THE HEALING FOUNDATION

Rebuilding the bodies, minds and lives of people with disfigurements

picker INSTITUTE

making patients' views count

Information for People Living with Conditions that Affect their Appearance

REPORT II

REVIEW AND ASSESSMENT OF EXISTING INFORMATION

HELEN MAGEE, PAUL HERON, JULIA CARTWRIGHT, JANET ASKHAM

Picker Institute Europe

JUNE 2007

Picker Institute Europe

The Picker Institute works with patients, professionals and policy makers to promote understanding of the patient's perspective at all levels of healthcare policy and practice. We undertake a unique combination of research, development and policy activities which together work to make patients' views count. There are three key strands to our work:

- Measurement - researching and evaluating patients' experience
- Improvement - leading initiatives that make improvements happen
- Policy - building evidence to inform health policy.

ISBN 1 905945 13 2
978 1 905945 13 9

© Picker Institute Europe 2007

Items may be reproduced free of charge in any format or medium provided that they are not for commercial resale. This consent is subject to the material being reproduced accurately and provided it is not used in a derogatory manner or misleading context.

Published by and available from:

Picker Institute Europe
King's Mead House
Oxpens Road
Oxford OX1 1RX
Tel: 01865 208100
Fax: 01865 208101
Email: info@pickereurope.ac.uk
Website: www.pickereurope.org

Registered charity no 1081688
Company limited by registered guarantee no 3908160

ACKNOWLEDGEMENTS

The Healing Foundation Patient Information Project was designed and managed by the Healing Foundation and generously supported by the GUS Charitable Trust.

The researchers would also like to express their gratitude to the healthcare staff, voluntary sector representatives and patients who gave up precious time to take part in and support the project. Without their commitment the project would not have been possible. We would particularly like to thank the staff and patients in the six collaborating centres.

During the course of the project, we received valuable insight and feedback from our Advisory Group members: Bette Baldwin, Eileen Bradbury, Brendan Eley, Ann Fowler, Tim Goodacre, Olivia Giles, John Hart, Anita Jadav, Catriona King, Shirley Large, Mark Lloyd, Jo Myers, James Partridge, Christine Piff and Diana Whybrew.

CONTENTS

1 Executive Summary

1.1 Introduction

This study comprises one part of a three-part programme of research on the information needs of people living with conditions that affect their appearance. Whilst the other two parts of the programme start from the perspective of the patients and users, the project reported in this paper takes as its starting point the information available and those who provide it, and then brings in the users to give their views about it.

Although the information needs of people with disfiguring conditions are similar in many ways to the needs of people with other types of condition, there are some features of conditions which affect appearance which make information a particularly important topic. These include the widely disparate nature of such conditions, the often very specific and special needs of patients, the long-term nature of many of the conditions and the fact that needs will change over time, and the often emotional as well as physical impact of the experiences, treatment and care which patients undergo.

The objectives of the project were to find out how much information is available, what sort of information it is, how it was produced, and what patients and professionals think of it.

1.2 Methods of investigation

The study was conducted by means of three approaches:

- A review and inventory of existing information. This was carried out by contacting a sample of clinical nurse specialists, voluntary organisations and professional association representatives in seven clinical areas, requesting them to complete a short questionnaire and also to send us copies of materials regularly provided to patients in their field. One hundred and forty nine people were contacted directly and 48 responses were received. From these we were able to compile a very long inventory of information materials.
- A study of information providers. We contacted and interviewed by telephone a small sample of eleven information providers, comprising condition-specific charities (3); large major disease charity (1); generic charities (2); professional association (1); NHS Trusts (3); commercial company (1). The purpose of the interview was to collect details about the provider, such as yearly expenditure on information, the number of people annually accessing their materials; and whether they have guidelines for producing health information; and to discuss the process of information development and dissemination in their organisation.
- An assessment of information by users. All the patients, users and health professionals who took part in our qualitative focus groups or individual interviews (see Report I) were also asked to participate in an assessment of samples of information material, selected to represent the range of materials available for

Copyright 2007 Picker Institute Europe. All rights reserved.

different conditions. For each item they completed an evaluation form. They also gave open-ended comments about the materials.

1.3 Findings

How much information is there?

There is an impressively large volume of information. Even with a relatively small sample of health care professionals and other providers we quickly amassed hundreds of items. The inventory is provided in full (Appendix 7.1) in the hope that it may be useful to readers as an aid to further initiatives.

What kind of material is available?

Most of the information we identified was print-based, although other kinds of media were also represented.

Much of the information is condition-specific and produced mainly by well-established organisations or specialist centres, including local health care providers and charities.

How is the material produced?

Organisations producing information material differ greatly in the resources they are able to expend on such production. This inevitably affects such aspects as the thoroughness with which they can prepare material, the kind of expert advice they can command, the extent to which they can involve users in its development, and the presentation of their material.

What do users think of it?

Both patients and professionals were largely positive about the information materials they were asked to rate, though the latter were somewhat more guarded in their approval than the former.

All placed strong emphasis on clarity of aims, language and presentation and the use of plain English. They also all stressed the importance of accuracy and reliability.

Patients particularly favoured material which was balanced, not over-loaded with references or technical jargon, and with a tone which avoided patronising or stigmatising their readers.

2 Introduction

2.1 Research aims

In September 2003, the Picker Institute began a three year research programme to investigate the information needs of patients with conditions that affect appearance, that is, they cause disfigurement and/or visible loss of function. The aims of the study were to:

- assess the need for information
- provide an overview of what is currently provided
- highlight gaps and weaknesses
- make recommendations for the improvement of the information available.

The investigation was in three parts:

1. An in-depth qualitative study of patients' information needs, preferences and experiences (Report I)
2. A review and assessment of existing information materials (Report II)
3. A questionnaire survey providing a wider assessment of the information needs of people with disfiguring conditions (Report III).

The three parts of the research are reported separately, together with a short Overview Report of the whole project (Report IV), drawing out key conclusions and presenting recommendations.

Much of this programme of work quite properly started from the perspective of the patients and users, asking what they thought, what they wanted, what their information-seeking experience had been like. The findings presented in this report are somewhat different, starting from the information available and those who provide it, and then bringing in the users to give their views about it. We wanted first of all to ascertain the volume and variety of material available and then ask patients and clinicians to give us their views about the material. The research questions we posed were:

- How much information is there for people with disfiguring conditions?
- What sort of information is there?
- How was it produced, and were there any difficulties or limitations in the way it was produced?
- What do patients and professionals think of it?

Copyright 2007 Picker Institute Europe. All rights reserved.

2.2 The importance of information to people with disfiguring conditions

Health care systems today place increasing emphasis on better informed patients, able to play a fuller part in decisions about their treatment and to assume greater control over their health care. People with conditions affecting their appearance are no different from other patients in this respect, and it is therefore important to determine their needs for information. There are also some key features of disfiguring conditions which make the study of the information needs of these groups of people particularly important. The heterogeneity of the conditions is one obvious factor; for example, one million people a year in the United Kingdom seek treatment for facial injuries caused by accidents, falls or assaults. Mouth cancer is the sixth most common cancer, with nearly 2,000 new cases per year. About 2,000 babies are born each year with severe defects such as cleft lip & palate or conditions associated with craniosynostosis. Burns cause a wide variety of skin disfigurements and loss of limbs, as do various kinds of disease. Other reasons why it is important to study the information requirements of such patients is that their needs may be very specialised rather than common to high proportions of the population, may be long-term rather than involve a single short episode, and may change over the course of time. Many of these conditions cause not only physical but also emotional or psychological distress and the need for information is thus multi-faceted and requires very careful presentation and communication.

Whilst information needs themselves are complex, the availability of information is also increasingly complex. Not only are there the massively proliferating resources of the internet, which can be daunting to users and producers alike, but there are also the challenges of the costs of producing good quality information, the increasingly sophisticated modes of information production and presentation, and the variety of producers with their differing interests and goals.

2.3 Methods of investigation

The three parts of this review and evaluation were carried out as follows:

i) Review of existing information

In order to gauge the extent of the information materials available, we contacted clinical nurse specialists, voluntary organizations and professional associations with a request to supply samples of patient information in the following clinical areas:

- Burns
- Dermatology
- Head & neck cancer
- Cleft lip & palate
- Craniofacial conditions
- Eye loss
- Amputation

Copyright 2007 Picker Institute Europe. All rights reserved.

They were asked to provide materials which were either produced by, or regularly given out by, their own organization. Thus, although commercial sources were not directly approached (a definitive list proved difficult to compile and many were US based), commercially produced materials were obtained as they were regularly given to patients by hospital trust staff. It should be borne in mind that the review and compilation of material was carried out in 2004 - 2005; it will thus not reflect the most recent position.

ii) Telephone interviews with information providers

Criteria for the assessment of information fall into two categories: those aimed at assessing specific information materials, and those that relate to the process of information production and dissemination. For this reason, as well as asking users to assess specific material (see below), we conducted a series of telephone interviews with a range of providers in relevant clinical fields and asked them to tell us about their production process. A topic guide was developed based upon the International Patient Decision Aids Standards (IPDAS) guidelines, the most up-to-date and evidence-based of the checklists listed in Appendix 7.3. These guidelines include:

- Accessibility
- Arrangements for updating
- Clarity of aims and target audience
- Consideration of minority group needs
- Dissemination plan
- Methodology for applying and assessing evidence
- Peer review and/or evaluation by patients
- User involvement in development

The purpose of the interview was to collect background information on the provider: for example, their yearly expenditure on health information development; the number of people annually accessing their materials; and whether they have guidelines for producing health information; and to discuss the process of information development and dissemination in their organisation.

iii) Assessment of information by users

From the materials collected we selected examples from each of the conditions above. These examples were then assessed by focus group participants and interviewees who took part in the qualitative study, at the end of each discussion and interview. Selection for evaluation was purposive rather than comprehensive, in that we aimed to achieve a balanced list of types of information provider including voluntary sector, health authorities and trusts, commercial sources and professional organizations. For practical reasons of time and access to equipment, mainly printed materials were chosen, although 5 videos, one website and one poster series were included.

Research participants were asked to complete a specially designed evaluation tool for each item. This was based on a number of checklists that have been developed in recent years to improve the quality of health information (see Appendix 7.3). There is a reasonable degree of agreement amongst these checklists and we used the widely accepted criteria of accuracy and reliability, comprehensibility and readability, clarity of aims, attractiveness of presentation and relevance to target group. We also asked people for their general comments about materials they particularly liked or disliked. For a copy of the questionnaire see Appendix 7.5.

Copyright 2007 Picker Institute Europe. All rights reserved.

3 Information Materials Collected

Table 1 gives details of the response to our request to clinical nurse specialists, voluntary organizations and professional associations for information materials. The overall response rate of 28% was low (though it varied between the different groups), but this was not unexpected as respondents were asked to fill in a questionnaire, as well as pull together examples of in-house materials and send them to us. This obviously required time. In a few cases materials were in the process of development or review so respondents were unable to send us anything. We added to materials acquired in this way with information collected on various visits to patient organisations and specialist units. The complete list of all materials obtained is set out in Appendix 7.1. It details the title of the information material, the name of the publisher, a brief summary of the content of the material, and the format in which the material is presented.

In addition to sending copies of their own information materials, we asked people to list any materials they regularly offered to patients from external sources, for example, particular voluntary or commercial organisations (see Appendix 7.2). The vast majority of NHS respondents say they supplement their own information materials with information from other sources, and it is clear from the lists that very many were produced by the voluntary sector. There was considerable overlap between the respondents – for example, many keep stocks of *Changing Faces* materials. It would be reasonable to assume, therefore, that non-respondents would be using similar materials. We also requested details on the format of the information produced.

Table 1: Response to request for patient information

Specialist group	**Number of requests sent**	**Number of requests returned**
Plastic surgery nurses newsletter	Not applicable[a]	7
Dermatology nurse specialists	35	4
Head & neck cancer nurse specialists	20	9
Cleft nurse specialists	18	2
Craniofacial nurse specialists	4	2
Oral & maxillofacial nurse specialists	9	2
Burns nurse specialists	23	10
Professional associations	17	3
Voluntary organisations	23	9
Total	**149**	**48**

[a] *The request to participate was made in a Newsletter rather than in a direct invitation to named individuals*

The lists show that the voluntary sector produces a high proportion of the information, though of the 48 respondents to our request for information, the vast majority said that, whilst using material from other sources, they also produced their own (only six said they did not). Material still tends to be print-based; there were relatively few organisations providing anything in other formats. The material ranged from short books or 70-page booklets to single sheet leaflets and guides.

The main finding to note of course is the huge amount of material available, particularly for some conditions, such as burns and skin conditions (see Table 2 for a summary).

Table 2: Summary of materials obtained by condition[a]

	Number of materials supplied	**Number of materials listed but not supplied**
Generic information on disfigurement	46	-
Dermatology	80	39
Skin cancer	16	4
Burns	93	-
Head & neck cancer	53	30
Cleft lip & palate	33	15
Craniofacial conditions/birthmarks	48	1
Skin camouflage	7	-
Eyes	11	-
Amputees and prostheses	30	-

[a] *See Appendices 7.1 and 7.2 for full details*

As this exercise was carried out in the early stages of our study, some material will undoubtedly have been updated and replaced. There is also no suggestion that this is a complete list of what was available at that time. However, bringing this information together not only provides an indication of the volume and variety of material available to people with disfiguring conditions, but also offers a starting point for those considering the development of new information initiatives. The detailed listings in Appendices 7.1 and 7.2 are offered in the hope that they will be an aid to such further initiatives.

