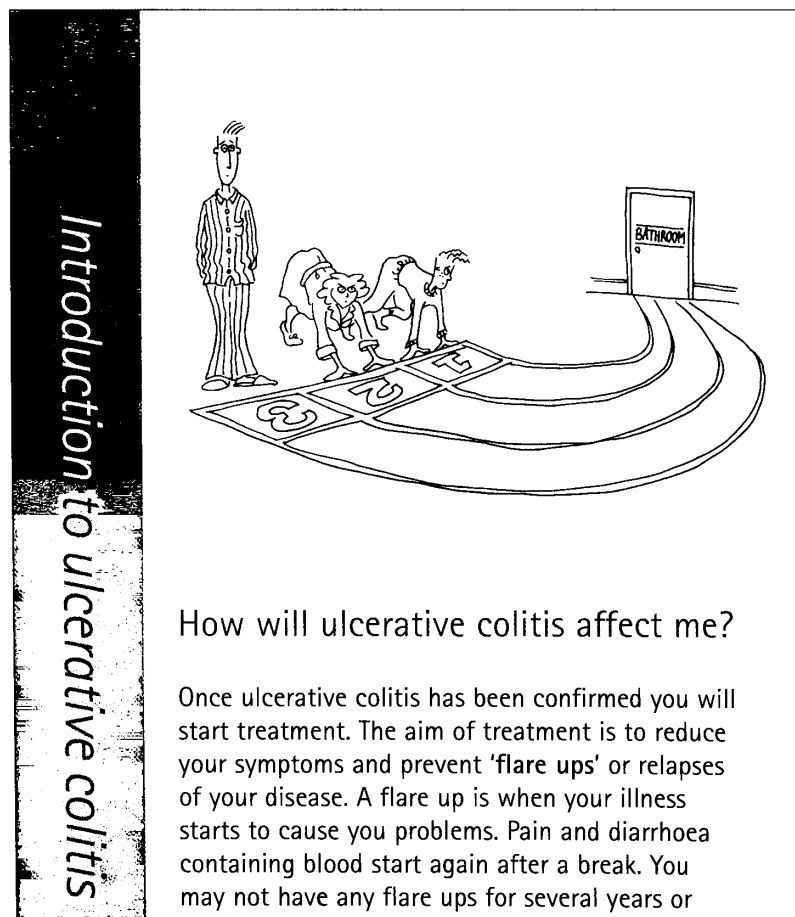
Source: Silver (1991)

Illustrations, cartoons and animation

Information in any medium can benefit from the use of pictures. The following factors may persuade you to use illustrations:

- they can simplify complex information, inform and entertain
- they break up large areas of text or speech and make the information less daunting (e.g. a picture of three out of ten pupils in a class with their hand up was used to depict 30 per cent to 7–14 year olds)
- statistical information is easier to understand in the form of tables, histograms or pie charts
- flow diagrams, decision trees (flow diagrams that illustrate the stages people go through when they are making decisions) and journey maps (see Figure 8) help patients to recognise where they are in the processes.

Figure 7: Illustrating patient information – humorous cartoon



Source: PCC Manchester: *Ulcerative colitis*

Cartoons and animations (moving cartoons and pictures used in video and multimedia) are a valuable tool in various media.

- A stylised representation is often more acceptable than a picture of the real thing. Patients may be squeamish about a medical 'cutaway' diagram (e.g. of the heart). Patients often prefer animation to real medical footage, especially for invasive tests such as inserting a catheter.
- Animation can be very useful in explaining difficult concepts such as the prevalence of a condition or the relative risks of side effects.
- Moving pictures are useful for anatomy lessons (e.g. how body parts work) because they give a more accurate presentation than a static picture. For animation and static images, show enough of the body around the part you are illustrating for patients to locate it.
- Cartoons work really well in helping people make decisions.
- Cartoons can successfully introduce a lighter tone to the information. However, not everyone has the same sense of humour so be cautious.

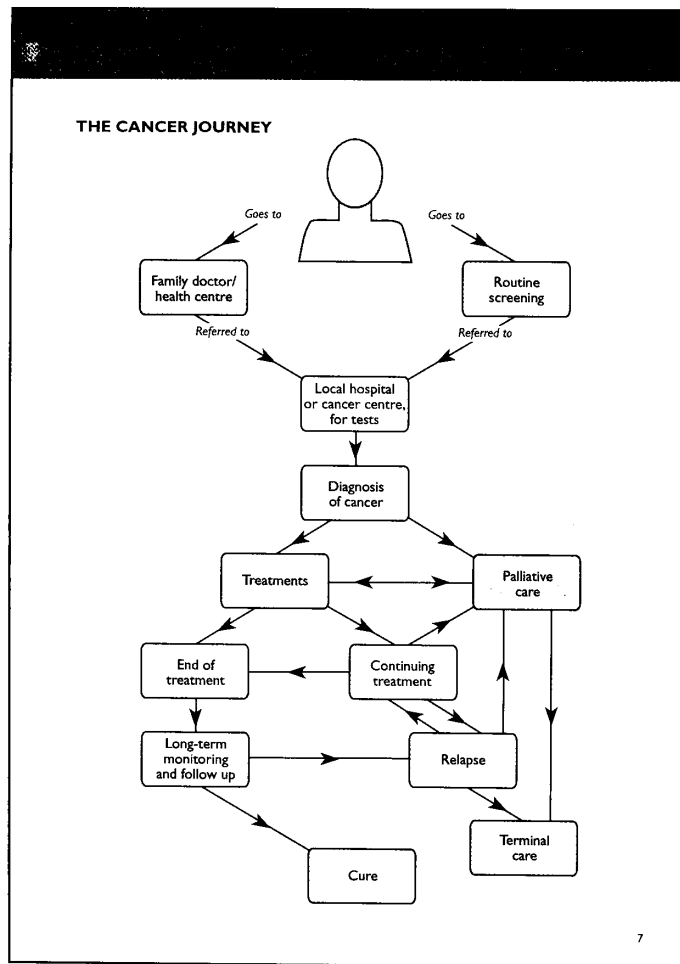


Action points

- Make sure that diagrams/photographs are representative of, and understood by, all your patients.
- Keep illustrations simple, including your cover design.
- Make sure a cover illustration represents the topic sensitively and encourages users to explore further.
- If the information is directed at young people, use pictures of young people.
- Use pictures of the correct ethnic groups if they will be part of your audience.
- Keep maps simple. For example, show the location of the hospital in relation to important landmarks. Do not attempt to show details unless the map is produced in a large format.
- Avoid information that might change in a few months, such as train or bus times.
- Show patients where they are along the care pathway.
- Take care with humour.
- Test the use of all illustrations with a range of potential consumers.
- If you are thinking of using recognisable photographs or pictures of real people, make sure that they sign a disclaimer in which they agree not to have any ownership of your material. Model release forms can be obtained from the British Association of Picture Libraries and Agencies (see *Appendix 1*).

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Figure 8: Illustrating a cancer 'journey'



Source: BBC/Macmillan Cancer Relief (1997)

Audio

Audio information could include producing an audiocassette or setting up a telephone line with a recorded message.

Consider the following criteria when you are deciding whether to produce information in an audio medium:

- people who have low levels of literacy can benefit from audio; the Basic Skills Agency estimates that 20 per cent of the adult UK population (around 8 million people) have difficulty with reading

- audio information can be offered in different languages to people who may not read in their first spoken language
- it is suitable for people who are visually impaired
- all audio information is potentially available to patients in their own home
- the equipment needed to listen to an audiocassette is not expensive and is widely available; most homes have a telephone
- audiocassettes can be used for dramatised examples of different scenarios (e.g. a doctor and patient encounter).



Action points

- Producing audio material requires a variety of technical expertise and resources.
- Written material cannot simply be directly recorded because the flow of information alters between the written and spoken word. Some information will have to be rewritten and the order of information reconsidered (this is often called resequencing). A script will need to be written from which audio material can be read.



