



THE HEALING FOUNDATION

Rebuilding the bodies, minds and lives of people with disfigurements

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INSTITUTE

making patients' views count

○ Information for People Living with Conditions that Affect their Appearance

SUMMARY AND RECOMMENDATIONS

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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.

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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. This paper provides an overview of the research programme, drawing out common themes, summarizing key findings and presenting recommendations.

2 Introduction

Living with a physical or health condition which affects one's appearance is not easy. Leaving aside any pain, discomfort or loss of function, ours is not a society which comfortably accepts bodily appearances which depart from the accepted norm. Reasons for disfigurement are wide-ranging and various, from congenital disorders to accidents, trauma and disease. Each year for example, one in every 600-700 children in the UK is born with a cleft lip and/or palate (Cleft Lip and Palate Association), there are approximately 250,000 burn injuries (The National Burn Care Review 2001) and nearly 8,000 cases of head & neck cancer (Cancer Research UK/Office of National Statistics). Patients with any form of disfiguring condition and accompanying loss of function, will need a range of resources to make successful adjustments to their altered body image and thereby enhance their recovery. Information is a key resource. Whatever their condition, patients, their carers and families need reliable, high quality and accessible information at every stage of their journey from initial concern or injury through diagnosis and treatment to long-term rehabilitation. In all areas of our social lives most of our information exchanges are purely verbal. But increasingly information for health is produced in hard or tangible form. This project includes both the tangible and intangible forms and recognises the strengths and weaknesses of both.

Patients with disfiguring conditions can theoretically look to a number of sources for information. They are treated by a multitude of health professionals including maxillo-facial, plastic and orthopaedic surgeons, dermatologists, oncologists, psychologists, occupational and speech therapists. Numerous support groups and charitable organisations exist to assist patients and raise awareness, for example, Changing Faces, CLAPA (Cleft Lip and Palate Association), Headlines, the Skin Care Campaign, Let's Face It and CancerBACKUP (the British Association of Cancer United Patients). Private companies also offer information and advice on prosthetics and skin camouflage products.

The production of information is an increasingly complex enterprise. Many of the organizations and professionals *offering* information to patients in this field also *produce* information, as well as using each others. Information for patients living with conditions which affect their appearance is produced by a huge variety of organizations, from local healthcare teams, to national and international organizations. They produce it using differing media, and varying scales of expenditure. With technological developments the options available are now enormous, and changing rapidly. It is thus an extremely important time for an investigation into the topic.

3 Methods of Investigation

The methods adopted for the three parts of the study were as follows:

The qualitative study

This study involved interviews with a sample of patients, health professionals and representatives of the voluntary sector. Thirteen focus groups and ten one-to-one interviews were conducted. Each was tape-recorded, transcribed, and analysed using qualitative data analysis methods. Participants were chosen from groups with: congenital disorders (cleft lip & palate and craniofacial conditions); accidents (burns, amputees); disease (head & neck cancer, cancer of the eye, amputees); and skin conditions (vitiligo). Patients and carers were recruited mainly via leading charities in the field. The health professionals were recruited via the six specialist centres collaborating with this study.

In addition to informing the development of the survey instrument, the focus groups and interviews conducted at this stage enabled the exploration of more complex themes and issues around patient information.

Review and assessment of existing information materials

This study involved three types of data collection. First, in order to get an idea of the extent of information materials available to people with disfiguring conditions, we requested examples of information from a range of different information producers within the NHS, voluntary sector and elsewhere. From 48 replies we compiled an inventory of several hundred items. Secondly, we carried out telephone interviews with 11 information producers, including charities, NHS Trusts, professional associations, etc., in order to investigate the process of information production. Thirdly, we asked all participants in the qualitative study to rate a selection of information materials and to give their views on them.

Questionnaire survey

In the final stage of the research the enquiry was expanded to a much larger patient sample by means of a postal questionnaire sent to over 1,000 patients based in five specialist centres in England. The development of the questionnaire was based on the findings from a search of relevant literature published within the last ten years and the findings of the qualitative study. This is the first time that a multi-condition survey of information experiences has been attempted in the area of disfigurement. Four hundred and forty-three respondents completed the questionnaire (an overall response rate of 46%).

Research activities common to the whole programme

A review of previous research on the topic of healthcare information was carried out. This informed all parts of the programme, but is reported particularly in the qualitative study (Report I). For this review we used all major research databases, including MEDLINE, AMED (Allied and Complementary Medicine), BNID (British Nursing Index), CINAHL

(Cumulative Index to Nursing and Allied Health), EMBASE (Excerpta Medica), King's Fund and PsychINFO.