Copyright 2007 Picker Institute Europe. All rights reserved.

4 Information Providers

If the information available to people with disfiguring conditions is to satisfy the increasingly sophisticated demands of those who use it, it is important that information providers meet certain quality criteria in the way they develop and produce that information. We conducted a series of telephone interviews with eleven information providers, comprising: condition-specific charities (3); large major disease charity (1); generic charity (2); professional association (1); NHS Trust (3); commercial company (1).

In the case of NHS Trusts, processes can vary from department to department, ward to ward or even clinician to clinician. Given this complexity, we opted to speak to someone who would be able to give an overview of the Trusts' practice; in most cases, this was a representative from the patient advice and liaison service, a patient and public involvement manager or patient information specialist.

Five of these organisations only provided information on one or more disfiguring conditions. The remaining six provided information on disfiguring conditions as part of more general information provision for patients. Although not all respondents were able to provide details on budgets for information production and dissemination, the estimates we received ranged from £1,000 p.a. to an annual turnover of £4.6 million for one large major disease charity. Whilst high quality development processes are not exclusive to organisations spending millions of pounds, some aspects of good practice are expensive. The £500 fee for the Plain English Crystal Mark is simply out of the question for most charities and websites cost a lot of money to set up and maintain.

To gain an indication of how widely their information was being used, we asked respondents if they recorded details of enquiries and website visits. Reports on website activity included 5,000 visits per month (small condition-specific charity); 250,000 visits per month (large major disease charity); one million per month (NHS Trust); one million per year (NHS Trust). Others reported 600 enquiries per month (condition-specific charity); 20-30 enquiries per month (small condition-specific charity); 70,000 calls to helpline and 2,000 emails per month (large major disease charity); 11,700 enquiries per month (condition-specific charity).

Information Development

Information providers were then asked questions about various aspects of their information production in order to assess how well they met the international Patient Decision Aids Standards (IPDAS) guidelines (Appendix 7.3).

Best practice in information production suggests that users should be involved in the development process from the start. Such involvement is essential to ensure the information meets the needs of those who will be using it including patients, carers and health professionals who give out the materials. There was however significant variation amongst the providers interviewed in the extent to which they fulfilled this criteria.

The large major disease charity has developed a very sophisticated information production process. Stakeholder working groups are established for all new information.

Copyright 2007 Picker Institute Europe. All rights reserved.

These groups include representatives from other organisations, legal and medical specialists, patients and users. One of the NHS trusts is setting up a user involvement panel and another leading disfigurement charity is moving towards involving users at the draft stage via different advisory groups formed for each type of information.

Most organisations involve professionals in writing and reviewing the materials, but only seven of the eleven providers have any system for allowing patients or carers to review information and this ranged from an established consultation panel of volunteer reviewers (NHS trust) to assessment of draft leaflets by appropriate support groups (professional association).

Clarity of aims and target audience

We asked respondents how they choose the topics for new information materials. It was interesting to see the extent to which this was user-driven. Most providers talked about enquiries and requests from patients, carers and professionals that highlight gaps in provision. The largest charity has a system for tracking the services users are accessing. In a few cases, organisations have specific programmes within which decisions on new information are made. One small charity and the professional association usually choose the topics themselves. This is not ideal as research shows that there can be significant disparities between experts' views of what information patients need and patients' own views. For the commercial company, information topics are always product-orientated.

Clinical evidence

A range of techniques are used by the information providers interviewed to ensure their materials are evidence based and accurate. In most instances, clinicians are commissioned to write the information and where this is not the case, organisations have expert advisory groups to oversee the content. The largest charity surveyed has huge resources including access to trial databases. One NHS trust specifies that notes and sources are provided and clinical guidelines followed and another carries out extensive literature searches. Information produced by the commercial company is based on case studies and clinical trials conducted on their products by clinicians. The difficulty of finding reliable clinical evidence for conditions that are rare or poorly researched was highlighted by one charity and one NHS trust. The potential risk in relying on medical experts to write patient information is that no one individual is likely to be aware of all the literature, particularly in areas that may be of interest to patients such as psycho-social support or alternative therapies. Additionally, clinicians do sometimes vary in their approach to a particular treatment. One NHS trust was not afraid to point this out in the information it provided to patients and carers, but this may not always happen, especially where charities may feel unqualified to comment. One leading charity adopts a psycho-social rather than a medical approach and therefore does not offer advice on treatment. Another differentiated between medical and quality of life issues. In these cases, research evidence comes from psychological research or "common sense".

Providers were asked how frequently they reviewed and updated their materials. Again, responses varied. Apart from two smaller charities, all organisations have some kind of mechanism by which they review their information, but this ranges from annually to up to every 4 years. Different strategies are used to make sure that new developments are covered. One small charity relies upon their members informing them of new procedures,

Copyright 2007 Picker Institute Europe. All rights reserved.

another attends as many conferences and seminars as possible, whilst the large major disease charity carries out daily press reviews and holds weekly journal clubs.

Accessibility

To reach all the potential users of their information, providers need to consider readability issues, offer information in a variety of formats for those with reading difficulties or sensory impairments, and in languages other than English. These demands place a considerable burden upon organisations, particularly small charities. As a consequence, hardly any of the organisations we spoke to were able to fulfil these criteria completely.

Only the largest charity has its information measured against standard readability scores, although the respondent interviewed said they do not get good scores because of all the medical terms used. Only one NHS trust and the commercial company have the Plain English crystal mark because it was considered too expensive by all the other respondents. However, one charity and one NHS trust mentioned following the Plain English guidelines. Organisations generally rely on more informal feedback on the readability of their materials from reviewers and users. One NHS trust mentioned the necessity of extensive editing to make materials that are written by clinicians patient friendly.

Three charities produce large print versions of their material in accordance with the Royal National Institute for the Blind (RNIB) guidelines on information for the visually impaired; other providers tend to do this on request only, if at all. A similar situation rules with alternative formats and non English versions. All the organisations have websites, but only a few have the funding to produce CDs and audio-tapes as a matter of course. One NHS trust produces its core information leaflets in tape format and another in Braille.

The translation of materials into other languages is a real problem for most information providers. Although one large charity mentioned wanting to do more, in practice it is expensive and labour intensive. NHS trusts tend to have translation and interpreting services they can call on. Two of the trusts in our survey offer some materials in languages that reflect the community they serve; anything in addition to that is only on request. Two of the charities translate some of their materials; two other charities and the professional association only produce materials in English; another uses Language Line. The respondent from one charity mentioned the difficulty of translating their approach to disfigurement into other languages. However, because the commercial provider is an international company, their literature is produced in a variety of languages.

Even fewer information providers field test their materials with people from traditionally hard to reach groups, for example, ethnic minority communities and people with learning disabilities. The consultation panel of volunteer reviewers at one NHS trust contains people with different needs and abilities. The major disease charity has tested with ethnic minority groups and worked with the Royal College of Psychiatrists when producing information for people with learning disabilities. But none of the other providers we spoke to carry out this kind of accessibility testing.

Copyright 2007 Picker Institute Europe. All rights reserved.

Dissemination

There is obviously little point in producing high quality patient information if it never reaches its target audience. A successful dissemination plan involves publicising information and facilitating access to that information. Crucially, it also involves encouraging health professionals to include information-giving as part of the care pathway. Although this latter aspect is more difficult to achieve, the producers we spoke to use a range of methods to disseminate their materials:

- pack of materials mailed annually to specialist clinical departments with a re-order form; posters sent to GP surgeries (condition-specific charity)
- copies sent to designated specialist units; newsletter containing a publications list sent to members and hospital units 3 times p.a. (condition-specific charity)
- new information publicised when it becomes available and onus is on the clinicians to distribute it (NHS trust)
- currently working with NHS logistics on distribution to PCT and hospital clinics; regular mail-shots to hospital managers (major disease charity)
- copies of all leaflets deposited in hospital information centre (NHS trust)
- staff kept informed of new leaflets available via email and posters. Information also available in library (NHS trust)
- resources listed on website; newsletter gives regular updates on new information; guides given out free to clients, health professionals pay; information publicised at workshops, study days and conferences (generic charity)
- mail-out from head office via local branches; talks, meetings; press releases, website, resource packs sent to hospital units (condition-specific charity)
- members receive newsletter and handbook; new leaflets are publicised and members can order stocks (professional association)
- leaflets distributed via the sales force (commercial company).

Accreditation

The Department of Health has announced the intention to establish an Information Accreditation Scheme in 2007. Producers of health information will be able to apply for a kite-mark if their information meets the required standards. We asked the respondents to our telephone survey for their views on such a scheme.

There was only qualified support for the system from most of the people we contacted. Only two NHS trusts and the commercial company said they would definitely apply. Cost was a very big concern with all the charities expressing reluctance if they had to pay to have their information materials accredited. For some of the smaller organisations such a scheme would be out of their reach and there was a feeling that it would be difficult to justify spending donations on this. One large charity and one NHS trust also raised the question of who would be responsible for awarding the kite-mark. When they were well-respected brands in their own right, it would not make sense to be accredited by any lesser agency. On the other hand an NHS scheme might jeopardise their independence.

One charity felt that it was more important that patients were educated to judge for themselves and pointed out that people will continue to access a whole range of materials from overseas (particularly the USA) that would fall outside the scheme. Another small

Copyright 2007 Picker Institute Europe. All rights reserved.

charity that only deals with rare syndromes was not convinced that those responsible for accreditation would know enough about these conditions.

Copyright 2007 Picker Institute Europe. All rights reserved.

5 Evaluation of Sample Materials by Research Participants

At the end of each focus group and interview participants were asked to evaluate a set of materials using a structured evaluation tool. A list of all the materials evaluated is set out in Appendix 7.4.

In total, 48 materials were evaluated and 37 patients/parents and 31 health professionals were asked to take part in the exercise (see Table 3).

Table 3: Number of materials evaluated and participants taking part, by condition

Condition	**Materials**	**Patients/ parents**	**Health professional**
Amputee	5	7	-
Burns	8	6	10
Cleft lip & palate	5	4	-
Craniofacial	9	4	6
Eye cancer	4	2	-
General plastics	6	2	8
Head & neck cancer	5	7	3
Vitiligo	6	5	4
Total	**48**	**37**	**31**

The questionnaire used for the evaluation gave participants an opportunity to rate the materials across three key areas:

- **Content** (4 questions) – Does the material make clear what it is about and whom it is for?
- **Presentation** (5 questions) – Is the material well designed, structured, easy to understand and have appropriate content?
- **Trust & Reliability** (8 questions) – Does the material make clear when and who produced the information and has it been produced in a balanced manner with evidence for any claims made?

Each question within these three areas was rated on a 10 point scale. The scores for each area were averaged and an overall total mean score was calculated. Figure 1 presents the overall total score for patients and health professionals across each of the eight conditions[1]. For patients, the most favourably rated materials were those from eye cancer, burns and general plastics. The total mean evaluation for each of these conditions was respectable and above eight out of ten. Amputee patients and those from head & neck

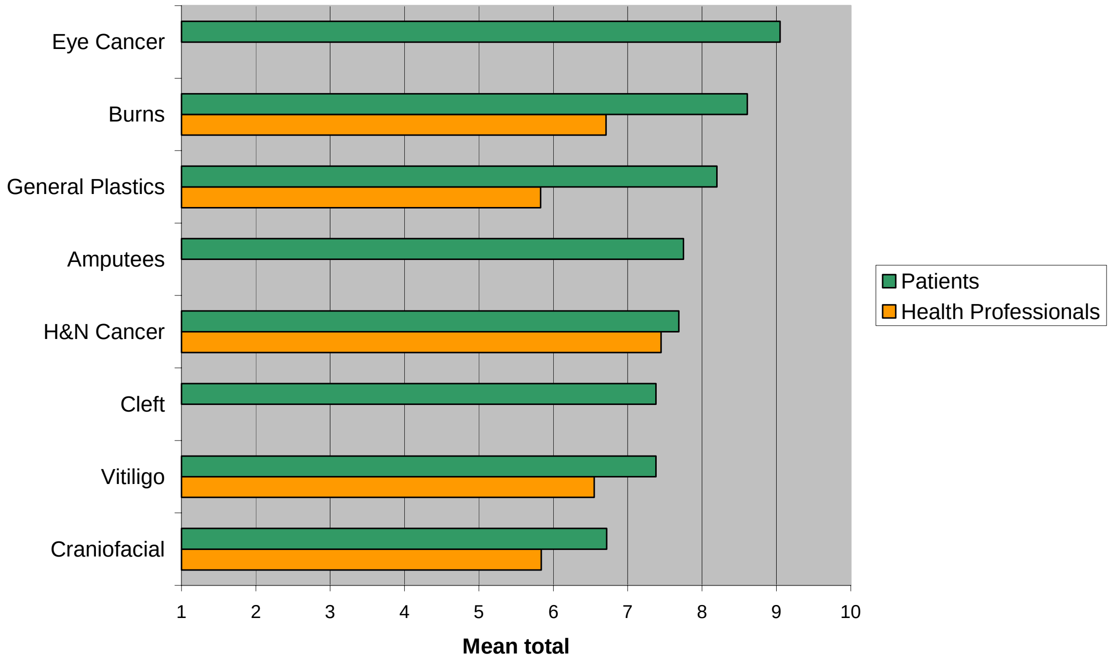
---

[1] Care must be taken with interpreting this data as different groups evaluated different materials and as such it is merely indicative rather than strictly comparable.