The Back Pain Guide was produced by the BBC in both booklet and in audiocassette form. Because of the need to script the written material and then to produce an audio version, experts from within BBC Radio 2 Social Action team were asked to conduct the work. Sadly, the uptake by the public for the audio version has not been great – a valuable lesson in determining audience need before producing material in different media.

BBC Radio 2 *Back to Basics Campaign*, March 1999



Further information

- RNIB. *Tape organisations which can be approached to undertake recording work*. List available from the Public Information Service at the RNIB. Tel: 020 7388 1266.
- The Department of Health runs 16 telephone helplines. Details are available on www.doh.gov.uk/phone.htm
- The Health Information Service is a national freephone network that provides free confidential information on a range of health-related issues. Tel: 0800 66 55 44 or 0800 22 44 88 in Scotland.

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- *Healthline* is run by the College of Health to provide callers with pre-recorded health information messages on over 500 health-related topics. Available for people living in London on Freephone 0800 66 55 44 and for people living outside London on 020 8983 1225. Ask for the taped message service.
- *Telephone Helplines Directory* produced by the Telephone Helpline Association (THA) includes over 900 national, regional and local telephone helplines throughout England, Wales, Scotland and Northern Ireland, all of which have demonstrated to the THA that they follow principles of good practice in their operation.

Video

Videos really should be produced by people with the relevant technical skills and are often expensive to commission. Local colleges that run media courses may be able to make videos at minimal cost, as practical experience for their students. Videos could, possibly, be offered in out-patients or in pre-operative packages for a returnable deposit. However, they are unlikely to be a suitable medium for producing information that is to be given to individual patients to take away and keep, so you will probably need to produce a patients' leaflet to complement a video production.

Video is especially useful for:

- demonstrating a skill that needs to be acquired, such as physical exercises
- expressing emotions, showing other people talking about their experience of medical conditions
- stimulating discussion among a group of patients and carers.

If patients themselves are to be included in a video you are making, you must obtain their consent in writing and they must be aware who may see the video (*see Legal liability, p.9*).



Our 'information for patients research group' conducted a formal study in which 300 patients were asked which educational tool would help them most to understand more about their cancer diagnosis and empower them to become more involved in decision-making. 89% indicated that an information video would be helpful and 87% had easy access to a video player.

Dr Robert Thomas
Macmillan Consultant Clinical Oncologist (rjt@hii.co.uk)
Addenbrooke's Hospital,
Cambridge & The Primrose Oncology Centre, Bedford



Further information

- *Effectiveness of video in health promotion* (Eiser and Eiser 1996). Recommendations for commissioning video-based interventions and examples of well planned and well evaluated projects.
 - *Videos for Patients* has produced over 40 patient information videos using celebrities such as John Cleese, Dr Robert Buckman and Dr Miriam Stoppard (see *Appendix 1*).
 - The BMA Library runs a Film and Video Service with titles suitable for patients and the general public. For general information contact the Sub Librarian (Film and Video Services) on 020 7383 6690 or see the link from the library's home page.
Internet: www.library.bma.org.uk
 - Focus TV (FTV) deliver a TV messaging service, with health and local news items, to waiting areas in NHS trust settings.
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Multimedia

Multimedia allows you to deliver information in a wide variety of ways within a single package. To be useful, a multimedia programme should offer patients something they cannot get from other sources, such as information leaflets. The principal advantage of a computer package is the way that the patient can interact with the programme.

- If multimedia is developed properly, users can choose between different ways of learning – through text, sound, symbols and animation.
- Patients can control the way they access the programme, with some people choosing to follow it in a linear manner and others jumping around according to their area of immediate interest and concern. They may also choose to replay sections of the presentation.
- Multimedia is especially suitable for children who may be reluctant to read printed information about their condition, or be unable to do so. An interactive computer programme is a child-friendly medium that is likely to encourage them to learn about their condition and find out about treatments.

Multimedia packages can incorporate feedback. These consist of an internal audit system that logs the various screens that are, and are not, viewed, and for how long. They may also pose questions to patients within the programme. These insights into the patient's learning process can be fed back into the development cycle.

Some systems can accept input of individual patient data such as age, gender, and symptoms. This was a feature of one of the pioneering systems developed by Wennberg

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and Mulley at the Foundation for Informed Medical Decision Making in the USA. In this kind of system, the decision-analysis software processes this data and helps to identify treatment options that are applicable to the particular patient. This information can be printed out for both the patient and the clinician.

A number of factors need to be taken into account in reaching a decision about presenting information through this medium:

- it can be a very costly medium and requires specific IT skills, as well as professional graphic design expertise
- many patients will not have encountered multimedia before and may be unfamiliar with its capabilities and nervous of using it; they will need to be shown what it can do
- children are likely to find multimedia easier and more exciting to use than older people who are less familiar with the technology
- you will need advice in assessing the shelf life of a multimedia package. Can it be linked to the Internet or integrated with other systems? How long will the equipment last before needing an upgrade and what will this cost?
- think about how you will distribute, and provide technical support, for such a product.

Appendix 5 lists a number of organisations that have developed digital patient information in touch screen and CD-ROM format.

e.g.

In the development of the colorectal cancer information package by Castle Hill Hospital, the patients involved in its development said that they would prefer written material until they were shown a computerised version of the information. They liked the flexibility to

choose which information to view, in what manner they viewed it and the ability to move through the package at their own pace. The developers went on to develop a multimedia version, which is soon to be developed for other specialties within the hospital, such as breast cancer.

PPC Hull: *Colorectal cancer*

Figure 9: Multimedia

Urinary Disorders & Male Health – A decision-making guide for patients is a CD-ROM developed by the Royal College of Surgeons, the British Association of Urological Surgeons and Merck Sharp & Dohme.

Urinary Disorders & Male Health
A decision-making guide for patients

This CD-ROM program is designed for men concerned about or diagnosed with a urinary problem. It guides the user through the latest information on symptoms, tests, treatments, and side-effects.

Contents:

- the enlarged prostate (BPH)
- inflammation of the prostate (prostatitis)
- bladder stones
- urinary tract infection
- prostate cancer
- bladder cancer

Presented as a dialogue between patient and urologist, a patient can use the program to educate and prepare himself to get the most out of his meetings at the hospital.

Patients who have had their urinary problem diagnosed can learn more about the latest treatments and the pros and cons of one compared with another.

Internal examination

Animated graphics and video-clips acquaint the user with tests, treatments, going into hospital and how to help recovery from operations.

TURP (transurethral resection of the prostate)

Pros:

- ▲ highly effective in relieving/abolishing symptoms
- ▲ restores that of 10 patients:
 - 8 will feel improvement
 - 1 feels an improvement but does not get worse
 - 1 will feel worse after the operation

Interactive question and answer screens help the patient consider what treatments might be best for him.

Side-Effect Scorer - 2

About 2 out of 10 men in the survey found it difficult to get an erection after the operation. How important is this risk to you?

This risk is unacceptable

It concerns me, but in view of my symptoms it's an acceptable risk

It does not present a problem for me

Click on the bar that best shows to you how you change your mind before you click on 'Next Question'

Choosing the medium

Source: The Royal College of Surgeons of England, 1998.

A number of organisations provide awards for the production of multimedia (see Appendix 1). These include:

- **BCS (British Computer Society)**. The chartered institution for professionals working in all aspects of information technology and information systems engineering. Has a number of health-related informatic sub-groups which will be of interest to people developing digital patient information.
- **BIMA (British Interactive Multimedia Association)**. The trade association for companies and individuals involved in the interactive media sector in the UK.
- **CTIC Medicine (Computers in Teaching Initiative)**. Develops computer systems for training pre- and post-graduate health care professionals.