During the course of this study, researchers attended a series of seminars, conferences and special events in the fields of disfigurement and more general health information. Contact was made with many individuals working in these areas. Again these enquiries informed all parts of the work. But they are used particularly in this summary report, which includes an overview of some recent information initiatives and examples of good practice in both the public and voluntary sectors. It is our contention that some of these could serve as models for improved information provision for those living with conditions that affect their appearance.

With such triangulation of data collection and analysis approaches it was hoped both to deepen and broaden our understanding of the information needs and experiences of people with disfiguring conditions.

4 Research Findings

The common sources of information

The key themes emerging from our initial consultations with patients, parents and professionals revealed the complexity of the information process. The most important information exchange still occurs in face to face consultations with health professionals, but the nature of this exchange appears to leave many feeling dissatisfied and there are now a variety of other ways in which patients can supplement that information if they choose to do so. Survey respondents also considered health professionals to be the main sources of information, but the majority indicated that clinicians are failing to signpost them to further information. However, amongst those who had been provided with this kind of guidance, most had followed it up. Focus group participants and interviewees valued the information provided by national voluntary organizations and local support groups very highly. But many of these participants were recruited via the voluntary sector. Interestingly, national voluntary organizations and local support group emerged from the survey as some of the least popular information sources. Again, the internet emerged as a less useful source amongst survey respondents than amongst focus groups and interviewees, although the parents of children with craniofacial conditions and people with psoriasis used it more than those with burn injuries or head & neck cancer.

The timing of information

Our research also highlighted the significance of the timing of information. The long-term nature of most of the conditions under scrutiny means that needs are likely to change and fluctuate, but it was apparent that in the early stages of diagnosis or treatment, patients and parents may find it difficult to assimilate and understand the information they are given. Over a third of survey respondents with head & neck cancer and over 40% of those with other conditions agreed that doctors dictate the timing of information. A third of parents of children with craniofacial conditions and people with psoriasis felt they had to push their doctors to provide information. Yet amongst the group participants and interviewees some preferred not to be given a lot of information and wanted time to come to terms with their situation first. For all these reasons we concluded that information and information providers need to be infinitely flexible to meet the growing demands of many patients whilst still addressing the needs of the less active information-seekers.

Weaknesses in information provision

The common theme running through all our research findings was the unmet demand for information to support psycho-social adjustment. Many people in the focus groups felt they had been given little preparation for the kind of emotional reactions they would experience following their injury or treatment and little advice about how to deal with those reactions or where to go for further support. This was echoed in the responses to the survey which revealed that psycho-social topics were some of the most difficult to find across all conditions. Whilst there was a great deal of praise amongst group participants for the materials produced by Changing Faces, this was not universal. A few people felt that the philosophy of that organisation was not appropriate for everyone. A

wider range of materials should be available offering strategies for dealing with the many implications of altered appearance, although those people experiencing high levels of psychological distress will require the kind of one to one support not covered by this research.

Despite a need for flexibility in information provision, our research demonstrated that few producers are able to offer their materials in a range of different formats or in languages other than English. There were only a small number of survey respondents for whom English was not their first language, but the majority did not have access to information in a language they could understand. Those respondents with burn injuries were the most likely to report that their condition acted as a barrier to accessing information. But the majority stated that this had not been taken into account and no alternative formats, for example, audiotape or large print, had been offered to them. The audio-taping of consultations proved controversial amongst survey respondents and focus group participants. Visual materials like photographs and 3 D images seemed a relatively popular idea amongst research participants who saw their value in helping them to manage expectations post surgery. Interestingly, while the majority of survey respondents were against seeing such materials, those that had were almost universal in declaring it helpful.

Another concern expressed across several different conditions was the lack of information at primary care level. People with skin conditions will invariably be treated by their general practitioners initially and patients discharged from specialist units often have to rely on their local health centres and hospitals for continuing care. Whilst non-specialists cannot be expected to provide specialist information, there were complaints about their lack of knowledge. These could be addressed through more awareness-raising programmes like that developed by CLAPA (Cleft Lip and Palate Association).

In addition to these more general weaknesses, the qualitative research highlighted specific areas where people wanted more information:

- **For head & neck cancer:** tests and investigations, treatment options, radiotherapy side effects, care and recovery after treatment, functional problems following surgery, appliance care, complementary medicine and support groups.
- **For congenital conditions:** information for young people with learning disabilities, information for the parents of children diagnosed with cleft lip & palate pre-natally, information for older people with cleft lip & palate.
- **For amputees:** phantom pain, prosthetic product guide, prosthetic services, new developments in prosthetics.
- **For skin conditions:** information to manage their condition while waiting for an outpatient appointment.
- **For burn injuries:** better discharge information on self-care, new research, wearing pressure garments.