Copyright 2007 Picker Institute Europe. All rights reserved.

cancer, cleft and lip palate and vitiligo also rated their information well with good overall mean scores above seven. The least favourable mean rating was given by craniofacial patients (6.7), but even this score was considerably above the midpoint indicating that all patients/parents were largely positive about the materials they were asked to evaluate.

Figure 1: Evaluation of information materials across different conditions



For health professionals the picture was slightly mixed. For each condition the overall mean score was less than that given by patients, but again all totals were above the midpoint. Health professionals from head & neck cancer gave the highest rating (7.4), whereas those from general plastics and craniofacial specialties rated their materials less positively and were close to the midpoint.

For interpreting the similarities and differences in evaluation of materials *between* patients/parents and health professionals, the data needed to be further clarified. Within each condition not all focus group participants and interviewees were given the same set of materials to evaluate. For strict comparison, therefore, within each condition the analysis focused only on the subset of materials rated by both patients and health professionals. The details of this analysis are presented in Table 4. The number of materials that were commonly evaluated ranged from two (general plastics and craniofacial) to six (burns) and the combined number of patients and health professionals ranged from six (general plastics) to 15 (burns). Three conditions did not have any comparable data – cleft lip & palate, eye cancer and amputees – and so were excluded from this analysis.

Table 4 shows the mean scores for the three evaluation areas – content, presentation and trust and reliability – along with the overall total[2]. As already discussed in relation to

---

[2] As the participant numbers within each condition are small we are unfortunately unable to analyse the data further in terms of characteristics such as age, gender etc. or condition related variables such as severity or length of time since diagnosis/trauma.

Copyright 2007 Picker Institute Europe. All rights reserved.

Figure 1, for craniofacial conditions both patients and health professionals rated their materials the lowest, and when controlling for common materials we find that there is a high level of consistency between their evaluations with no significant difference between them on any of the three areas. Presentation was judged particularly poor for craniofacial material with mean scores of 4.0 (patients) and 4.5 (health professionals). There was also no significant difference between head & neck cancer patients and their health professionals, with both content and presentation scores around eight out of ten. The lowest scoring areas were for trust and reliability with mean scores of 7.2 (patients) and 6.9 (health professionals). A similar set of results was found for the vitiligo condition, with the exception of the trust and reliability of materials which was rated significantly higher by patients (7.2) than health professionals (5.9).

Table 4: Mean ratings of materials by patients/parents (P) and health professionals (HP)

	Vitiligo		**Gen. plastics**		**Craniofacial**		**Burns**		**H & N Cancer**	
	P	**HP**	**P**	**HP**	**P**	**HP**	**P**	**HP**	**P**	**HP**
Content	8.1	7.7	8.0	8.0	6.5	6.2	9.3	7.3***	7.9	8.1
Presentation	7.6	6.8	8.5	7.0	4.0	4.5	8.7	7.5***	8.2	7.8
Trust & reliability	7.2	5.9*	8.1	7.0	5.6	5.2	8.2	6.6***	7.2	6.9
Total	**7.6**	**6.6**	**8.2**	**7.3***	**5.3**	**5.3**	**8.6**	**7.1*****	**7.7**	**7.5**

*Mean scores are significantly different between P and HP at * p < .05 or *** p < .001*

Patients and health professionals from general plastics were in agreement about the high quality of the content of their materials (eight out of ten). However, patients consistently rated presentation and trust and reliability higher than the health professionals, which contributed to a significantly higher overall total mean of 8.2 compared to 7.3 for the professionals. The highest patient ratings were given by those evaluating the burns material where we found that patients gave an average rating for content of 9.3, for presentation of 8.7 and of 8.2 for trust and reliability. Each of these ratings was significantly higher than those given by the health professionals. Whilst the scores given by both groups are still favourable, there is obviously some aspects of the materials that resonate with patients but less so with health professionals.

After completing the evaluation questionnaire for each item of information presented, focus group participants and interviewees were asked to give their general comments about the materials. Although the evaluation tool invited people to assess material on the quality criteria of content, trust and reliability, and presentation, in their more spontaneous comments patients, parents and professionals responded in a rather more personal and direct way to the materials, and also commented on other aspects. These views are presented as an indication of what patients and professionals look for in good quality information. They are not intended to single out any particular items for criticism and therefore where negative views are expressed, the titles have not been included. People certainly talked about content, presentation, accuracy and reliability, but also stressed the importance of clarity, visual information, information on treatment options and not being overloaded with information. It was also interesting to see how patients and professionals differed in their views.

Content

Patients and parents particularly valued other people's stories and guidance on dealing with their own emotional reactions. This very much reflected the group discussions which preceded the evaluation and were detailed in Report I, when patients and parents talked about the value of peer support and the need for more information about psycho-social re-adjustment.

> *To hear stories from other people I found very good.*
>
> *Vitiligo patient re Living with Vitiligo - video*

> *I wished I'd read that many years ago because it just makes you realize that the way you sometimes handle people's reactions is not possibly the most positive and you don't have to be defensive all the time.*
>
> *Craniofacial parent re Changing Faces: My Child Looks Different*

They also appreciated information that reduced uncertainty and prepared them for what was going to happen.

> *If I was going to have a scan I think I would have liked, that would have helped, you know so that it prepares you for that beforehand.*
>
> *Eye patient re Twenty Twenty for Channel 4 Blinded (video)*

> *I think that is really very good.... because it goes through all the stages.... and that is just exactly what happens.*
>
> *Amputee re The Murray Foundation: The Way Forward (video)*

However, some people thought certain information could be frightening if given out at the wrong time.

> *I wouldn't have liked to have been given that one.... pre-treatment, because I think if you gave it to someone when they first got the news you'd be scared off.*
>
> *Eye patient re Moorfields Eye Hospital NHS Trust Insight into the removal of an eye*

Visual information

Perhaps not surprisingly, given that this study is about people with conditions affecting appearance, the desirability of visual information came out strongly amongst patients and parents; and was also recognised by health professionals. This again echoed comments made in the general focus group discussions.

> *It's got pictures. Every mother with a child with a craniofacial syndrome wants to see other children with craniofacial syndromes.*
>
> *Craniofacial parent re Great Ormond Street: Your Child has Craniosynostosis*

Clarity

Clarity is important to everyone: clarity of aims, language and presentation. Failure to state clearly what a piece of information was about and whom it was for, left people feeling confused or misled.

Copyright 2007 Picker Institute Europe. All rights reserved.

> *It says discharge information but it's actually about outreach so why didn't they just call it an outreach leaflet about outreach services.*
>
> *Burns professional re discharge information leaflet*

> *It doesn't specify that it's talking about the side effects after treatment.*
>
> *Head & neck cancer patient re radiotherapy leaflet*

However, when a piece of information does make clear its aims and fulfils them, it is appreciated. This is the essence of good information.

> *Straight forward – it does what it says on the tin.*
>
> *Amputee re The Murray Foundation: Wheelchairs - advice on private purchase*

Although many patients become familiar with complex terminology in the course of a long treatment process, there was general agreement that technical language and jargon should be avoided.

> *Very good…in laymen's language.*
>
> *Head & neck cancer patient re CancerBACKUP: Understanding cancers of the head and neck*

> *It's very good English, it's plain English to read.*
>
> *Plastics nurse re Changing Faces: Facing disfigurement with confidence*

Above all, evaluators liked the information to be clearly presented. They appreciated clear indexing, bullet-pointing and distinct sections that enabled them to find relevant information more easily.

> *On this the writing is very clear, each page has got a title and it's set out well, things are in bold, your eyes jump to the bits that are relevant.*
>
> *Craniofacial parent re Great Ormond Street: Your child has craniosynostosis*

> *This is bullets points and people who are not wanting to do lots of reading can just quickly look at that and get something out of it.*
>
> *Burns professional re Mount Vernon Hospital: Care of your skin graft and donor site*

Some comments, particularly from voluntary sector representatives, were obviously based on knowledge gained in the actual production of materials.

> *I'm afraid the one that everybody likes doesn't really pass does it because it's using a wiggly font…and the colour, the orange you shouldn't use. It's not very easy to read.*
>
> *Voluntary sector re radiotherapy leaflet*

> *They're on the wrong sort of paper though…because it's shiny and if you get the light on it you have to move it.*
>
> *Voluntary sector: general comment*

Accuracy and reliability

There was rather more concern about accuracy and bias amongst the health professionals and voluntary sector representatives. This was particularly so in the case of commercially produced information.

> *I think that one's very obvious it's from a supplier…a manufacturer and it gives very one sided information.*
>
> *Craniofacial professional re leaflet on facial prostheses*

Patients and parents seemed willing to assume information was reliable if it came from an apparently authoritative source.

> *There are too many references; there is a whole list of information from other books they are quoting. To be honest if someone produced that then I trust them, I don't need to know all the sources as if I was writing a dissertation.*
>
> *Vitiligo patient re cosmetic camouflage handbook*

Information on treatment options

Some of the most popular material - that produced by *Changing Faces* - offers no treatment advice. A few people specifically mentioned the importance of being given information about treatment options or commented on the absence of information about alternative treatments, for example, prosthetic options in head & neck cancer. For others, there appeared to be an acceptance that options were very limited.

> *I'd never thought about whether or not it gives different opinions about operations, whether it was balanced or unbiased, but reading it, it's very one-sided…90% of the people who are given this pamphlet, they're going to have surgery so…it is very biased because it's just this is the operation your child will have. I don't think that's a bad thing.*
>
> *Craniofacial parent re booklet on craniosynostosis*

Tone

The tone of the material is also very important to patients. Some patients were particularly sensitive to this and found one or two items very patronising and negative.

> *I thought that one was appallingly bad…I will just pick two examples, there was something about…sports and hobbies, "a surprising number of activities are possible." Who are they to say it is surprising [and] the drawings of the caricatures is appallingly bad taste.*
>
> *Amputee re hospital prosthetic service booklet*

> *One of the real prominent things about the home page is that it's very, very negative, you go there for a bit of advice and it tells you how awful it is to be a parent of a child, a disabled child and I have an issue with the word 'disabled'.*
>
> *Craniofacial parent re disability website*

Copyright 2007 Picker Institute Europe. All rights reserved.

Information overload

Some professionals and voluntary sector representatives were concerned about overloading their patients and clients with information.

> *It's certainly not something you could quickly leaf through in an outpatient setting, it's something you need to sit at home with and read, I mean it would take an hour or so to run through the whole thing, it's about 40 pages long, so yes, useful, but you'd need to take it in context, yes.*
>
> *Plastics professional re CancerBACUP: Understanding cancers of the head and neck*

> *And less is more, there's a huge amount of verbiage in some of those which is not actually necessarily helpful, you're talking information overload and what we want is a judgement about what people want and need to know about something in order to get the best from the information.*
>
> *Voluntary sector: General comment*

Whereas one parent was concerned at the inadequate detail in at least one leaflet.

> *It's not a very weighty leaflet and it's a big thing at the moment…if I received that I don't know that I'd go away feeling happy about my child's condition.*
>
> *Craniofacial parent re leaflet on Occipital Plagiocephaly*

Differing reactions

The difficulty of producing information that satisfies everyone's needs was highlighted by a few examples where people had very different reactions to materials. In most cases these differences were between patients/parents and health professionals, or patients/parents and the voluntary sector representatives. This is somewhat worrying because it is the NHS and the voluntary sector that produce the information. It highlights the need for producers to involve patients from a very early stage in the development process.

For example, one particular piece of information was criticised by clinicians and voluntary sector representatives for its commercial bias. However, for one head & neck cancer patient, it was exactly what she needed to give her a visual impression of prosthetic implants.

> *When I saw these* [photographs of implants] *…exactly what I wanted to see.*
>
> *Head & neck cancer patient re leaflet on facial prostheses*

Changing Faces material was generally highly regarded by all the patients and parents in our groups, but not necessarily so among the health professionals.

> *I just think they're rather heavy going personally, I've always thought that about Changing Faces.*

This difference was most noticeable in the response to the showing of two videos. When a burns centre admissions video was shown to a group of health professionals, there was a fair degree of criticism:

Copyright 2007 Picker Institute Europe. All rights reserved.

> *Too much information all in one go.*
>
> *I couldn't quite work out when you'd play it.*
>
> *I'm guessing it's aimed at adults, when they showed the side room they had like a children's cartoon on and then they had children's pictures in the corridor and I found it a bit…confusing.*

However, when shown to a group of burn survivors, they responded far more positively.

> *Knowing that you can have splints and things and the physio that's available, it went through every stage that we've been through and I think if you had been shown that as soon as you were able to take that in, I think that would be very important.*
>
> *I think it's very useful for the families as well….your brain's not good at taking in information when you've just gone through such trauma…. I think it's as important that the family….will see it as well.*

Clinicians were shown an excerpt from a video that demonstrated communication skills for those who look different. They reacted angrily to the unsympathetic way the medical profession was portrayed in the reconstruction of a consultation with a person about laser treatment for a facial birthmark.

> *It's setting up an adversarial condition and that is my concern about it.*
>
> *That's clearly contrary to everything that we've already said that we do.*

On the other hand, the parents of children born with a cleft lip & palate felt it was a fairly accurate depiction and echoed their own experiences.

> *I've done that, I have, I've waited for them to be quiet and then asked them again and again until I've got the answer.*

Copyright 2007 Picker Institute Europe. All rights reserved.

6 Summary and Discussion

On this hugely diverse topic it is sometimes hard to see the wood for the trees. This review and small-scale evaluation allows us, however, to draw out some key issues for future consideration.