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Further information

- Developing shared decision-making programs to improve the quality of health care (Kasper *et al.* 1992).
 - *Interacting: multimedia and health* (Leonard 1994).
 - Consumer-health-informatics. List for those who are developing or evaluating new computer-based methods for the direct use of patients and the public. Includes patient education, information about services and other sources of help, and computer-patient interviewing. (Description courtesy of Mailbase.)
Internet: www.mailbase.ac.uk/lists/consumer-health-informatics/
 - Foundation for Informed Medical Decision Making. The original developers of patient information materials that allow the physician and the patient to select a treatment that reflects the values and preferences of the patient as well as important clinical considerations. Internet: www.healthdialog.com/foundation.htm
 - Science Panel on Interactive Communication and Health (SciPICH). Convened by the Office of Disease Prevention and Health Promotion of the US Department of Health and Human Services (DHHS) to examine interactive health communication (IHC) technology and its potential impact on the health of the public. The panel has produced a series of journal articles and final reports intended to accelerate the appropriate development, adoption, use, and evaluation of IHC applications. Includes recommendations targeted for specific audiences and stakeholders that promote quality IHC applications, such as the utilisation of the proposed Evaluation Reporting Template.
Internet: www.scipich.org/pubs/pubs.htm
 - Society of Public Information Networks (SPIN). Has over 200 members, including local authorities, health agencies, libraries, museums, central government departments, voluntary organisations and private sector companies. All are involved in disseminating or exchanging information with the public and staff within their own organisations.
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Health information on the Web

A vast array of health information is available on the Web. The following web sites will provide good starting points for those interested in this area:

- **A guide to producing health information.** Useful ideas and practical advice for producing good quality information materials for patients and members of the public about health and health care interventions.
Internet: www.abdn.ac.uk/public_health/hsru/guide/Guide.htm
- **Centre for Health information Quality (CHiQ).** National UK organisation which aims to improve the quality of consumer health information. Provides advice to patients and carers, information providers and others on products, services, tools and guidelines. Raises awareness of good practice through education and training.
Internet: www.hfht.org/chiq/
- **Health On the Net Foundation (HoN).** Not-for-profit international organisation, based in Switzerland, dedicated to advancing the development and application of new information technologies in the fields of health and medicine, and realising their benefits. Has a code of conduct covering eight principles for publishing health information on the Web. Internet: www.hon.ch/
- **QUICK (QUality Information ChecKlist).** A web site designed to help children and young people assess the quality of the information they find on the Internet, with the necessary tools to decide whether or not a site is giving them useful information. Offers quizzes, puzzles and a chance to pit their wits against Cyberquack.
Internet: www.quick.org.uk
- **BBC Health & Fitness** contains a wide array of independent, high quality health information and, with a daily feed from BBC News, keeps you up-to-date with the latest health developments. The site allows you to monitor upcoming BBC health programmes (from soaps through to specialist documentaries) and to register for both a weekly health newsletter and for details of all forthcoming BBC health-related broadcasts (the Alert! service). Online voting, quizzes and discussion forums – such as *Fighting Fat*, *Fighting Fit* and *Kick the Habit* – provide users with varying degrees of interactivity. Visitors are encouraged to comment on the site and to identify their own favourite health web sites. Internet: www.bbc.co.uk/health
- **Health Insite.** The Australian government's pilot consumer health site, which currently has information on diabetes, cancer and cardiovascular disease.
Internet: www.healthinsite.gov.au
- **healthfinder** is a free gateway to reliable health information developed by the US Department of Health & Human Services (DHHS). It links to carefully selected information from US government agencies, major non-profit organisations, state health departments and universities. It covers over 1000 topics and every link has been reviewed according to strict quality guidelines. It currently serves over 400,000 visitors each month. Internet: www.healthfinder.gov

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- **NHS Direct Online.** Outlined in the *Information for Health* strategy (see p.4), NHSDO is a UK Internet gateway to good quality information for the public. It allows access to NHS Direct services and forms the patient floor of the National electronic Library for Health (NeLH). Internet: www.nhsdirect.nhs.uk

If you're unsure of the Internet, phone 0800 100 900 for details of where you can go for a BBC WebWise taster session. This offers you free 'hands-on' experience of using the Internet at a range of places in your local area. Or visit the web site: www.bbc.co.uk/webwise



Further information

- Published criteria for evaluating health related web sites (Kim *et al.* 1999).
 - Reviewing and evaluating web sites – some suggested guidelines (Murray and Rizzolo 1997).
-

7 Dissemination

Inside the organisation

During the planning process you will almost certainly have thought about some of the ways in which you will circulate and distribute the finished product within your own organisation (*see Section 3*) and you may have informed those people who will disseminate it. Even so, you will still have to make sure that it gets to the right place and to the right people – the patients, carers and staff.

There are a number of things you can do at this stage.

- Inside your trust or practice, take the package to all the staff who work directly with patients. Ask them to discuss the material with you and to think about ways they can make sure that it is given to patients. This personal contact with individuals is almost always appreciated.
- Make sure that the relevant departments/staff have enough copies to give out and that they are kept in a place where they won't be forgotten or lost.
- Give staff details of how to contact you if they, or the patients, want to have more discussion about the material.
- Internal 'work in progress' meetings and reflection days are useful for disseminating your material, and for collecting views within your own organisation.
- Consider holding a launch event and inviting a local celebrity to introduce your package.



Action points

- When you are ready to distribute your material inside your own organisation, let the appropriate staff know and, if possible, take it to them and ask if they have any questions about the material and how and when they should give it to patients/carers.
- Or you could invite all the people who will be using the material to a short workshop to demonstrate the material and the process of giving it to patients.

Outside the organisation

Dissemination outside your organisation for patients with the same condition can be more challenging. The costs can be high, and once you publicise the existence of the package you may have a lot of enquiries from patients and staff outside your area. Consider what it will cost to send out the package. Will you need to charge people for it? If so, who will deal with distribution and with administering the payments?

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Action points

- If you plan to distribute the material to people outside an NHS trust or general practice, consider the cost of distribution and the administration.



Once the children's bedwetting CD-ROM was completed, it received a lot of publicity in the press and on radio. This publicity resulted in many public and professional requests for copies of the CD-ROM and booklet. The development grant did not include money for dissemination and the developers found themselves with a successful product which they were unable to produce in sufficient numbers to satisfy demand.

PPC Nottingham: *Bedwetting*

Here are some ways you can reach other people interested in the same topic if you decide that you want your material to have a wider audience.

National publicity

- **Centre for Health information Quality (CHiQ).** This is one of the best places to begin your external dissemination if you want a national profile. If you send copies to them, it will be listed in their database and publicised nationally. They also plan to accredit the quality of patient information and have begun to do this in the fields of breast cancer and back pain, amongst others.
- **National patient and professional groups.** See *Appendix 1*.
- **Web site.** A large number of patient information sites are now available on the World Wide Web (Internet: www). Speak to your IT developers about putting the information on your organisation's web site or about identifying an appropriate service provider or space on the Internet: www if you don't have a web site. This could result in a lot of attention. Be sure that you want it!
- **Link your package with national awareness events.** A diary of national events like *No Smoking Day* or *World Mental Health Day* is available from the Health Promotion Information Centre (HPIC).
- **Enter for an award.** Patient information packages may be eligible for the increasing number of awards listed on p.13. Remember to look outside the normal range of healthcare awards, e.g. IT awards (see *Multimedia*, p.67). Although there is satisfaction and pleasure in it, submitting your package for an award can be time-consuming and expensive – especially if you have to travel to collect your prize!

- **Take part in conferences and events on patient information.** Increasingly, conferences are being organised on the topic of patient information itself or patient partnership developments. Depending on the medium you have chosen, you may consider conferences on video and multimedia.