Volume of information

There is an enormous amount of information for people with disfiguring conditions. Our request to information providers in NHS, voluntary and professional organisations enabled us to identify hundreds of items (and there must be very many more). Most of the voluntary, commercial and professional association providers also have websites providing additional information, and more and more NHS Trusts are offering downloadable material on a range of disfiguring conditions on their websites. This suggests that if users know where to look they may well be able to find what they want. But they may need help, through better signposting from health professionals and services such as information prescriptions

Format of information material

Although most of the information we receive from healthcare professionals is verbal, this project focused inevitably on 'hard' or tangible resources. Most of the information we identified was print-based, though other kinds of media were also represented. Such heavy reliance on print-based material is problematic for people with limited literacy, and of course also for people whose main language is not English, unless it is translated. Most of the providers we talked to found translation of material into other languages very problematic, because of the high cost compared with the limited demand.

Duplication of information material

Some of the information is generic, but much of it is condition-specific. It is produced mainly by well-established organisations or specialist centres from a wide variety of sources, including local health care providers. This is of course very encouraging, though it does suggest that unless there is good communication between centres there may well be much repetition of effort. Some sort of clearing house or information bank at a national level could be extremely useful in such circumstances.

How material is produced

There are considerable differences between information providers, with some having plentiful resources at their command whilst others work to very tight budgets indeed. Increasing usability through alternative formats and different language versions remains too expensive for many.

We identified a number of limitations to the provision of information, which need addressing. First, the involvement of users in the development of material varied considerably. Virtually all the organisations we spoke to recognised the importance of involving patients or carers in the development process, but only the larger and betterresourced have systematic processes for facilitating this. Some providers could perhaps usefully learn from the experience of others, through a sharing of good practice. Secondly, the way topics are chosen varies, with user-demand not always being a key driver. Patients' views about their information needs are known to differ from those of health care professionals and it is important that they are examined and taken into account. Third, more could be done by some providers to ensure that information is regularly up-dated. Although this might suggest the need for an accreditation scheme, doubts were expressed among our providers about any Department of Health scheme, on grounds of cost, on whether it was really needed, and on the possibility of it restricting the independence of the information providers.

Views about the material

When asked to evaluate a sample of information materials, the responses from patients and carers were largely positive, though health professionals were slightly more critical.

In their more open comments, our research participants highlighted a number of important factors that, in their eyes, contributed to high quality information. Patients emphasised that:

- the aims of the information should be stated clearly
- it should be pitched at the right level for its target audience
- printed material should be written in plain English, avoiding jargon
- lay-out should be clear and simple
- the tone of the material is important; it should not patronise the reader
- it should include appropriate illustrations
- it should be honest, but avoid negativity
- it should provide balanced information
- it should not be overloaded with references, but the source and date of the information should be clear.

In terms of content, patients liked the materials that:

- prepared then for what was going to happen
- offered reassurance about their own emotional reactions and guidance on how to deal with them
- offered contact details for further support and information
- provided stories from other people's experiences
- gave information about treatment options
- provided information for families and friends.

The professionals also approved clarity of aims, language and presentation, and the use of plain English. They too stressed the importance of accuracy and reliability and worried about commercially produced information.

Providers are seen to be doing a generally good job, but there is wide variation and room for improvement. This is confirmed in our other two reports where some of these issues are explored in greater detail.

Copyright 2007 Picker Institute Europe. All rights reserved.

7 Appendix

7.1 Materials obtained

A: Generic information on disfigurement

Title	Publisher	Description
Facing Disfigurement with Confidence	Changing Faces www.changingfaces.org.uk	A small booklet with photographs and personal testimonies from people who are successfully tackling the challenges of disfigurement.
My child looks different.	Changing Faces	A 21 page guide for parents offering strategies for dealing with other peoples reactions to disfigurement.
Looking Different Feeling Good.	Changing Faces	A general overview for young people.
Exploring Faces through Fiction.	Changing Faces	A short guide for parents of children with disfigurement offering practical advice on how to discuss and manage children's feelings about the way they look.
Everybody's Staring at Me!	Changing Faces	How to communicate when you have an unusual face.
When Facial Paralysis Affects the Way You Look.	Changing Faces	A 17 page booklet on how to managing a change in appearance.
Talking to Health Professionals about Disfigurement	Changing Faces	A 9 page booklet to help people with a disfigurement plan how to talk to professionals involved in their care.
Meeting New People, Making New Friends.	Changing Faces	A step-by-step guide for people with a facial disfigurement.
Do Looks Count? What Happened to You? You're in Charge. Looking different Feeling good.	Changing Faces	4 short guides for young people with a facial disfigurement to manage their lives better.
The Psychology of Facial Disfigurement. A Guide for Health and Social Care Professionals.	Changing Faces	A 21 page booklet for health and social care professionals working with people who have a facial disfigurement and the psychology of appearance.
Humpty Dumpy Faces the Future.	Changing Faces	A short cartoon style book for anyone concerned about the way they look.
Facing Changes: changing the way we see	Changing Faces	31 page booklet intended for a wide audience, challenging the way we see

A: Generic information on disfigurement

Title	Publisher	Description
disfigurement		disfigurement
Working with a difference	Changing Faces	Folder containing 5 fact sheets on equal opportunities for people with disfigurements
Your rights as an employee and as a customer: a guide for people with disfigurements	Changing Faces	7 page fact sheet
Taking the initiative in the workplace: Using Reach Out to your advantage	Changing Faces	6 page fact sheet
Getting a job: a guide to using Job Centres and Recruitment Agencies	Changing Faces	5 page fact sheet
Support for families – self-help groups and other organisations	Changing Faces	3 page fact sheet
Supporting a child with a disfigurement: a teacher's guide: An Introduction	Changing Faces	4 page fact sheet
Supporting a child with a disfigurement: a teacher's guide: When a new pupil starts playgroup, nursery or school	Changing Faces	5 page fact sheet
Supporting a child with a disfigurement: a teacher's guide: When a new pupil starts at your school	Changing Faces	5 page fact sheet
A list of books for children and young people	Changing Faces	6 page fact sheet
Newsletter	Changing Faces	Autumn/Winter 2003 issue
Changing Faces	Changing Faces	Fold-out leaflet describing the organisation
Reach Out	Changing Faces	Video on communication skills for people with a facial disfigurement
Me and My Face	Let's Face It www.lets-face-it.org.uk	A carton book for children to help them cope with disfigurement.
Children's Faces	Let's Face It	A compilation of words and pictures from children who are disfigured.
Junior Lets Face It	Let's Face It	A small leaflet explaining how the organization Lets Face It can help and support children with a facial disfigurement.

A: Generic information on disfigurement

Title	Publisher	Description
Lets Face It	Let's Face It	A small leaflet explaining how the organization Lets Face It can help and support individuals with a facial disfigurement.
Face to Face – makes the difference	Entific Medical Systems www.entific.com	Brochure on facial prostheses
When you look different	Outlook, Frenchay Hospital www.northbristol.nhs.uk/depts/surgicalservices/outlook	Fold-out leaflets (2 versions)
Information Sheet for Parents	Outlook, Frenchay Hospital	A4 fact sheet
Outlook Information Sheet	Outlook, Frenchay Hospital	A4 fact sheet
Coping with feeling angry	Outlook, Frenchay Hospital	4 page leaflet
Unhelpful thinking styles	Outlook, Frenchay Hospital	6 page fact sheet
Pleasurable activities	Outlook, Frenchay Hospital	4 page list
Notes on self-confidence/assertivenesss	Outlook, Frenchay Hospital	2 page fact sheet
Look after yourself	Outlook, Frenchay Hospital	4 page fact sheet
Force field analysis	Outlook, Frenchay Hospital	2 page fact sheet on problem-solving
About disfigurement	Disfigurement Guidance Centre www.timewarp.demon.co.uk	Small illustrated book
Does the way you look really matter?	Disfigurement Guidance Centre	Small illustrated book
Guidelines for parents: Good Beginnings	Disfigurement Guidance Centre	Small illustrated book
Guidelines for parents: Early Days	Disfigurement Guidance Centre	Small illustrated book
Share an idea	Contact a Family www.cafamily.org.uk	Magazine published 3 times p.a. Spring 2004 issue
When your child has additional needs	Contact a Family	19 page guide for parents (inc. rare disorders)
Aids, Equipment and Adaptations	Contact a Family	11 page fact sheet on how to obtain equipment and where to go for further advice
Contact a family	Contact a Family	Fold-out leaflet about the charity in different languages (x2)

Copyright 2007 Picker Institute Europe. All rights reserved.

B: Dermatology

Title	Publisher	Description
Acne. Key Facts	British Association of Dermatologists www.bad.org.uk/about/	A 3 page booklet with pictures explaining the cause and treatment of acne.
Contact Dermatitis. Key Facts	British Association of Dermatologists	A 3 page booklet with pictures explaining the cause and treatment of dermatitis.
Psoriasis. Key Facts	British Association of Dermatologists	A 3 page booklet with pictures explaining the cause and treatment of psoriasis
Moderate and Severe Psoriasis.	British Association of Dermatologists	A 5 page booklet explaining the treatment of moderate and severe psoriasis.
Psoriasis	British Association of Dermatologists	7 page pull-out leaflet: questions; answers; treatment advice
Ichthyosis. Key facts	British Association of Dermatologists	Fold-out leaflet
Urticaria and angioedema. Key facts	British Association of Dermatologists	6 page booklet
Atopic Eczema. Key Facts	British Association of Dermatologists	A 5 page booklet explaining the treatment of atopic eczema.
Atopic eczema.	British Association of Dermatologists	10 page booklet: questions; answers; treatment advice
Looking after Someone with Eczema	National Eczema Society www.eczema.org/	A small booklet explaining the different types of eczema, how it can be treated and what it means to live with the condition.
Eczema on your Mind?	National Eczema Society	A small booklet looking at psychological aspects of living with eczema.
Living with Eczema	National Eczema Society	A small booklet explaining the different types of eczema and sources of information about the condition.
What is Eczema?	National Eczema Society	A small booklet explaining the different types of eczema and sources of information about the condition.
Information for Teenagers with Eczema	National Eczema Society	A small booklet for teenagers on how to cope with living with eczema.
All about atopic eczema	National Eczema Society	Fold-out cartoon illustrated leaflet
Information for children with eczema	National Eczema Society	Fold-out cartoon illustrated leaflet
A parents' guide to atopic eczema in the under 5s	National Eczema Society	Fold-out cartoon illustrated leaflet
Exchange: December 2003	National Eczema Society	Quarterly journal
Emollients	National Eczema Society	4 page information sheet about emollients
Questions need answers	National Eczema Society	4 page information sheet with FAQs

Copyright 2007 Picker Institute Europe. All rights reserved.

B: Dermatology

Title	Publisher	Description
Allergy	National Eczema Society	7 page information sheet
Ear eczema	National Eczema Society	3 page information sheet
Stress and Eczema	National Eczema Society	3 page information sheet about stress and eczema
Tell me more about Eczema	National Eczema Society	Information sheets in Urdu and Panjabi
Facial Eczema	National Eczema Society	A4 Leaflet about eczema and its treatment
Understanding, supporting, making a difference	National Eczema Society	Fold out leaflet about the Society
Coping with Eczema	Stiefel Laboratories Ltd www.stiefel.com/	A 10 page booklet for parents about eczema.
Eczema Management: A Guide for Patients	Dermal Laboratories http://www.dermal.co.uk/dermal/index.html	Book of tear-off information sheets
About Skin Problems	Disfigurement Guidance Centre http://www.timewarp.demon.co.uk/dgc.html	A small booklet about types of skin problems and their treatments
Skinlaser Directory 10	Disfigurement Guidance Centre	International directory of centres offering laser treatments for skin conditions.
Is my face red	Disfigurement Guidance Centre	Small booklet about Rosacea
The Little Book of Spots	Disfigurement Guidance Centre	Small booklet for children
Campaign News	Skin Care Campaign www.skincarecampaign.org/	Newsletter: Feb and May 2004
Skin Care Campaign Directory 2003/04	Skin Care Campaign	Directory of skin conditions, treatments, patient organizations.
Skin Care Campaign	Skin Care Campaign	Fold-out leaflet about the campaign
The All Party Parliamentary Group on Skin	APPGS	Fold-out leaflet about the group
Psoriasis: More than skin deep	The Psoriasis Association www.psoriasis-association.org.uk/	A small booklet about psoriasis
The Psoriasis Association Journal: March 2003	The Psoriasis Association	Journal of Psoriasis Association
The Psoriasis Association	The Psoriasis Association	Information pack about all aspects of living with psoriasis and details of the role of the association.
Psoriatic arthritis	The Psoriasis Association	Fold-out leaflet
A Guide to Emollients	Psoriatic Arthropathy	Booklet

Copyright 2007 Picker Institute Europe. All rights reserved.

B: Dermatology

Title	Publisher	Description
	Alliance www.paalliance.org	
What is Psoriasis	Psoriatic Arthropathy Alliance	Fold-out leaflet
Occupational therapy and joint protection	Psoriatic Arthropathy Alliance	7 page booklet
Clinical trials	Psoriatic Arthropathy Alliance	11 page booklet
Physiotherapy and exercise	Psoriatic Arthropathy Alliance	11 page booklet
Nail psoriasis	Psoriatic Arthropathy Alliance	Fold-out leaflet
What is psoriatic arthritis?	Psoriatic Arthropathy Alliance	Fold-out leaflet
Skin 'n' Bones Connection	Psoriatic Arthropathy Alliance	Journal Issue 18 2003
The Neurofibromatosis Association	The Neurofibromatosis Association http://www.nfauk.org/	Fold-out leaflet about the condition and the association
Understanding neurofibromatosis	The Neurofibromatosis Association	21 page booklet
More than skin deep	DEBRA www.debra.org.uk	Fold-out leaflet about Epidermolysis Bullosa
The genetics of EB: an explanation	DEBRA	20 page booklet
Adult nursing service	DEBRA	4 page pamphlet
Children's nursing service	DEBRA	4 page pamphlet
Seeking Employment	DEBRA Adult Nursing Service	8 page booklet
Patient Guidelines for Acne	Dermal Laboratories	A4 sheet about acne.
Management of Dry Skin Conditions	Dermal Laboratories	A4 sheet about dry skin conditions
Working Towards Health skin for All	British Skin Foundation www.britishskinfoundation.org.uk	Explanatory booklet about the research of the British Skin Foundation
Acne Your Guide to Health Skin	Neutrogena www.neutrogena.com	Leaflet about acne
Dry skin	Neutrogena	Fold-out leaflet on skin problems and treatments
Immediate, long lasting relief for dry skin	Neutrogena	Fold-out leaflet
Using emollients	E45	Fold-out leaflet

Copyright 2007 Picker Institute Europe. All rights reserved.

B: Dermatology

Title	Publisher	Description
successfully		
Dispatches: July 2001	The Vitiligo Society www.vitiligosociety.org.uk	Quarterly newsletter of the Vitiligo Society.
What is Vitiligo?	The Vitiligo Society	Information about vitiligo and its treatment.
Best Treatments: Eczema (Atopic eczema)	BMJ Publishing http://www.besttreatments.co.uk	Website about eczema.
Ichthyosis Support Group	Ichthyosis Support Group www.ichthyosis.org.uk	Information pack about the support group, the condition, treatments and disability living allowance.
Ichthyosis Support Group News	Ichthyosis Support Group	Newsletter. August 2004 issue
Facing the World	The British Association of Skin Camouflage www.skin-camouflage.net	Leaflet about use of skin camouflage
When a medical skin condition affects the way you look	Changing Faces	Booklet about coping with a skin condition
Damned White Spots	Karin Schallreuter University of Bradford UK	Book with comments by patients living with vitiligo.
First Aid for Eczema & Dry Skin	Sankyo Pharma UK	Booklet for healthcare professionals about eczema
Eczema	Queen's Medical Centre, Nottingham	One page information sheet
Topical steroids	Queen's Medical Centre, Nottingham	4 page booklet
Things are looking up for psoriasis sufferers	Leo Pharmaceuticals www.leo-pharma.com	Leaflet about treatment for psoriasis
Eczema spoils life	Leo Pharmaceuticals	Booklet with photographs about eczema
Acne: The Facts	Acne Support Group www.m2w3.com/acne	Booklet about the causes and treatment of acne and the role of the support group.
Face facts: living with rosacea	Acne Support Group	6 page pamphlet
Quinoderm: one less thing to worry about	Adams Healthcare	Fold-out leaflet about treatment for acne
Treatment Notes: Steroid treatments for eczema	Which? http://www.treatmentnotes.co.uk/	Part of a series based on matching information from Drug and Therapeutics Bulletin, a monthly publ. for doctors and pharmacists.
Living with Vitiligo	Green House Productions for the Vitiligo Society	Video: people talk about what having vitiligo means to them

Copyright 2007 Picker Institute Europe. All rights reserved.

C: Skin cancer

Title	Publisher	Description
All about Solar Keratosis	Bioglan www.bradpharm.com	7 page booklet
Treating Basal Cell Carcinoma	North Bristol NHS Trust	Fold-out leaflet
Treating Squamous Cell Carcinoma	North Bristol NHS Trust	Fold-out leaflet
Skin cancer: how to be smart and reduce your risk	Cancer Research UK www.cancerresearchuk.org	Fold-out leaflet
Malignant Melanoma	Cancer Research UK	Fold-out leaflet on early signs and prevention
Photodynamic therapy for non melanoma skin cancers	Galderma (UK) Ltd www.galderma.com	7 page booklet
Primary Cutaneous B-Cell Lymphoma	St John's Institute of Dermatology http://www.guysandstthomas.nhs.uk	5 page booklet on lymphoma affecting the skin
Primary Cutaneous T-Cell Lymphoma	St John's Institute of Dermatology	6 page booklet on lymphoma affecting the skin
Photopheresis	St John's Institute of Dermatology	Fold out leaflet about extracorporeal photochemotherapy
142.Malignant melanoma	Wessex Cancer Trust	Fold-out leaflet
Squamous cell carcinoma	Wessex Cancer Trust	Fold-out leaflet
Living with melanoma	Wessex Cancer Trust	7 page booklet
Skin cancer	Imperial Cancer Research Fund www.icnet.uk/	Fold-out leaflet on dispelling myths and prevention
Moles and other skin lumps	The Skin Cancer Research Fund www.skin-cancer-research-fund.org.uk	Small leaflet
Photodynamic therapy	Disfigurement Guidance Centre	24 page booklet
Squamous Cell Tumour	PatientWise http://www.patientwise.net/	2 page A4 fact sheet

Copyright 2007 Picker Institute Europe. All rights reserved.

D: Burns

Title	Publisher	Description
Take Home Medicines	The Mid Yorkshire Hospitals (Pinderfields) http://www.midyorks.nhs.uk	2 page booklet: pain-killers, anti-itch tablets and moisturiser
Integra	The Mid Yorkshire Hospitals (Pinderfields)	2 page booklet: artificial skin
Tissue Expansion	The Mid Yorkshire Hospitals (Pinderfields)	2 page booklet: procedure to reconstruct skin
Steroid injections	The Mid Yorkshire Hospitals (Pinderfields)	One page booklet: treatment for scars
Silicone Gel (Cica care/silon ses)	The Mid Yorkshire Hospitals (Pinderfields)	2 page booklet: treatment for scars
Silicone Gel (Mepiform)	The Mid Yorkshire Hospitals (Pinderfields)	2 page booklet: treatment for scars
Silicone cream (Zeraderm)	The Mid Yorkshire Hospitals (Pinderfields)	2 page booklet: treatment for scars
Information for Adult Inpatients on the Burns Unit	The Mid Yorkshire Hospitals (Pinderfields)	8 page booklet
Going Home from Hospital	The Mid Yorkshire Hospitals (Pinderfields)	8 page booklet: discharge planning
Instructions for Conformer Appliances	The Mid Yorkshire Hospitals (Pinderfields)	2 page booklet:
Bathing and creaming	The Mid Yorkshire Hospitals (Pinderfields)	2 page booklet
Scar tissue	The Mid Yorkshire Hospitals (Pinderfields)	2 page booklet
Pressure garments	The Mid Yorkshire Hospitals (Pinderfields)	2 page booklet
Dressings	The Mid Yorkshire Hospitals (Pinderfields)	2 page booklet
Itching	The Mid Yorkshire Hospitals (Pinderfields)	2 page booklet
Holidays and Sunshine	The Mid Yorkshire Hospitals (Pinderfields)	2 page booklet
Physiotherapy and exercise after a burn injury	The Mid Yorkshire Hospitals (Pinderfields)	2 page booklet
Burns Centre	The Mid Yorkshire Hospitals (Pinderfields)	2 page booklet
Cosmetic camouflage	The Mid Yorkshire Hospitals (Pinderfields)	2 page booklet
Support agencies for the burn injured adult and child	The Mid Yorkshire Hospitals (Pinderfields)	2 page booklet
Scars	The Mid Yorkshire	2 page booklet

D: Burns

Title	Publisher	Description
	Hospitals (Pinderfields)	
Surgical scar revision	The Mid Yorkshire Hospitals (Pinderfields)	2 page booklet
Burn Information A-Z	The Mid Yorkshire Hospitals (Pinderfields)	6 page booklet
Adult Support Group	The Mid Yorkshire Hospitals (Pinderfields)	2 page booklet for any adult that has been on Burns Unit
Pinderfields Burns Club	The Mid Yorkshire Hospitals (Pinderfields)	2 page booklet about young people's club
Admission to the Yorkshire Regional Burns Centre	The Mid Yorkshire Hospitals (Pinderfields)	Video
Welcome	The Burned Children's Club (Pat Wade) www.burnedchildrensclub.org.uk	6 page brochure describing the activities of the club (in large and small format +CD of kids at burn camp)
The Camouflage Club	Estee Lauder www.esteelauder.co.uk	2 page brochure on skin camouflage for children up to 16
Scarred for Life	Smith and Nephew www.wound.smith-nephew.com.uk	Fold-out leaflet on Cica-Care treatment for scars
Scar information service	Smith and Nephew	6 page booklet about the service
Cica-Care: Your questions answered	Smith and Nephew	Fold-out leaflet
For scars old and new	ICN Pharmaceuticals www.valeant.com/	8 page booklet on Dermatix: scar gel
Scar Care	South Tees Acute Hospitals NHS Trust	Fold-out leaflet
Home at Last	McIndoe Burns Support Group www.queenvic.demon.co.uk/volntry	23 page booklet on continuing care
McIndoe Burns Support Group	Queen Victoria Hospital	Fold-out leaflet
How to Cope at Home	Beiersdorf Medical www.beiersdorf-medical.com	23 page booklet
Burn Aftercare Information	The Newcastle Upon Tyne Hospitals (Royal Victoria Infirmary) www.newcastle-hospitals.org.uk	13 page discharge booklet
Information for patients having a skin graft	North Bristol NHS Trust www.nbt.nhs.uk	Fold-out leaflet

D: Burns

Title	Publisher	Description
Going Home	Frenchay Health Authority	10 page discharge booklet
Burns Unit Group Support	Salisbury Health Care NHS Trust http://www.salisbury.nhs.uk/	Fold-out leaflet
Burns Unit advice sheet (adults)	Salisbury Health Care NHS Trust	Fold-out leaflet
The Tissue Support Clinic	Salisbury Health Care NHS Trust	4 page booklet
Advice on discharge from the Burns Unit	Salisbury Health Care NHS Trust	2 page booklet (new info in production – see below)
I am Leaving – What Now?	Salisbury Health Care NHS Trust	Draft of new B.U.G.S booklet to help discharged burns patients adjust back into life outside hospital
Your Stay on the Burns Unit	Salisbury Health Care NHS Trust	4 page booklet for 10-16 year-olds
B.U.G.S. Autumn 2004 Newsletter	Burns Unit, Salisbury District Hospital	A4 sheet
The Vital B.U.G.S. DVD for adults	Burns Unit, Salisbury District Hospital	DVD: reminder of information given and FAQs
Psychological Responses to Traumatic Events	Burns Unit Wythenshawe Hospital http://www.smuht.nwest.nhs.uk/	6 page booklet (DRAFT)
Psychological Issues	Burns Unit Wythenshawe Hospital	4 page booklet (DRAFT)
The Manchester Action Group for Burns	Burns Unit Wythenshawe Hospital	Fold-out leaflet (early version)
Discharge information leaflet: What Happens When I Go Home?	South Manchester University Hospitals	Fold-out leaflet
Burns After-Care	South Manchester University Hospitals	13 page booklet – photocopy (to be updated)
Rehabilitative Activity Holidays for Injured Children	Booth Hall Children's Hospital www.cmht.nwest.nhs.uk/hospitals/childrens/	Fold-out leaflet about Manchester Burns Camp
Burn Survivors Association UK	BSA www.burnsurvivorsassociation.com	One page leaflet
The Survivor	BSA	Newsletters: issues 1-3
Scar Formation and After Care	West Hertfordshire Hospitals (Mt Vernon)	A4 sheet

Copyright 2007 Picker Institute Europe. All rights reserved.

D: Burns

Title	Publisher	Description
	http://www.raft.ac.uk/plastics/index.html	
Burns After-Care Information for GPs	West Hertfordshire Hospitals (Mt Vernon)	A4 sheet
Patients having plastic surgery on the face	West Hertfordshire Hospitals (Mt Vernon)	A4 sheet
Care of your skin graft and donor site	West Hertfordshire Hospitals (Mt Vernon)	A4 sheet
Dressing information for patients	West Hertfordshire Hospitals (Mt Vernon)	A4 sheet
Treatment options within reach	Integra LifeSciences www.integra-ls.com	9 page booklet about dermal replacement product
Managing the Future After Burns: My child has burns	Changing Faces	13 page booklet for parents
Managing the Future After Burns: Managing the effects of burns	Changing Faces	14 page booklet for adults with burn injuries
Managing the Future After Burns: Back to school	Changing Faces	13 page booklet for teachers
Show Time	Changing Faces	Children's book about coping at school
Care of your donor area	West Lothian NHS Trust (St John's Hospital)	A5 sheet
Instructions for patients with a burn injury	West Lothian NHS Trust (St John's Hospital)	A4 sheet
General Advice for Patients with Facial Burns	Mid Essex Hospital Services (St Andrews) www.meht.nhs.uk/departments/burnsplastics	4 page booklet
Skin graft to the lower leg	St Andrews Centre	A4 fact sheet
Guidelines for the care of skin grafts and donor areas	St Andrews Centre	A4 fact sheet
Care of pin sites	St Andrews Centre	A4 fact sheet
High temperature following burns and scalds	St Andrews Centre	A4 fact sheet
About your pressure garment	St Andrews Centre	A4 fact sheet
Desensitisation	St Andrews Centre	A4 fact sheet
Instructions for the use of silicone gel	St Andrews Centre	A4 fact sheet
Instructions for the use of Novogel	St Andrews Centre	A4 fact sheet
Instructions for use of elastomer and putty	St Andrews Centre	A4 fact sheet

Copyright 2007 Picker Institute Europe. All rights reserved.