Local publicity

- **Contact local media.** Prepare a press release about the package and send it to local newspapers and local radio stations. These media are especially interested in running personal interest stories. Keep a press file to reference appropriate articles. Local TV and radio are also useful for reaching distant audiences and for reaching minority ethnic groups. Asian radio stations, for example, are good ways of reaching local ethnic communities.
- **Meetings of local groups.** Offer to bring the package to meetings of local groups, such as CHCs, VHOs and self-help groups.
- **Local meetings of medical and nursing staff.** Make a presentation at any meetings of professional staff related to the clinical topic.



Action points

- Send copies of your material to CHiQ and the relevant patient and professional organisations if you want a national profile.
- Consider putting the information on the Internet either through your own organisation's web site, if there is one, or through another appropriate service provider.
- Consider submitting your package for a national communication award (see Section 2, p.13).
- Arrange to speak to local meetings of medical and nursing staff and to local Community Health Councils (CHCs).
- Use local press and other media to let people know about the material and where they can get it.



To meet the demand for their bedwetting CD-ROM Nottingham paired up with ERIC – the Enuresis Resource Information Centre. ERIC used their national and local networks to handle public and professional enquiries and to distribute copies of the CD-ROM where appropriate.

PPC Nottingham: *Bedwetting*

8 Evaluation and updating

Annual review

Changes in practice at local and/or national level make it essential to review your material regularly. All patient information should be reviewed after one year, and no longer than two years, once it has started to be used by patients. The best way to ensure regular reviewing is to build it into an audit process.

The process of review involves a number of stages.

- Go back to the original aim for producing the information to assess whether it is being achieved, and whether or not it is meeting current needs. This will involve talking to patients using one of the methods described in *Section 4*.
- Checking whether the material is being given to patients correctly. This will involve talking to staff and observing how they give the information to patients.
- Checking whether it is still up to date. This will involve a search for any clinical evidence that has changed since the package was produced and checking both local and national clinical guidelines on the topic of the information (*see Section 4*).
- If regular reviews have not been included in audits so far, try to make sure that patient information is included in future.

If you did not originally include a form in each copy of the material inviting feedback, include one at the review stage.



Action points

- Plan the timing of the reviews.
- Check with patients that the information still meets their needs.
- Check that the evidence-base has not changed.
- Check that the information is still being given to patients at the right time.
- Reassess how many copies of the material you will need each year, and how much they will cost to provide.



Further information

- Evaluating interventions to promote patient involvement in decision-making (Entwistle, Sowden and Watt 1998).
- In the clear (Beenstock J *et al.* 1998).

Methods of evaluation

From the outset, you should build in evaluation of the material you produce. There are two main forms of evaluation: formative and summative. Mays *et al.* (1997) distinguish between them thus:

- **formative evaluation** is usually built in to project development and is more concerned with process
- **summative evaluation** is normally used to assess the outcome(s) of a project and is more concerned with determining the effects on or impact of a package or a project.

Formative evaluation

If you have followed this guide, you should have carried out some of the elements of formative evaluation by:

- asking patients what their information needs are
- continuously getting feedback on your draft material from them, and from the other people such as advisers and team members who have been working with you.

Summative evaluation

This is usually carried out once the work has been completed and there are several ways in which you can do it.

- Evaluate patient satisfaction with the information by asking them whether they have found it useful or whether it has increased their knowledge of their condition/illness and how to manage it. To do this kind of evaluation you should use one of the methods outlined in *Section 4*.
- You could invite comments from clinical staff about ways in which they have used the information, whether it has altered their practice in any way and whether they have found it to be useful. To do this also, you should use one of the methods outlined in *Section 4*.

You might consider using routinely collected statistics to evaluate the impact of your material. For instance, the number of visits people have made to out-patient clinics or the number of prescriptions for drugs treating their conditions. Dunning *et al.* (1999) give a more detailed description of the ways of doing this kind of evaluation.

The most thorough evaluation of the outcomes of any clinical intervention is the randomised controlled trial (RCT). Such trials involve the random allocation of patients to a group which receives the new intervention and a group who do not receive it, but neither patients nor doctors know which group is which during the trial. Although such evaluations are the most rigorous if they are conducted properly, they take two or three years to carry out and are expensive. Most producers of patient information will not be

able to afford to evaluate their material in this way. Without an RCT you will not be able to reliably assess whether or not patients' *behaviour* has changed as a result of the information you have developed. This does not mean that you cannot evaluate other outcomes for patients using your information.

As well as evaluating the content of the package, you might wish to evaluate the process of development. For example, how much did the project cost, how well did the team work? You may wish to invite an independent evaluator to do this because their assessment will not be coloured by the experience of the development.



Action points

- Build formative evaluation into your project design at the start.
- Be clear about what you want to achieve with your evaluation so you can collect the appropriate data.
- Think through the most appropriate design for a summative evaluation to be used at the end of the development, using one or more of the methods discussed above and in *Section 4*.



Patient involvement is an emotive topic and the possibility that measures of effect will be selected in order to prove its advantage or disadvantage cannot be ignored. Evaluations of interventions should reflect, but not be unduly constrained by, their intended purposes and the frameworks within which their likely effects are viewed ... Attempts should be made to ascertain which potential effects patients and health professionals consider most important.

Entwistle, Sowden and Watt (1998)

Conclusion

To conclude, using the terms of the Centre for Health information Quality, ensure that the development and evaluation of your patient information package is:

- well planned
- evidence-based
- clearly communicated
- involves consumers.

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Appendix I

Contact details for organisations mentioned in the guide

Age Concern England

Astral House
1268 London Road
London SW16 4ER
Tel: 020 8679 8000

Association of Community Health Councils of England & Wales (ACHCEW)

Earlsmead House
30 Drayton Park
London N5 1PB
Tel: 020 7609 8405

Association of Health Care Communicators

Wakefield Health Authority
White Rose House
West Parade
Wakefield WF1 1LT
Tel: 01924 213 094

Association of Information Officers in the Pharmaceutical Industry (AIOPI)

P O Box 297
Slough SL1 7XT
E-mail: aiopi@aiopi.org.uk

Bandolier (Evidence-based health care)

Pain Relief Unit
The Churchill
Oxford OX3 7LJ
E-mail: andrew.moore@prv.ox.ac.uk
Internet: www.jr.ox.ac.uk/Bandolier

Basic Skills Agency (formerly The Adult Literacy and Basic Skills Unit – ALBSU)
Commonwealth House
1/19 New Oxford Street
London WC1A 1NY
Tel: 020 7405 4017

Books Beyond Words Series

Department of Psychiatry of Disability
St George's Hospital Medical School
Cranmer Terrace
London SW17 0RE
Tel: 020 8725 5501

British Association of Picture Libraries and Agencies (BAPLA)

18 Vine Hill
London EC1R 5DX
Tel: 020 7713 1780
Fax: 020 7713 1211

British Computer Society

1 Sanford Street
Swindon SN1 1HJ
Tel: 01793 417417
Fax: 01793 480270
E-mail: bcsHQ@bcs.org.uk
Internet: www.bcs.org.uk/

BIMA (British Interactive Multimedia Association)

5/6 Clipstone Street
London W1P 7EB
Tel: 020 7436 8250
E-mail: enquiries@bima.co.uk

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British Medical Association (BMA)

Patient Information Award
BMA Library
BMA House
Tavistock Square
London WC1H 9JP
Tel: 020 7383 6698
E-mail: Mary.Last@bma.org.uk
Internet:
www.library.bma.org.uk/html/patinfox.html
General enquiries Tel: 020 7387 4499

BMJ Publishing Group

BMA House
Tavistock Square
London WC1H 9JP
Books Tel: 020 7383 6185
Bookshop Tel: 020 7383 6244
Journal Subscriptions Tel: 020 7383 6270

Bromley Health

Global House
10 Station Approach
Hayes
Kent BR2 7EH
Tel: 020 8315 8315

BUPA – Communications Award

c/o Lady Nourse
12 Old Square
Lincoln's Inn
London WC2A 3TX
Tel: 020 7404 0809

Cancer BACUP

3 Bath Place
Rivington Street
London EC2A 3DR
Tel: 020 7696 9003
Fax: 020 7696 9002
E-mail: annao@cancerbacup.org
Internet: www.bacup.org.uk/

Carers National Association

20–25 Glasshouse Yard
London EC1A 4JS
Tel: 020 7490 8818

**Centre for Health
information Quality (CHiQ)**

Highcroft
Romsey Road
Winchester
Hampshire SO22 5DH
Tel: 01962 863 511 x200
E-mail: chiq@chfht.org.uk
Internet: www.hfht.org/chiq

**Centre for Reviews and
Dissemination (CRD)**

University of York
York YO1 5DD
Tel: 01904 433 634
Effective Health Care Bulletins
Internet: www.york.ac.uk/inst/crd

**Clinical Negligence Scheme for Trusts
(CNST)**

Howard House
Queens Avenue
Bristol BS8 1SN
Tel: 0117 926 2091

Cochrane Collaboration

The UK Cochrane Centre
Summertown Pavilion
Middle Way
Oxford OX2 7LG
Tel: 01865 516 300

**Cochrane Consumers and
Communications Review Group**

Group Co-ordinator
GPO Box 4057
Melbourne
Victoria 3001 Australia
Tel: +61 3 9637 4211
E-mail: rio@hna.ffh.vic.gov.au

College of Health

St Margaret House
21 Old Ford
London E2 9PL
Tel: 020 8983 1225
Fax: 020 8983 1553

Commission for Racial Equality

Elliot House
10-12 Allington Street
London SW1E 5EH
Tel: 020 7828 7022

**Consumers' Advisory Group for
Clinical Trials (CAG-CT)**

Saionara
31 Regent Street
Rowhedge
Colchester CO5 7EA
Tel: 01206 728178
E-mail: hazelcagct@aol.com

**Consumer Health Information
Consortium (CHIC)**

St Thomas' Hospital
Lambeth Bridge Road
London SE1 7EH
Tel: 020 7928 9292 x 2507

**Consumer Research Institute
of Australia**

PO Box 8
Hackett
Act 2602
Australia
Tel: +61 2 6 257 3155
Fax: +61 2 6 247 5056

Contact a Family (CaF)

170 Tottenham Court Road
London W1P 0HA
Tel: 020 7383 3555
Internet: www.cafamily.org.uk

Council for Disabled Children (CDC)

c/o National Children's Bureau
8 Wakley Street
London EC1V 7QE
Tel: 020 7843 6000

**Critical Appraisal Skills
Programme (CASP)**

Institute of Health Sciences
Old Road
Headington
Oxford OX3 7LF
Tel: 01865 226 968
Fax: 01865 226 959
E-mail: rowan.williams@phru.anglox.nhs.uk
Internet: www.phru.org/casp

CTIC Medicine

(Computers in Teaching Initiative)
Institute for Learning and Research
Technology
University of Bristol
8 Woodland Road
Bristol BS8 1TN
Tel: 0117 928 7492
E-mail: cticm@bristol.ac.uk

Data Protection Registrar

Office of the Data Protection Registrar
Wycliffe House
Water Lane
Wilmslow
Cheshire SK9 5AF
Tel: 01625 545 700
Information Line: 01625 545 745
E-mail: data@wycliffe.demon.co.uk
Internet: www.dataprotection.gov.uk

Directory of Social Change

24 Stephenson Way
London SW1 2DP
Tel: 020 7209 5151

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Equal Opportunities Commission

Overseas House
Quay Street
Manchester M3 3HN
Tel: 0161 833 9244

Family Planning Association (FPA)

2-12 Pentonville Road
London N1 9FP
Tel: 020 7837 5432

Fife Healthcare NHS Trust

Health Promotion Department
Cameron House
Cameron Bridge
Leven KY8 5RG
Tel: 01592 712 812

FocusTV (FTV)

62-72 Victoria Street
St Albans
Hertfordshire AL1 3XH
Tel: 01727 810 101
Fax: 01727 840 745
E-mail: robert@focus-tv.demon.co.uk

**Foundation for Informed Medical
Decision Making**

Health Dialog
60 State Street
Suite 700
Boston, MA 02109
Tel: +1 617 854 7440
Fax: +1 617 854 7441
E-mail: weborder@healthdialog.com
Internet: [www.healthdialog.com/
Ofoundation.htm](http://www.healthdialog.com/Ofoundation.htm)

Health Action International – Europe

(HAI)
Jacob van Lennepkade 334-T
1053 NJ Amsterdam
The Netherlands
Tel: + 31 20 683 3684
Fax: + 31 20 685 5002
E-mail: HAI@HAI.ANTENNA.NL
Internet: www.haiweb.org

Health Coalition Initiative (HCI)

28 Queensbury Street
London N1 3AD
Tel: 020 7688 9208
Fax: 020 7359 4583
E-mail: tinafunnell@compuserve.com

Health Education Authority

Trevelyan House
30 Great Peter Street
London SW1P 2HW
Tel: 020 7222 5300

**Health Education Board for Scotland
(HEBS)**

Woodburn House
Canaan Lane
Edinburgh EH10 4SG
Tel: 0131 536 5500

**Health Promotion Agency for
Northern Ireland**

18 Ormeau Avenue
Belfast BT2 8HS
Tel: 028 9031 1611

Health Promotion Division

National Assembly for Wales
Ffynnon-las
Ty Glas Avenue
Llanishen
Cardiff CF4 5DZ
Tel: 029 2075 2222

Health Promotion Information Centre (HPIC)

Trevelyan House
30 Great Peter Street
London SW1P 2HW
Tel: 020 7413 1995
E-mail: hpicenquiry@hea.org.uk

Health Quality Service (HQS)

11-13 Cavendish Square
London W1M 0AN
Tel: 020 7307 2400
E-mail: hqs@kehf.org.uk

Healthwise

1st floor
Cavern Walks
8 Mathew Street
Liverpool L2 6RE
Tel: 0151 227 4150
Fax: 0151 227 4019
E-mail: admin@healthwise.org.uk

Help for Health Trust

Highcroft
Romsey Road
Winchester
Hampshire SO22 5DH
Tel: 01962 849 100
Internet: www.hfht.demon.co.uk

Help the Aged

St James's Walk
London EC1R 0BE
Tel: 020 7253 0253

Institute of Medicine, Law and Bio-ethics (IMLAB)

Room 207
Williamson Building
University of Manchester
Oxford Road
Manchester M13 9PT
Tel: 0161 275 7703

Institute of Translation and Interpreting

377 City Road
London EC1V 1NA
Tel: 020 7713 7600
Fax: 020 7713 7650
E-mail: info@ITI.org.uk
Internet: www.iti.org.uk/

Irish Patients' Association

78 Seafield Court
Killiney
Co. Dublin
Eire
Tel: + 353 1 283 2293
E-mail: tonyos@tinet.ie
Internet:
www.stjames.ie/patient/ipa/ipahome.html

King's Fund Library

11-13 Cavendish Square
London W1M 0AN
Tel: 020 7307 2400
E-mail: libenq1@kehf.org.uk

Library Association of Ireland

c/o Wexford Public Libraries
Abbey Street
Wexford
Eire
Fax: + 353 53 21097
E-mail: laisec@iol.ie

Long-Term Medical Conditions Alliance (LMCA)

Unit 212
16 Baldwins Gardens
London EC1N 7RJ
Tel: 020 7813 3637

Macmillan Cancer Relief

Information Consultancy Programme
15 Britten Street
London SW3 3TZ
Tel: 020 7351 7811

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Medical Defence Union (MDU)

3 Devonshire Place
London W1N 2EA
Tel: 020 7486 6181

MIND

(National Association for Mental Health)
Granta House
15-19 Broadway
London E15 4BQ
Tel: 020 8519 2122