D: Burns

Title	Publisher	Description
conformers		
Instructions for the use of mepiform	St Andrews Centre	A4 fact sheet
Exercise and advice for arm burns	St Andrews Centre	2 x A4 fact sheets
Neck burns – exercises and advice	St Andrews Centre	2 x A4 fact sheets
Scars: surgical and others	St Andrews Centre	A4 fact sheet
Scar massage information sheet	St Andrews Centre	A4 fact sheet
Scars and keloids	British Association of Aesthetic Plastic Surgeons www.baaps.org.uk	Fold-out leaflet
Children's discharge advice sheet	Nottingham City Hospital www.nuh.nhs.uk/nch/patientinfo/	A4 fact sheet
For patients discharged from the outpatient dressing clinic	Nottingham City Hospital	A4 fact sheet
Caring for your facial burn	Nottingham City Hospital	Fold-out leaflet
How to care for dressings on burns and scalds	Nottingham City Hospital	A4 fact sheet
Information for patients who have undergone a skin graft	Nottingham City Hospital	A4 fact sheet
How to care for your granuflex dressings	Nottingham City Hospital	A4 fact sheet
Looking after your child's burn injury at home	Birmingham Children's Hospital http://www.bch.org.uk/	8 page leaflet
Burns	BUPA www.bupa.co.uk	5 page fact sheet downloaded from internet
Burn Healing	Dutch Burns Foundation www.brandwonden.nl	17 page booklet
Tools RG	PhysioTools www.physiotools.com	CD to enable physios to produce personalized education & exercise handouts for patients

Copyright 2007 Picker Institute Europe. All rights reserved.

E: Head & neck cancer

Title	Publisher	Description
The Teamwork File	The National Cancer Alliance www.nationalcanceralliance.co.uk	Information aid (book, health record, audiotape)
Instructions for patients taking liquid morphine	Oxford Radcliffe Hospitals www.oxfordradcliffe.nhs.uk	2 page booklet
Laryngectomy Stoma Care	Oxford Radcliffe Hospitals	6 page booklet
Major head and neck operation with reconstruction	Oxford Radcliffe Hospitals	7 page booklet
Partial Glossectomy	Oxford Radcliffe Hospitals	3 page booklet
Neck Dissection	Oxford Radcliffe Hospitals	7 page booklet
Specialist nurses: head and neck cancer	Oxford Radcliffe Hospitals	6 page booklet
A guide to the management of a sore mouth etc	Oxford Radcliffe Hospitals	6 page booklet
Information about the head and neck team at The Radcliffe Infirmary	Oxford Radcliffe Hospitals	7 page booklet
Gastro-oesophageal reflux	Oxford Radcliffe Hospitals	5 page booklet
Parotidectomy	Oxford Radcliffe Hospitals	5 page booklet
CF Chemotherapy	Oxford Cancer Centre	3 page A4 fact sheet
Methotrexate Information Leaflet	Oxford Cancer Centre	2 page A4 fact sheet
If you have poor lip-closure	Oxford Radcliffe Hospitals	1 page A5 fact sheet
If your dentures or dental plate do not fit	Oxford Radcliffe Hospitals	1 page A5 fact sheet
If your jaw is tight and stiff	Oxford Radcliffe Hospitals	2 page A5 fact sheet
If you have problems moving food to the back of your mouth with your tongue	Oxford Radcliffe Hospitals	2 page A5 fact sheet
Oral care for oncology patients	Anglian Pharma Sales and Marketing Ltd www.anglianpharma.com/anglian/	Fold-out leaflet
Nozoil	Anglian Pharma Sales and Marketing Ltd	Fold-out leaflet
The complete dry mouth treatment	Anglian Pharma Sales and Marketing Ltd	Fold-out leaflet
Patient's guide to the mould room	Oxford Cancer Centre	Fold-out leaflet

Copyright 2007 Picker Institute Europe. All rights reserved.

E: Head & neck cancer

Title	Publisher	Description
Radiotherapy for cancer of the head and neck	Oxford Cancer Centre	Fold-out leaflet
When cancer affects the way you look	Changing Faces	22 page booklet
Understanding cancers of the mouth and throat	CancerBACUP www.cancerbacup.org.uk	45 page booklet
Understanding cancers of the head and neck	CancerBACUP	72 page booklet
Understanding cancer of the larynx	CancerBACUP	56 page booklet
Coping with hair loss	CancerBACUP	46 page booklet
Information for Laryngectomy patients	The National Association of Laryngectomee Clubs www.nalc.ik.com/	3 page booklet
Emergency resuscitation	The National Association of Laryngectomee Clubs	Fold-out leaflet
The National Association of Larngectomee Clubs	The National Association of Laryngectomee Clubs	Fold-out leaflet
Living with a pharyngo-laryngo-oesophagectomy	The National Association of Laryngectomee Clubs	4 booklets in folder
Professional care for laryngectomees	The National Association of Laryngectomee Clubs	3 leaflets in folder
Living with a Laryngectomy	The National Association of Laryngectomee Clubs	4 booklets in folder
Laryngectomy stoma care	The National Association of Laryngectomee Clubs	Fold-out leaflet
Handbook for laryngectomy patients	The National Association of Laryngectomee Clubs	40 page booklet
Nursing and Laryngectomee Care	The National Association of Laryngectomee Clubs	Video (primarily for health professionals)
Talking it Through	Sunderland Laryngectomee Club	Video
Maggie's cancer caring centre Edinburgh	Maggie's Centre www.maggiescentres.org	Fold-out leaflet
The Countess Howe Cancer Information Room	Stoke Mandeville Hospital	Fold-out leaflet
Mouth cancer: how to reduce your risk	Cancer Research UK www.cancerresearchuk.org	Fold-out leaflet
General information for patients undergoing head and neck surgery	Ulster Community and Hospitals Trust www.ucht.n-i.nhs.uk	10 page booklet
Exercises to increase	South Devon Healthcare	A4 fact sheet

Copyright 2007 Picker Institute Europe. All rights reserved.

E: Head & neck cancer

Title	Publisher	Description
mobility following a neck dissection	www.sdhct.nhs.uk/services/headneck	
Care of your Blom Singer Valve	South Devon Healthcare	A4 fact sheet
Making of radiotherapy treatment masks	South Devon Healthcare	A4 fact sheet
Care of the skin during and after radiotherapy to the head and neck	South Devon Healthcare	A4 fact sheet
Neck dissection	South Devon Healthcare	2 page A4 fact sheet
Salivary gland cancer	South Devon Healthcare	2 page A4 fact sheet
Nasal Sinus and Nasal Cavity cancer	South Devon Healthcare	2 page A4 fact sheet
Patient information about The Joint Head and Neck Oncology Clinic	South Devon Healthcare	2 page print-out from intranet site
Information for Patients having a Percutaneous Endoscopic Gastronomy	South Devon Healthcare	3 page print-out from intranet site
Community Macmillan Nurse Specialists	South Devon Healthcare	2 page print-out from intranet site
Care of the mouth during and after radiotherapy	South Devon Healthcare	3 page print-out from intranet site
General information for patients undergoing head & neck surgery	Ulster Community Hospitals	4 page booklet

F: Cleft lip & palate

Title	Publisher	Description
Alveolar Bone Graft	Nottingham City Hospital	2 page booklet
Pharyngoplasty or Veloplasty	Nottingham City Hospital	2 page booklet
Lip Adhesion	Nottingham City Hospital	2 page booklet
Cleft Palate	Nottingham City Hospital	4 page booklet
Cleft Lip	Nottingham City Hospital	2 page booklet
CLAPA	CLAPA www.clapa.com	Fold-out leaflet (2 versions)
Jessica's Cleft Lip and Palate	CLAPA	26 page illustrated booklet for children
Help with feeding	CLAPA	7 page booklet
Bottles and teats	CLAPA	4 page catalogue
Antenatal diagnosis of cleft lip and palate	CLAPA	7 page booklet

Copyright 2007 Picker Institute Europe. All rights reserved.

F: Cleft lip & palate

Title	Publisher	Description
Speech	CLAPA	11 page booklet
Children Born with Cleft Lip & Palate: The School Years	CLAPA	15 page booklet for teachers, parents and carers
Children Born with Cleft Lip & Palate	CLAPA	15 page booklet for parents and carers
Lifeline	CLAPA	Video. Item on fundraising programme about the work of CLAPA. Channel 4.
Sherwood Forest	CLAPA	Video of Summer Camp 2001
Cleft lip and palate: a guide for sonographers	CLAPA	19 page booklet
Left Clip	CLAPA	Magazine for young people (Jan. 2004)
CLAPA News	CLAPA	Annual newsletter (2003 & 2004)
Help with feeding	CLAPA	7 page booklet in Urdu (photocopy)
Cleft Lip and Palate	CLAPA	6 small posters: Antenatal Diagnosis; Early Care; Surgery – treatment options; Orthodontics; Speech and Language Therapy; Psychology
A guide to orthognathic surgery	GOSH www.gosh.nhs.uk	6 page booklet
Speech and language development	GOSH	6 page booklet
Speech prostheses in the management of nasal speech	GOSH	3 page booklet
Investigations of nasal speech	GOSH	3 page booklet
Early speech development	GOSH	6 page booklet
The treatment of cleft lip and palate	The Royal College of Surgeons of England www.rcseng.ac.uk	36 page booklet
Feeding your baby with cleft lip and palate	NHS www.nhs.uk	16 page booklet
North Thames Cleft Centre	GOStA	Fold-out leaflet
Caring for your baby following cleft lip repair	North Bristol NHS Trust	2 page booklet
Caring for your baby following cleft palate repair	North Bristol NHS Trust	2 page booklet
Advice following surgery for speech improvement	North Bristol NHS Trust	2 page booklet
Advice following an alveolar	North Bristol NHS Trust	2 page booklet

Copyright 2007 Picker Institute Europe. All rights reserved.

F: Cleft lip & palate

Title	Publisher	Description
bone graft		
Feeding a baby with a cleft lip and palate	Birmingham Children's Hospital www.bch.org.uk	6 page leaflet

G: Craniofacial conditions

Title	Publisher	Description
Headline News	Craniofacial Support Group www.headlines.org.uk	Quarterly magazine (Issue nos. 28, 29, 31-34, 37)
The Headlines from Headlines Craniofacial Support 2003-2004	Craniofacial Support Group	Annual Report
Resource List	Craniofacial Support Group	7 page booklet
What causes Craniosynostosis?	Craniofacial Support Group	15 page booklet
Non-syndromic Craniosynostosis	Craniofacial Support Group	7 page booklet
The Surgical Treatment of Hand Anomalies	Craniofacial Support Group	7 page booklet
NSCAG and the Four Designated Craniofacial Units	Craniofacial Support Group	4 page booklet
Glossary of terms associated with Craniosynostosis	Craniofacial Support Group	10 page booklet
Muenke Syndrome	Craniofacial Support Group	7 page booklet
Coping with disfigurement	Craniofacial Support Group	8 page booklet
Eye aspects of craniofacial conditions	Craniofacial Support Group	7 page booklet
Occipital (Positional) Plagiocephaly	Craniofacial Support Group	3 page booklet
The Craniofacial Support Group is here to help	Craniofacial Support Group	Fold-out leaflet
Aperts' Syndrome	Craniofacial Support Group	3 page booklet
Craniofacial Surgery	Craniofacial Support Group	8 page booklet
Crouzon Syndrome	Craniofacial Support Group	3 page booklet
Pfeiffer Syndrome	Craniofacial Support Group	3 page booklet
Saethre-Chotzen Syndrome	Craniofacial Support Group	2 page booklet
Parental Aspects of Craniofacial Conditions	Craniofacial Support Group	8 page booklet
Your child in hospital	Craniofacial Support Group	3 page booklet
The genetic background to	Craniofacial Support Group	2 page booklet

G: Craniofacial conditions

Title	Publisher	Description
Craniosynostosis		
Breathing problems in craniofacial syndromes	Craniofacial Support Group	6 page booklet
Craniofacial Rehabilitation	Entific Medical Systems www.entific.com/Vistafix.asp	15 page booklet
What happens in the craniofacial unit	Oxford Radcliffe Hospitals	Fold-out leaflet
What is Occipital Plagiocephaly?	Royal Liverpool Children's NHS Trust www.alderhey.org.uk	2 page booklet
Information for children young people and families	Royal Liverpool Children's NHS Trust Craniofacial Unit	7 page booklet
The CRANE Database	Craniofacial Anomalies Network www.perinatal.org.uk/crane	Fold-out leaflet
Orthognathic Surgery	British Orthodontic Society www.bos.org.uk	Fold-out leaflet
Information on Orthognathic Surgery	Eastman Dental Hospital www.eastman.ucl.ac.uk	3 page booklet
The Facemask Appliance	Eastman Dental Hospital	6 page booklet
A Guide to Goldenhar Syndrome and Hemifacial Microsomia	Goldenhar Syndrome Hemifacial Microsomia Family Contact Group	12 page booklet
Looking Different	GOSH	3 page booklet
Your child has Craniosynostosis	GOSH	20 page booklet
Hydrocephalus	GOSH	9 page booklet
Tiger Ward	GOSH	10 page booklet
Bringing up a child whose face looks different	GOSH	9 page booklet
Craniofacial Unit	GOSH	Patient folder
Single Suture Synostosis	GOSH	2 page fact sheet
So you've been framed	National Craniofacial Benchmarking Group and Martin	12 page booklet for patients and parents on the red frame
Posterior Plagiocephaly	GOSH	2 page letter for child's GP
Rigid External Distraction	Gebruder Martin GmbH	19 page booklet for clinicians
The Leipzig Retention Plate	Gebruder Martin GmbH	7 page booklet for clinicians

Copyright 2007 Picker Institute Europe. All rights reserved.