**National Association of Patient
Participation (NAPP)**

PO Box 999
Nuneaton CV11 5ZD
Tel: 0151 630 5786 (answerphone)

National Asthma Campaign

(National Asthma Campaign
Scotland)
Providence House
Providence Place
London N1 0NT
Tel: 020 7226 2260
(Scotland: 0131 226 2544)
Fax: 020 7704 0740
(Scotland: 0131 226 2401)
Internet: www.asthma.org.uk/

National Cancer Alliance

PO Box 579
Oxford OX4 1LB
Tel: 01865 793 566
Fax: 01865 251 050

**National Centre for Health Outcomes
Development**

PO Box 777
London SE1 6XH
Fax: 01623 724 524

National Consumer Council

20 Grosvenor Gardens
London SW1
Tel: 020 7730 3469

NHS Executive Headquarters

Quality and Consumers Branch
Quarry House
Quarry Hill
Leeds LS2 7UE
Tel: 0113 254 5000

NHS Health Information Service

Freephone: 080 66 55 44
*For general enquiries, a limited central
co-ordination is offered by the Help for Health
Trust (see above).*

NHS Regional Libraries Group

John Rylands University of Manchester
Oxford Road
Manchester M13 9PP
Tel: 0161 275 3717

National Information Forum

Post Point 10/10
BT Burne House
Bell Street
London NW1 5BZ
Tel: 020 7402 6681

Patient Concern

4 Old Manor Yard
London SW5 9AB
Tel/Fax: 020 7373 0794

Patient information Forum (PiF)

c/o Brian Glasser
Clinical Information Centre
Royal Free Hampstead NHS Trust
Pond Street
London NW3 2QG
Tel: 020 7830 2804
E-mail: briang@rfhsm.ac.uk

Patient Information Publications (PIP)

25 Polwarth Crescent
Brunton Park
Newcastle upon Tyne NE3 2EE
Tel/Fax: 0191 217 1536
E-mail: tk-pip@easynet.co.uk
Internet: www.patient.co.uk

Patients' Association (PA)

PO Box 935
Harrow HA1 3YJ
Helpline Tel: 020 8423 8999
Admin Tel: 020 8423 9111

Patients' Forum

c/o 20/25 Glasshouse Yard
London EC1A 4JS
Tel: 020 7490 8818

Plain English Campaign (PEC)

PO Box 3
New Mills
High Peak
Derbyshire SK22 4QP
Tel: 01663 744 409
E-mail: info@plainenglish.co.uk

Promoting Action on Clinical Effectiveness (PACE)

King's Fund
11-13 Cavendish Square
London W1M 0AN
Tel: 020 7307 2400

Promoting Patient Choice (PPC)

King's Fund
11-13 Cavendish Square
London W1M 0AN
Tel: 020 7307 2400

Research Council on Complementary Medicines (RCCM)

60 Great Ormond Street
London WC1N 3JF
Tel: 020 7833 8897
Internet: www.gn.apc.org/rccm/

Royal College of Psychiatrists

17 Belgrave Square
London SW1X 8PG
Tel: 020 7235 2351
Fax: 020 7245 1231
Internet: www.rcpsych.ac.uk

Royal College of Surgeons

35 Lincoln's Inn Fields
London WC2A 3PN
Tel: 020 7405 3474

Royal National Institute for the Blind (RNIB)

224 Great Portland Street
London W1N 6AA
Tel: 020 7388 1266

Royal National Institute for Deaf People (RNID)

19-23 Featherstone Street
London EC1Y 8SL
Tel: 020 7296 8000

Royal Pharmaceutical Society of Great Britain (RPSGB)

1 Lambeth High Street
London SE1 7JN
Tel: 020 7735 9141
Fax: 020 7793 0232
E-mail: enquiries@rpsgb.org.uk
Internet: www.rpsgb.org.uk

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SCHARR Information Resources

University of Sheffield
Regent Court
30 Regent Street
Sheffield S1 4DA
Tel: 0114 222 5454

**Scottish Association
of Health Councils (SAHC)**

24 Palmerston Place
Edinburgh EH12 5AL
Tel: 0131 220 4101
E-mail: sahc@sol.co.uk

SHARE Database

King's Fund
11-13 Cavendish Square
London W1M 0AN
Tel: 020 7307 2400

**Society for Health
Education/Promotion Specialists**

Sheffield Health
Dept of Social and Community
Development
5 Old Fulwood Road
Sheffield S10 3TG
Tel: 0114 271 1307

**Society of Public
Information Networks (SPIN)**

Tel/Fax: 0118 961 2920
E-mail: spin@informativ.co.uk

**Telephone Helplines
Association (THA)**

4 Deans Court
St Paul's Churchyard
London EC4V 5AA
Tel: 020 7248 3388
Fax: 020 7248 3399
E-mail: info@helplines.org.uk
Internet: www.helplines.org.uk

Videos for Patients Ltd

18 Denbigh Close
London W11 2QH
Tel: 020 7266 2852/9051
Fax: 020 7266 1206

**Voluntary Health Organisations
(VHOs)**

See Contact a Family, Help for Health Trust,
Healthwise, Patients' Association or Patient
Information Publications.

Wellcome Trust

Unit for Policy Research in Science and
Medicine (PRISM)
210 Euston Road
London NW1 2BE
Tel: 020 7611 8888

Appendix 2

Sources of project funding

If you cannot fund your patient information development from within your organisation's resources, there are a number of places you can go to ask for financial support. The places listed below are the ones we know about which might be able to help. There are, however, very useful publications that list grant-giving agencies with details of the kinds of projects they support and when to apply for money. They include:

- *A guide to major trusts* (Fitzherbert *et al.* 1999)
- *Grants from government departments and agencies* (Forrester and Pilch 1998).

Most university and reference libraries will have copies of these and other directories of grant-making trusts, including grants from European sources.

Many areas have a Council for Voluntary Service (CVS) which will have details of local and national trusts, and will know how you can access various computer databases, such as *Funderfinder*, that can search for grant-making trusts relevant to your area of interest.

Association of Medical Research Charities

29 Farringdon Road
London EC1M 3JB
Tel: 020 7404 6454

King's Fund Grants Department

11-13 Cavendish Square
London W1M 0AN
Tel: 020 7307 2400

Gatsby Charitable Foundation

9 Red Lion Court
London EC4A 3EB
Tel: 020 7410 0330

Nuffield Foundation

28 Bedford Square
London WC1B 3EG
Tel: 020 7631 0566

Wellcome Trust

Grants Officer
The Wellcome Building
183 Euston Road
London NW1 2BE
Tel: 020 7611 8888

National Lottery Charities Board

Health and social research grants programme
St. Vincent House
16 Suffolk Street
London SW1Y 4NL
Tel: 020 7747 5300
Enquiry line: 020 7747 5299

NHS Research & Development (R&D) Programme

Internet: www.doh.gov.uk/research/index.htm
Details of current initiatives and funding application procedures.

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Appendix 3

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Appendix 4

Promoting Patient Choice: King's Fund 1991-1998

Promoting Patient Choice was a programme of research and development that aimed to promote the concepts of evidence-based medicine and shared clinical decision-making through the development of good quality patient information. The work began in 1991 when the King's Fund Development Centre formed an alliance with the US Foundation for Informed Medical Decision Making to promote a series of interactive videos for patient choice. These videos were used by patients in collaboration with their doctors. The information on the videos was based on the most up-to-date clinical evidence and treatments available. The work of the Foundation in the USA has taken forward the production of these videos (*Appendix 1*).

In England, the King's Fund initiated British trials of two of their interactive video programmes: benign prostatic hyperplasia at Ashford Hospital in Middlesex and two early breast cancer videos at the Royal Marsden Hospital in London (Maslin 1998).

Subsequently, the King's Fund worked with other agencies and clinicians to enter three other US videos into randomised controlled trials (RCTs). The three conditions in these trials were:

- benign prostatic hyperplasia (BPH)
- benign uterine conditions (BUC)
- hormone replacement therapy (HRT) in general practice in London and Oxford.

An English video, based on the same principles as the US videos, providing information about treatments for menorrhagia (heavy menstrual periods) was developed and entered into an RCT with funding from the NHS R&D research programme, in a joint project with Brunel, Bristol and Oxford Universities. The results of this trial will be available in 2000.

Alongside this work, the *Promoting Patient Choice* programme initiated the development, and evaluation, of seven patient information packages, funded jointly by the King's Fund and The Gatsby Foundation. Based on eight quality criteria, these projects covered seven conditions and were produced in a range of media. The quality criteria are shown in Box 1 and the projects in Box 2.

Box 1: Criteria for good quality patient information

- informs patients about their clinical condition and includes information about all available treatments or management options, including non-interventions
- provides comprehensive and unbiased information about outcomes (risks and benefits) based on systematic reviews of research evidence

- outlines uncertainties and gaps in scientific knowledge
- involves users and professionals in developing and evaluating the materials
- caters for people from a variety of ethnic and cultural backgrounds and for people with learning difficulties
- is regularly reviewed and updated
- is integrated into a planned programme for shared clinical decision-making
- has language and design that are simple and easily understood.

Box 2: Promoting Patient Choice development sites

- anxiety in Asian women; audiotapes, a directory of services and booklets in four Asian languages for Asian women (Redbridge and Waltham Forest Health Authority)
- bedwetting (nocturnal enuresis); multimedia package for children (Nottingham University/Nottingham City Hospital)
- colorectal cancer; multimedia package (Hull University/Castle Hill Hospital)
- post-operative pain relief; booklet (Queen's Medical Centre, Nottingham)
- ulcerative colitis; personal organiser (Manchester University/Hope Hospital)
- urge incontinence; multimedia package (Bristol Urological Institute)
- Hormone Replacement Therapy (HRT); trial in general practice in Oxford of the interactive video on HRT produced by the Foundation for Informed Medical Decision Making

A separate but related study was started in 1996 to investigate the quality of existing patient information. Funded by the NHS R&D programme, this study – *Materials for Informed Choice: Evaluation* (MICE) – selected ten conditions where systematic reviews had produced good quality clinical evidence and subjected a collection of related patient information materials to evaluation by patients with these conditions. The information materials evaluated in the study came from a range of sources including the voluntary sector, commercial organisations and information produced within the NHS. These packages were also reviewed by clinical specialists. The MICE work has been published as *Informing Patients* (Coulter *et al.* 1998).

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The conditions covered are shown in Box 3.

Box 3: Materials for Informed Choice: Evaluation – Topics

- | | |
|------------------------------|-----------------------|
| Back pain | Glue-ear |
| Benign prostatic hyperplasia | Total hip replacement |
| Cataract | Menorrhagia |
| Cholesterol | Stroke rehabilitation |
| Depression | Subfertility |

By 1996, the *Promoting Patient Choice* (PPC) programme moved into a more developmental phase. Research, evaluation and production of good quality patient information represented the first stages of development work. The subsequent stage publicised and disseminated the work to patients, commissioners and providers. To achieve true partnership working, the concepts of shared clinical decision-making and evidence-based patient information need to be embedded within organisations and practised by individuals. To achieve this, the PPC programme created a number of 'organisations' to work towards wider implementation of these concepts and materials.

Patient information Forum (PiF)

The Patient information Forum was created at the beginning of 1997 to act as a support and information network for people responsible for producing patient information in the NHS. The Forum promotes and supports the role of patient information managers/officers mainly in NHS trust settings. It produces a newsletter, a directory of people working in the patient information field and holds regular conferences. Details of activities and membership can be obtained from the address in *Appendix 1*.

Promoting excellence in consumer medicines information

The Promoting Excellence in Consumer Medicines Information (*pecmi*) initiative was set up to look at ways of improving the safety, quality, usability, accessibility and consistency of consumer medicines information. *pecmi* aims 'to incorporate the health consumer's view in everything we do', and to look at medicines issues 'through the patient's end of the telescope'.

Specifically, its objectives are to:

- identify gaps in provision of medicines information useful to consumers
- collect examples of best practice in patient information in the UK and world wide
- disseminate and suggest ways of filling the gaps.

Further information can be obtained from:

David Dickinson
 Tel: 020 8673 4403
 E-mail: david.dickinson@consumation.com

Throughout the seven years of the *Promoting Patient Choice* programme, the focus was on the dissemination of the lessons learned about the value of patient information, shared clinical decision-making and patient partnerships. These activities culminated in an international conference and a series of publications, of which *The POPPi Guide* is the final one. Published titles in the *Promoting Patient Choice* series (available from the King's Fund bookshop) are:

Buckland S, Gann B. *Disseminating treatment outcomes information to consumers*. London: King's Fund, 1997.

Duman M, Farrell C. *The POPPi Guide: Practicalities of producing patient information*. London: King's Fund, 2000.

Edwards D. *Face to Face: head and neck cancer services*. London: King's Fund, 1997.

Entwistle VA, Watt IS, Herring JE. *Information about Health Care Effectiveness*. London: King's Fund, 1997.

Farrell C, Gilbert H. *Health Care Partnerships*. London: King's Fund, 1996.

Hope T. *Evidence-based Patient Choice*. London: King's Fund, 1996.

Walker G, Bradburn J, Maher J. *Breaking bad news*. London: King's Fund, 1996.

Wallace S. *The Future's Bright; the Future's Digital*. London: King's Fund, 1996.

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Appendix 5

Electronic patient information systems

This list is not comprehensive nor is there any suggestion that the authors or contributors to POPPi endorse these products.

Touch screen kiosks

Care Partnership and Systems

Cliff Price Associates
Frodsham Business Centre
Bridge Lane
Frodsham
Cheshire WA6 7HL
Tel: 01928 734 176
Fax: 01928 734 177
E-mail: cliffp@cpa.u-net.com
Touch screen computer systems which can be personalised for the individual customer for use in health centres, hospital wards, doctors waiting rooms, etc.

Health Check Points

Health Checkpoint Ltd
PO Box 406
Milton Keynes MK4 1AH
Tel: 0973 187 136
Fax: 01527 576 065
E-mail: 100104.3630@compuserve.com
Interactive health risk appraisal and education covering lifestyle, clinical, stress and family factors. It is offered in Windows NT, Touch screen and interactive.

Healthy Living Centre

Egli Research
Egli House
2 Meadfoot Road
Torquay
Devon TQ1 2BZ
Tel: 01803 201065
Fax: 01803 201002
E-mail: egli@egli.co.uk
Healthy Living Centres can be found in supermarkets, shopping malls and job centres. The overall health check booths have been designed for members of the public, who can give themselves a health check up which ranges from asking the computer health-orientated queries to taking a routine blood pressure check.

Healthpoint

Healthpoint Ltd
College of Health
St Margaret's House
21 Old Ford Road
London E2 9PL
Tel: 020 8983 1225
Fax: 020 8983 1553
E-mail: r.b.jones@udcf.gla.ac.uk
A public access kiosk giving general information. Can easily be configured by the kiosk owner to include local information. In existence as a research project since 1989, it has been extensively evaluated and is available commercially from the College of Health

Health Promotion Information Kiosks

Health Promotion Division
The National Assembly for Wales
Ffynnon-Laf, Ty Glas Avenue
Cardiff, CF14 5DZ
Tel: 029 2075 2222
Fax: 029 2075 6000
E-mail: phil.hutchinson@wales.gsi.gov.uk
A touch screen system providing health promotion information.

Intouch With Health

Intouch With Health Ltd
Overley Court
Daglingworth
Cirencester
Gloucestershire GL7 7HX
Tel: 01285 657 516
Fax: 01285 650 480
E-mail: pblackburn@intouchwithhealth.co.uk
Providers of touch screen health information kiosks to hospitals, surgeries and pharmacies in the UK.