G: Craniofacial conditions

Title	Publisher	Description
Technique		
External Rigid Distraction Device	Gebruder Martin GmbH	Video for clinicians

H: Birthmarks

Title	Publisher	Description
Looking Different	GOSH	3 page booklet for children
Smile and face it	The Birthmark Support Group www.birthmarksupportgroup.org.uk	Fold-out leaflet
About birthmarks	Disfigurement Guidance Centre	40 page book
Puss Puss and the magic laser	Disfigurement Guidance Centre	Booklet for children
Strawberry marks and port wine stains	B.A.D.	5 page booklet

I: Skin camouflage

Title	Publisher	Description
The Skin Camouflage Cosmetic Handbook	Disfigurement Guidance Centre	Book about skin disorders, treatments and cosmetic camouflage.
Help to regain your confidence	British Red Cross www.redcross.org.uk	Fold-out leaflet
Veil Cover Cream	Thomas Blake and Co.	4 page booklet
The Dermablend Cover System	Brodie and Stone Plc	Fold-out leaflet
Facing the world	The British Association of Skin Camouflage www.skin-camouflage.net	Fold-out leaflet
British Association of Skin Camouflage Newsletter	British Association of Skin Camouflage	Newsletter (Issues 62 and 63)
Skin Camouflage	Changing Faces	3 page fact sheet

J: Eyes

Title	Publisher	Description
Insight into removal of an eye (Enucleation)	Moorfields www.moorfields.org.uk	13 page booklet
Insight into Ptosis	Moorfields	13 page booklet
Insight into DCR (Dacryocystorhinostomy)	Moorfields	9 page booklet
Summary of insight into	Moorfields	3 page booklet

Copyright 2007 Picker Institute Europe. All rights reserved.

J: Eyes

Title	Publisher	Description
corneal graft		
Summary of insight into Squint (strabismus)	Moorfields	3 page booklet
Orbital Decompression for Thyroid Eye Disease	Moorfields	4 page A4 fact sheet
Make friends with Moorfields	The Friends of Moorfields	Fold-out leaflet
Thyroid Eye Disease	TED Association	Fold-out patient information leaflet
What Happened to Your Eye?	Changing Faces	26 page booklet
A Singular View: The Art of Seeing with One Eye	Frank. B. Brady Edgmore Publishers	A short paperback book about one mans experience of living with one eye.
Blinded	Twenty-Twenty for Channel Four www.twentytwenty.tv	3 x 1 hour TV documentaries about Moorfields Eye Hospital

K: Amputees & prosthetics

Title	Publisher	Description
Your prosthetic finger	South Manchester University Hospitals www.smuht.nwest.nhs.uk/	Fold-out leaflet
Your implant retained prosthesis	South Manchester University Hospitals	Fold-out leaflet
Your NAC Prosthesis	South Manchester University Hospitals	Fold-out leaflet on prosthetic nipples
Your prosthesis	South Manchester University Hospitals	Fold-out leaflet
Counselling and hypnosis	South Manchester University Hospitals	Fold-out leaflet for patients attending the Disablement Services Centre
Champs	British Amputee & Les Autres Sports Association	Fold-out leaflet about sport for young amputees
We don't take walking for granted	The National Association for Children with Lower Limb Abnormalities www.steps-charity.org.uk	Fold-out leaflet about STEPS self-help group
Counselling and Support	Murray Foundation www.murray-foundation.org.uk	Fold-out leaflet
About The Murray Foundation	Murray Foundation	Fold-out leaflet
The Murray Foundation Conference Day	Murray Foundation	7 page conference programme including sections on paediatric rehabilitation, above and below knee prosthetics

K: Amputees & prosthetics

Title	Publisher	Description
Hospital visitors: code of ethics and practice	Murray Foundation	4 page booklet for amputees who visit new patients
Hospital visitors: prosthetic illustrations – upper limb	Murray Foundation	4 page booklet of illustrations for use by hospital visitors
Hospital visitors: prosthetic illustrations	Murray Foundation	6 page booklet of illustrations for use by hospital visitors
Information for new patients	Murray Foundation	7 page booklet
Foundations	Murray Foundation	Quarterly magazine
Hospital Visitors Register	Murray Foundation	Contact details and availabilty
Within Reach	Association for Children with Hand or Arm Deficiency www.reach.org.uk	Quarterly magazine
Goal	Manchester Prosthetic User Group	Quarterly magazine (issues 3-5)
The art of living	Dorset Orthopaedic www.dorset-ortho.co.uk	Information pack containing details of different prostheses available, individual patient stories and newsletters.
Looking after yourself	The Murray Foundation	Video
Living with your prosthesis	The Murray Foundation	Video
Physiotherapy and occupational therapy	The Murray Foundation	Video
Manufacture of artificial limbs	The Murray Foundation	Video
Going Home	The Murray Foundation	Video
The Way Forward	The Murray Foundation	Video
Information for New Patients	The Murray Foundation	Booklet with photographs about rehabilitation process post amputation
Who we are, where we are, what we do.	Disabled Living www.dlf.org.uk	Booklet
The Prosthetic Service Information for Patients	South Manchester University Hospitals NHS Trust	Booklet about the prosthetic services at the Disablement Services Centre
Wheelchairs: Advice on Private Purchase	The Murray Foundation	Booklet on aspects of purchasing a wheelchair
Phantom Limb Following Amputation	The Murray Foundation	A4 sheet on effects of phantom limb.

Copyright 2007 Picker Institute Europe. All rights reserved.

7.2 Materials listed by respondents but not supplied

Title	**Publisher**
Dermatology	
Ciclosporin	National Eczema Society
Topical steroids	National Eczema Society
Varicose eczema	National Eczema Society
Nickle allergy	National Eczema Society
Eczema can afflict anyone	National Eczema Society
Tacrolimus ointment	National Eczema Society
Pimecrolimus cream	National Eczema Society
Topical corticosteroids	National Eczema Society
Wet wraps	National Eczema Society
Gravitational eczema	National Eczema Society
Hand eczema	National Eczema Society
Seborrhoic eczema	National Eczema Society
Discoid eczema	National Eczema Society
Information for patients on patch testing	Crawford Pharmacy, Milton Keynes
A parent's guide to wet wrap treatment	Seton Health Care Management Division, Oldham
Vitiligo Society	Vitiligo Society
All about solar keratosis	Bioglan Laboratories
Treatment with effudix	ICN Pharmacy, Hants
Psoriasis: what is it?	Psoriasis Association
Psoriasis in children	Psoriasis Association
Psoriatic arthritis	Psoriasis Association
Scalp psoriasis	Psoriasis Association
Genital psoriasis	Psoriasis Association
Alopecia	Rotherham NHS Trust
Solar (actinic) keratosis	Rotherham NHS Trust
Pulsed dye laser	Rotherham NHS Trust
Polymyositis	A.R.C. Laser
Raynauds	A.R.C. Laser
Vasculitis	A.R.C. Laser
Acne	British Association of Dermatologists
Strawberry marks and port wine stains	British Association of Dermatologists
Itchthiosis	British Association of Dermatologists
Contact dermatitis	British Association of Dermatologists
Scleroderma	Raynauds and Scleroderma Society
Raynauds	Raynauds and Scleroderma Society
Skin care	Raynauds and Scleroderma Society

Copyright 2007 Picker Institute Europe. All rights reserved.

Title	Publisher
Mixed tissue disease	Raynauds and Scleroderma Society
Understanding psoriasis	Leo Laboratories
Dovobet	Leo Laboratories
Skin cancer	
Understanding malignant melanoma	CancerBACKUP
Skin cancer	Cancer Research UK
Malignant melanoma	Cancer Research UK
Basal cell carcinoma	Wessex Cancer Trust
Head & neck cancer	
Laryngectomy: your questions answered	Royal Marsden NHS Trust
Helping people live with cancer	CancerBACKUP
Understanding Radiotherapy	CancerBACKUP
Understanding Chemotherapy	CancerBACKUP
Cancer of the larynx	CancerBACKUP
Facing the challenge of advanced cancer	CancerBACKUP
Nurses	Macmillan Cancer Relief
Patient Grants	Macmillan Cancer Relief
About Macmillan information services	Macmillan Cancer Relief
What can I claim	Macmillan Cancer Relief
Talking to children	Macmillan Cancer Relief
The cancer guide	Macmillan Cancer Relief
Help with the cost of cancer	Macmillan Cancer Relief
Living with cancer	Macmillan Cancer Relief
Beating worries that won't go away	Neurolink
Overcoming depression	Neurolink
Caring for your silver tracheostomy tube	Southampton University Hospitals NHS Trust
General radiotherapy leaflet	Southampton University Hospitals NHS Trust
Mould Room	Southampton University Hospitals NHS Trust
CT Scan	Southampton University Hospitals NHS Trust
Laryngectomy and Voice Restoration Drop-in Clinic	Southampton University Hospitals NHS Trust
Tracheostomy: Adult home care guide (booklet and video tape)	Mallinckrodt
Body talk: Dr Hilary Jones tells you all about tracheostomy	Mallinckrodt
Tracheostomy Care	Simms Portex
Build Yourself Up	Wessex Cancer Trust
Life as a Laryngectomee	Platon Medical
Heat and moisture exchange filters	Platon Medical
Platon News	Platon Medical
Tracheo oseophlageal voice restoration after Total	INHEALTH

Copyright 2007 Picker Institute Europe. All rights reserved.

Title	Publisher
Laryngectomy	
Provox Patient information video	Atos Medical Platon
Cleft lip & palate	
Feeding booklet	Nottingham City Hospital
Prenatal leaflet	Nottingham City Hospital
Breast feeding video	Nottingham City Hospital
Feeding videos	Nottingham City Hospital
I had an incomplete unilateral cleft lip	Nottingham City Hospital
I had a complete unilateral cleft lip	Nottingham City Hospital
I had an incomplete bilateral cleft lip	Nottingham City Hospital
I had a complete bilateral cleft lip	Nottingham City Hospital
I had Pierre Robin Sequence	Nottingham City Hospital
Unilateral cleft lip and bilateral cleft lip with lengthening of columella	Nottingham City Hospital
Post operative leaflets	Nottingham City Hospital
Cleft lip (male and female leaflets)	North Bristol NHS Trust
Unilateral cleft lip and palate (m/f)	North Bristol NHS Trust
Bilateral cleft lip and palate (m/f)	North Bristol NHS Trust
Cleft treatment schedule	North Bristol NHS Trust
Birthmarks	
Vascular birthmarks	British Association of Dermatologists

Copyright 2007 Picker Institute Europe. All rights reserved.

7.3 Production/evaluation guidelines and toolkits

Title	Publisher	Description
How to produce information for parents, children and young people	Birmingham Children's Hospital (2003) www.bch.org.uk/patients	Guidelines to help staff write patient information leaflets
Good Practice Resource Pack for cancer self help and support groups	Cancerlink www.cancerlink.org	Ring-binder format with section on giving information
Involving consumers in the development and evaluation of patient information	Centre for Health Information Quality (1999)	Bulletin outlining how health professionals and users can work together to develop information materials
Judge: Web Sites for Health	Contact a Family, the Information Management Research Inst. Northumbria University and CHIQ (2003) www.judgehealth.org.uk	Guidelines for judging the quality of health information web sites based on the views of health consumers and support groups
Toolkit for producing patient information	Department of Health (version 2 Dec. 2003) www.doh.gov.uk/nhsidentity	Guidance on how to produce written information for patients and a series of templates
Quality criteria for health-related websites.	European Commission (2002) http://europa.eu.int/information_society	EU communication setting out core set of quality criteria
EQIP: Ensuring Quality Information for Patients	GOSH (2004) www.gosh.nhs.uk/gosh_families	Assessment tool and quality check
How to produce information for children and families	GOSH (2004)	Support tool for staff
QUICK (Quality Information Checklist)	HDA and CHIQ (2000) www.quick.org.uk	Resource to help young people evaluate information on the internet
Health on the Net principles.	Health on the Net Foundation (2006) www.hon.ch/HONcode/conduct	Code of conduct for medical and health websites
Producing information about health and health care interventions: a practical guide	Health Services Research Unit, University of Aberdeen (2003) www.abdn.ac.uk/hsru	Useful ideas and practical advice on how to assess, develop and revise health information materials
Guidelines for Reviewers of Health Information	Help for Health Trust (2002)	Guidelines to assess quality of health information
Guidelines for producing health information	Help for Health Trust (2002)	Guidelines to ensure high standards in health information
International Patient Decision Aids Standards.	IPDAS Collaboration (2005) http://ipdas.ohri.ca	Internationally approved set of criteria to determine the quality of patient decision aids

Copyright 2007 Picker Institute Europe. All rights reserved.