Medi Books

Julia Schofield Consultants
Century House
351 Richmond Road
East Twickenham
Middlesex TW1 2ER
Tel: 020 8891 4455
Fax: 020 8891 4555
E-mail: jsc@jsc.co.uk
A range of patient information, CD-ROMs and books that are designed to answer the questions which patients and their families forgot, or don't have the time, to ask the consultant.

PARIS

Patient And Relative Information Service (PARIS)
53 Waldren Close
Poole
Dorset BH15 1XR
Tel: 01202 666 366
E-mail: PARIS.Limited@virgin.net
Available free over the NHS-net to doctors to help them inform their patients. Has been peer-reviewed by 150 consultants to ensure clinical accuracy, checked for clarity and currency.

Pharmacy Information Points

Active Response
20-30 Wilds Rents
London SE1 4QG
Tel: 020 7378 7731
Fax: 020 7403 8488
E-mail: visual@response.demon.co.uk
Computer focused health care information for use in the pharmacy.

StartHere

c/o BSS
Union House
Shepherds Bush Green
London W12 8UA
Tel: 020 8735 5050
Fax: 020 8746 0796
E-mail: starthere@prudential.co.uk
Aims to bridge the divide between health and social care by connecting people in need to relevant services and information.

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Tesemed (European Union Project)

c/o Dr Ken Henderson

August Field

Charvil Lane

Sonning

Berkshire RG4 6TH

Tel: 0118 969 3027

Fax: 0118 969 3027

E-mail: 100432.1013@compuserve.com

Although very much in its pilot stage the scheme is trying to make health information (especially on Self-Medication) available to the public at large.

CD-ROM/computer packages

All about Nocturnal Enuresis

ERIC Enuresis Resource and Information Centre

34 Old Schoolhouse

Britannia Road

Kingswood

Bristol BS15 2DB

Tel: 0117 960 3060

Fax: 0117 960 0401

E-mail: enuresis@compuserve.com

Internet: www.ccc.nottingham.ac.uk/~mcz

Internet: www/enuresis.htm (demonstration)

Multimedia package to improve the information that children receive about their bedwetting.

Cancer BACUP

M&C Dept.

3 Bath Place

Rivington Street

London EC2A 3JR

Tel: 020 7696 9003

Fax: 020 7696 9044

Internet: www.cancerbacup.org.uk

Cancer treatment guidelines from the UK and a searchable database of support groups, cancer organisations and hospices.

Colorectal cancer – A guide for patients

Castle Hill Hospital

The Academic Surgical Unit

Castle Hill Hospital

Castle Road

Cottingham

Nr. Hull HU16 5JQ

Tel: 01482 875 875 x 3882

Fax: 01482 62 3274

Information package for patients, professionals and carers covering all aspects of bowel cancer care.

Yourhealth (Demonstration CD)

HealthWise
Freepost LV 6535
Liverpool L2 3BR
Tel: 0151 227 4150
E-mail: admin@healthwise.org.uk
Internet: www.healthwise.org.uk
Information on health, exercise and social welfare. Covers conditions and treatments explaining where to get help locally and nationally.

Med IT

Med IT Ltd
Bristol Urological Institute
Southmead Hospital
Bristol BS10 5NB
Tel: 0117 959 5522
Fax: 0117 950 2229
E-mail: medit@bui.ac.uk
Education information systems to benefit the healthcare organisations that deliver it, e.g. electronic demonstrations of pharmaceutical products.

Oxford PILS

(Patient Information Leaflets and Self-Help Groups) on CD-ROM
Healthworks
30-38 Doc Street
Leeds
LS10 1JF
Tel: 0113 234 6624
Fax: 0113 442 7782
E-mail: sales@d-access.demon.co.uk
This consists of over 200 patient leaflets with details of more than 500 self-help groups.

PatientWise

John Wiley & Sons Ltd
1 Oldlands Way
Bognor Regis
West Sussex PO22 9SA
Tel: 01243 843295
Fax: 01243 843228
E-mail: cs-books@wiley.co.uk
An information guide with explanations of over 400 different conditions, ranging from Tumour Therapy to Obesity. Each sheet has a further tier of communication and care. Available in two formats, either two quick reference loose-leaf volumes with information sheets or an interactive software version for PC on Windows format.

Quay Interactive Learning To Manage Your Health

Interactive Euro Health Ltd
1 Hay Hall Cottage
Boyton
Woodbridge
Suffolk IP12 3LG
Tel: 01394 411 406
Fax: 01394 411 406
E-mail: 100775.3034@compuserve.com
Internet: www.interactiveeurohealth.com
Four programmes on offer to GP's, health centres and health professionals consisting of: Learning Diabetes (for insulin dependants), Learning Asthma, Learning Healthy Hearts and Learning Diabetes (for non-insulin dependants). The purpose of the programmes are to enable people with these conditions to understand them better and to therefore improve the management of their health.

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**Urinary disorders and male health:
A decision making guide for patients.**

Merck Sharp & Dohme
Heartford Road
Hoddesdon
Hertfordshire EN11 9BU
Tel: 01992 467272

Designed for men concerned about, or diagnosed with, a urinary problem. It has interactive question and answer screens to help the patient consider what treatments might be best for him.

Satis-Fax

Scalpel Information Systems
St. Cuthberts Consulting Rooms
20, St.Cuthberts Way
Darlington DL1 1GB
Tel: 01325 364 624
Fax: 01325 364 624
E-mail: michaelhedwards@compuserv.com
Internet: www.Scalpelfax.com

Customisable information for surgical patients, covering two-thirds of all operations.

Showme Multimedia Ltd

Suite 5N
North Mill
Bridgefoot
Belper
Derbyshire DE56 1YD
Tel: 01773 825050
E-mail: ian@showme.demon.co.uk
Internet: www.showme.demon.co.uk

All About Diabetes. Interactive, accessible information with animation for children from 7 to 14.

Asthma (as yet untitled) An 'adventure game' for children from 7 to 14. Created in conjunction with Nottingham City Hospital NHS Trust.

Feedback form: What did you think of The POPPi Guide?

Please photocopy and return to: The POPPi Guide – Feedback, Centre for Health information Quality (CHiQ), Highcroft, Romsey Road, Winchester, Hampshire SO22 5DH. Fax: 01 962 849 079.

- 1 Did the guide provide too much / too little / or just enough information?
- 2 Which topics were most useful?
- 3 Which topics were least useful?
- 4 What would you wish to see added to / removed from the guide?
- 5 Did you think the guide was clearly written and presented?
- 6 Do you think you will use the guide again? If so, how often?
- 7 Do you produce your own patient information packages? Yes No
If so, have you registered it with the Centre for Health information Quality (CHiQ)?
- 8 Any other points?

Name

Contact details

Date

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The POPPi Guide: Practicalities of producing patient information is a timely guide for all who are aiming for excellence in the production of health information materials. Based on the evaluation of, and lessons learned from, the King's Fund *Promoting Patient Choice* programme, the guide is a hands-on resource that provides information for producing good quality patient-based information, as well as sources of specialist information for people who need more technical help. Its clear layout, illustrative case studies and action points provide a step-by-step guide to the processes involved in the production of information packages.

The provision of high-quality, nationally standardised health information for patients is currently high on the NHS agenda: National Service Frameworks are setting standards for the quality of the information given as part of patient care; every trust must develop an information strategy and policy, to agreed standards; the Patient's Charter lists certain rights to information for patients, and the standards expected from those who provide this information. The clear presentation of good quality, evidence-based information for patients is a vital component of every health organisation's future strategy.

The POPPi Guide meets these needs. It is an essential resource for people working to make their organisations' information more accessible. It is intended for those working in the NHS, and will also be of use to voluntary organisations and patient and carer groups.

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