Title	Publisher	Description
Informing Patients	King's Fund (1998) www.kingsfund.org.uk	Includes guidelines for the development of good quality patient information materials
Macmillan Black and Ethnic Minority Toolkit	Macmillan Cancer Relief (2002) www.macmillan.org.uk	Effective communication with South Asian people affected by cancer
Macmillan Black and Ethnic Minority Toolkit	Macmillan Cancer Relief (2004)	Effective communication with African-Caribbean and African men affected by prostate cancer
Make it clear	MENCAP (2005) www.mencap.org.uk	A guide to making information easy to read and understand
The LIDA Instrument	Minervation (2004) www.minervation.com	Validation instrument for health care web sites
Lynda Jackson Macmillan Centre and the Mount Vernon Cancer Centre procedure for producing written information	Mount Vernon Cancer Network (2003) www.mountvernoncancernetwork.nhs.uk	12 point plan
Improving Communication in Cancer Care	NHS Modernisation Agency (2003)	Basic principles in communication improvement
Improving the patient and carer experience across Cancer Services Collaborative "Improvement Partnership"	NHS Modernisation Agency	Quick guide to ensuring that cancer patients and carers are offered high quality information
How to write medical information in plain English	Plain English Campaign (2001) www.plainenglish.co.uk	Guide to making notices, letters and medical information clearer
Raising the Standard: Information for Patients	Royal College of Anaesthetists and The Assoc of Anaesthetists of GB (2003) www.rcoa.ac.uk	Book + CD. Principles, samples of current practice and new text
See it Right Guidelines	Royal National Institute for the Blind www.rnib.org.uk	Practical advice on designing, producing and planning for accessible information.
Right from the Start	SCOPE (2003) www.scope.org.uk	Template for giving difficult information to parents
BIOME guidelines.	University of Nottingham (2006) www.biome.ac.uk/guidelines	Detailed criteria for selecting resources for guide to biomedical information.
DISCERN	University of Oxford (1999) www.discern.org.uk	Instrument for judging the quality of written information

Copyright 2007 Picker Institute Europe. All rights reserved.

7.4 Material evaluated by patients and health professionals

		Evaluated by:	
Title of material & publisher	**Condition**	**Patient**	**Health Pro.**
Disabled living (Disabled Living Charity)	Amputee	Y	N
Phantom Limb following amputation (Murray Foundation)	Amputee	Y	N
The prosthetic service: information for patients (Sth Manchester University Hospitals NHS Trust)	Amputee	Y	N
Upper Limb: Information for New Patients (Murray Foundation)	Amputee	Y	N
Wheelchairs. Advice on private purchase (Murray Foundation)	Amputee	Y	N
Admission to the Yorkshire Regional Burns Centre (video) (Pinderfields Hospital)	Burns	Y	Y
Burns (BUPA website)	Burns	N	Y
Care of your skin graft and donor site (Mount Vernon Hospital)	Burns	Y	Y
Discharge information leaflet for patients with burns (South Manchester University Hospitals)	Burns	N	Y
Home at Last! (McIndoe Burns Support Group)	Burns	Y	Y
Managing The Future After Burns (Changing Faces)	Burns	Y	Y
Scar Information Service / Cica Care (Smith & Nephew)	Burns	Y	Y
Treatment Options Within Reach (Integra)	Burns	Y	Y
A guide to orthognathic surgery (GOSH)	Cleft lip & palate	Y	N
Caring for your baby following cleft lip repair (North Bristol NHS Trust)	Cleft lip & palate	Y	N
Cleft lip and palate (mini-poster series) (CLAPA)	Cleft lip & palate	Y	N
Feeding your baby with a cleft lip and palate (Trent Regional Cleft Lip & Palate Team)	Cleft lip & palate	Y	N
The treatment of cleft lip & palate (Royal College of Surgeons)	Cleft lip & palate	Y	N
A Guide to Goldenhar Syndrome and Hemifacial Microsomia (Goldenhar Syndrome Hemifacial Microsomia Family Contact Group)	Craniofacial	N	Y
Contact a family (website) (Contact a Family)	Craniofacial	Y	N
Craniofacial rehabilitation (Entific Medical Systems)	Craniofacial	N	Y
Craniofacial surgery (Headlines)	Craniofacial	Y	N
My Child Looks Different (Changing Faces)	Craniofacial	Y	N
Supra Regional Craniofacial Unit: Info… (Royal Liverpool Children's NHS Trust)	Craniofacial	Y	N
What causes craniosynotosis? (Headlines)	Craniofacial	Y	Y
What is Occipital Plagiocephaly? (Royal Liverpool Children's NHS Trust)	Craniofacial	Y	Y

Copyright 2007 Picker Institute Europe. All rights reserved.

		Evaluated by:	
Title of material & publisher	**Condition**	**Patient**	**Health Pro.**
Your child has craniosynostosis (Great Ormond Street Hospital)	Craniofacial	Y	N
A singular view. The art of seeing with one eye (Frank B. Brady/Edgemore Publishers)	Eye cancer	Y	N
Insight into removal of an eye (Moorfields Eye Hospital NHS Trust)	Eye cancer	Y	N
Make friends with Moorfields (The Friends of Moorfields Eye Hospital)	Eye cancer	Y	N
What happened to your eye? (Changing Faces)	Eye cancer	Y	N
After care at home following breast surgery (St Andrew's Centre of Plastic Surgery)	Gen Plastics	N	Y
Face to face makes the difference (Entific Medical Systems)	Gen Plastics	N	Y
Facing disfigurement with confidence (Changing Faces)	Gen Plastics	Y	Y
Frenchay Hand Centre (North Bristol NHS Trust)	Gen Plastics	N	Y
Living with Melanoma (Wessex Cancer Trust)	Gen Plastics	N	Y
Talking to health professionals about disfigurement (Changing Faces)	Gen Plastics	Y	Y
General info for patients undergoing head & neck surgery (Ulster Community Hospitals Trust)	H&N cancer	Y	Y
Radiotherapy for cancer of the head and neck (Clinical Oncology, Churchill Hospital Oxford)	H&N cancer	Y	Y
Specialist Nurses: Head and Neck Cancer (Oxford Radcliffe Hospitals NHS Trust)	H&N cancer	Y	Y
Understanding Cancers of the Head and Neck (Cancerbacup)	H&N cancer	Y	Y
When cancer affects the way you look (Changing Faces)	H&N cancer	Y	Y
Damned White Spots (Karin Uta Schallreuter, Bradford University)	Vitiligo	Y	Y
Facing the World (British Association of Skin Camouflage)	Vitiligo	Y	Y
Moderate and severe psoriasis (British Association of Dermatologists)	Vitiligo	Y	N
The Skin Camouflage Cosmetic Aid Handbook (The Skin Camouflage Campaign)	Vitiligo	Y	Y
What is Vitiligo? (The Vitiligo Society)	Vitiligo	Y	Y
When a medical skin condition affects the way you look (Changing Faces)	Vitiligo	Y	Y

Copyright 2007 Picker Institute Europe. All rights reserved.

7.5 Questionnaire for users evaluating material

Title of Material:………………………………………………………………………………..

…………………………………………………………………………………………

<u>Please give your rating for each question by circling the number that best corresponds to your view of the material</u>

Content

1. Does the information material make clear what it is about? *(Hint: does it say what topics it is meant to cover)*

Not at all clear   Very clear
1 2 3 4 5 6 7 8 9 10

2. Does the information material cover all the topics it says it will?

None of them   All of them
1 2 3 4 5 6 7 8 9 10

3. Does the information material make clear who it is for? *(Hint: does it say whether it is aimed at adults, children, newly diagnosed, carers etc)*

Not at all clear   Very clear
1 2 3 4 5 6 7 8 9 10

4. Is it useful to the people it says it is for?

Not at all useful   Very useful
1 2 3 4 5 6 7 8 9 10

Presentation

5. Is it easy to understand the language used in the information material?

Not at all easy   Very easy
1 2 3 4 5 6 7 8 9 10

6. Is the tone of the information material appropriate for its content and audience? *(hint: is it friendly? patronising? formal? chatty?)*

Not at all appropriate   Very appropriate
1 2 3 4 5 6 7 8 9 10

7. Does the information material explain technical terms clearly?

Not at all clearly   Very clearly
1 2 3 4 5 6 7 8 9 10

8. Is the information material well designed? *(hint: look at colour, lay-out, etc)*

Not at all well Very well
1 2 3 4 5 6 7 8 9 10

9. Is the information material well structured? *(hint: look at the way the information is organised)*

Not at all well Very well
1 2 3 4 5 6 7 8 9 10

Trust and reliability

10. Is it clear **who** produced the information material? *(hint: look for an author, sponsor, name of organisation or production company)*

Not at all clear Very clear
1 2 3 4 5 6 7 8 9 10

11. Is it clear **when** the information material was produced? *(hint: look for date or year of publication)*

Not at all clear Very clear
1 2 3 4 5 6 7 8 9 10

12. Does the information material provide evidence for any statements or claims it makes? *(hint: does it back up its claims by referring to scientific papers etc?)*

No evidence Lots of evidence
1 2 3 4 5 6 7 8 9 10

13. Does the information material discuss gaps in knowledge about [condition] or any differences of opinion about treatments? *(hint: does it say whether there are any uncertainties about causes, treatment effects etc)*

Not at all Yes, definitely
1 2 3 4 5 6 7 8 9 10

14. Is the information balanced and unbiased? *(hint: is it presented from a one-sided point of view or does it give lots of different points of view?)*

Not at all balanced Very balanced
1 2 3 4 5 6 7 8 9 10

Copyright 2007 Picker Institute Europe. All rights reserved.

15. Does the information material provide details of how to get further information or support? *(hint: does it have a list of other organisations providing advice or information? does it provide a helpline number?)*

Not at all Yes, definitely
1 2 3 4 5 6 7 8 9 10

16. Would this information material make you feel more confident about coping with your condition?

Not at all Yes, definitely
1 2 3 4 5 6 7 8 9 10

17. Would you recommend this information material to someone with the same condition?

Not at all Yes, definitely
1 2 3 4 5 6 7 8 9 10

18. Having completed the checklist, what overall rating would you give this information material?

1 2 3 4 5 6 7 8 9 10

19 At what stage on a patient journey would this information have been most useful?

Initial Diagnosis Pre-Treatment Treatment Self-Care

Copyright 2007 Picker Institute Europe. All rights reserved.

7.6 Topic guide for health information providers

How long you have been producing information for patients/parents?

Do you have a written statement of your information development process?

How much do you spend each year on developing and disseminating patient information?

Are you able to estimate how many patients/parents or members of the public access your information materials?

Section 1: The development process

There's a wide variety of information that patients/parents might need - how do you choose which topics and issues to address?

- How do you find out what patients' information needs are?
- Are there opportunities for patients and health professionals to be involved in the development process?

Once information materials have been drafted, what procedures do you have for reviewing them?

- Do you ask patients to field-test or read over draft materials?
- Are draft materials reviewed by health professionals?

Do you find that changes are often made on the basis of expert review/patient or parent feedback?

- Are there situations in which you wouldn't make changes based on comments from patients/professionals?

Thinking about any medical content in the information, what research do you do prior to drafting the materials?

- Where and how do you look for the research evidence?
- Do you find any sources of evidence particularly useful when preparing materials?
- How easy it is to find research evidence for the topics you're covering?
- Are there topics where it has been difficult to identify relevant research evidence?

Given the rate at which new research is being published, how easy do you find it to keep the content of your patient information up to date?

- Do you have a process for revising and updating information materials?
- What length of time do you tend to leave before reviewing the content of information patients?

How do you ensure that patients/parents are able to easily read and understand your information materials?

- Do you test materials for readability?
- Do any of your materials have the Plain English Crystal Mark?
- Are materials field-tested by patients/parents with different needs and abilities?
- Do you produce information in alternative formats or languages?
- How do accessibility issues shape the information development process?

Once materials have been developed, do you have any methods for ensuring that the information gets to patients/parents that need it?

- How is your information distributed?
- How are your leaflets/website publicised?
- Have you found any effective ways of promoting your information to health professionals?
- Have you received feedback from patients/parents or health professionals on your information?

Section 2: Opinions on accreditation/quality standards

We've drawn up a set of quality criteria for patient information:

Section 1: Content

Does the information leaflet/website...

- Start with a clear statement of its aims
- Contain accurate information
- Disclose conflicts of interest
- Have a clear structure and layout
- Help patients to make appropriate decisions

Section 2: Development

Does the information provider...

- Follow a systematic development process, with opportunities for patient and professional involvement
- Identify and use up-to-date information
- Identify and address usability issues, such as readability and accessibility
- Have a plan to promote access to and use of their information

How useful do you think the above criteria would be for assessing the quality of patient information?

- Do these criteria cover all the important aspects of information quality?
- Is there anything else you would add to them?
- Do you like the idea of having two sets of criteria – one relating to the content of materials and the other to the development process?

What do you think about the idea of accrediting patient information on the basis of these criteria?

- What impact do you think accreditation would have on the quality of information for patients with conditions that affect their appearance?
- Do you think patients/parents are more likely to use information that's been accredited?
- How do you feel about a scheme that would accredit provider organisations rather than individual pieces of information?

If an accreditation scheme was established using these quality criteria, do you think you would be likely to apply?

- Do you already have any form of accreditation for your patient information? Would this affect your interest in applying for accreditation through a new scheme?
- Is there anything in particular which would discourage you from applying?
- What benefits would you expect Headlines to gain from achieving accreditation?
- Are there any particular areas or issues which might need attention before applying for accreditation?
- Can you think of any support needs you might have in working towards the standards for accreditation?
- If you had to pay for accreditation [£500/£1000 etc], would your organisation be likely to apply?

Copyright 2007 Picker Institute Europe. All rights reserved.

Picker Institute Europe
King's Mead House
Oxpens Road
Oxford OX1 1RX

Tel: +44 (0)1865 208100
Fax: +44 (0)1865 208101
Email: info@pickereurope.ac.uk
Website: www.pickereurope.org

Charity Registration no: 1081688

picker INSTITUTE

making patients' views count