Information producers

There is increasing pressure upon information producers to meet certain quality criteria. It is the Department of Health's intention to introduce an information accreditation scheme, whereby organisations will be kite-marked as producers of quality health information and there has been a proliferation of guidelines for the production and

evaluation of information materials. Our research indicated that without additional support, only the large and well-resourced organisations will be able to satisfy all these criteria. Smaller charitable organisations will struggle to provide information in alternative formats, languages other than English and involve users in the development process.

The impact of appearance on information needs

The survey demonstrates a clear correlation between high levels of self-consciousness about appearance with a greater demand for information and a more critical approach to the information available in the clinical areas represented. Respondents with psoriasis registered particularly high levels of self-consciousness and rated the information they received significantly lower than all other conditions.

5 New Initiatives in Information Provision

During the course of this research we encountered several projects developed to improve the provision of information for people living with conditions that affect appearance. This is obviously to be welcomed, but feedback from our focus groups and postal survey suggests that delivery on the ground is failing. The reasons for this could in part be explained by two key factors: inadequate long-term funding which threatens their sustainability, and the limited extent to which knowledge of the schemes is disseminated amongst health professionals and others. We have divided these initiatives into two main categories: those developed within the NHS and those developed within the voluntary sector.

Health service initiatives

The provision of high quality information has become much more central to Department of Health policy in the last few years. Several initiatives illustrate this:

- **Information Prescriptions:** given to patients by health professionals, signposting them to relevant sources of information and support.
- **Information Accreditation Scheme:** quality kite-marking for the producers of health information to be introduced in 2007.
- **Patient Information Bank:** on-line resource allowing NHS staff to print off quality assured information to give to patients.
- **Expert Patient Programme:** self-care courses for people with long-term conditions led by trained tutors who also have long-term conditions.

In addition to the above, in 2004 the DH launched NHS Direct Interactive Digital TV, the only health information service on satellite TV and is currently developing the National Library for Health (NLH) which will extend NHS library services to patients and the public for the first time. Specialist libraries within NLH so far include skin disorders and head & neck cancer.¹ In response to the recommendations of the Expert Group on the Regulation of Cosmetic Surgery, the DH launched a new website in December 2005. It provides information to support decision-making on cosmetic surgery.²

The former Modernisation Agency's "Action On" Programme ran for 3 years from 2002-2005 and thus overlapped with this research study. Under its auspices, 3 information initiatives were funded that had the potential to impact on people living with disfiguring conditions. Unfortunately, the Modernisation Agency was superseded on 1st July 2005 by the NHS Institute for Innovation and Improvement. Without alternative funding all the initiatives are experiencing problems in developing further.

- **NISPS: National Information System for Plastic Surgery.**³ This website was developed at the Royal Free Hospital in London to provide patients with validated information by links to the most relevant, accurate and up-to-date information on the internet on all areas treated by plastic surgeons and associated specialities. There are currently basic sections on breast reduction and augmentation, breast cancer, cosmetic surgery, head & neck cancer and skin cancers. At the time of writing this site

was experiencing both technical and financial problems and is likely to be hosted in the future by the North London Cancer Trust. This will obviously move the emphasis away from plastic surgery to cancer.

- **BADPIG: British Association of Dermatologists Patient Information Gateway.**⁴ A collaboration between the British Association of Dermatologists, the NHS Action On programme and the Centre for Evidence-Based Dermatology at Nottingham. Three in-depth resources designed for internet use were produced by writing teams that included dermatologists, nurses and patients, but the lack of any further funding has made it impossible to develop any more materials.
- **Interactive hand surgery web site.**⁵ Developed at the Mid Yorkshire Hospitals NHS Trust under the aegis of the Action On programme, this website was intended to form part of an information package including a patient diary and interactive CD-ROM. Only one page is active at the moment, although several consultants have contributed sections, and the maintenance and further development of the site relies on the dedication and commitment of one specialist registrar.

The **National Cancer Alliance Teamwork File**⁶ has been more successful in terms of sustainability, although only in a limited geographical area. This is a cancer information pack developed with substantial user and professional involvement. Its built-in flexibility means that it can be customized to each individual patient according to their tumour type, treatment options and local services. Funding for the first phase of the project was provided by the National Lotteries Charities Board and the DH. The second phase, completed in 2003 and funded by the New Opportunities Fund, focused on the information needs of older/socially disadvantaged users and South Asian patients and carers. The File has been used at Stoke Mandeville, Reading and Bristol but is probably only in use in Oxford at the moment. Printing costs can be quite off-putting (even though each individual copy is only £3), so the development team is now working on an on-line version. This has the potential for greater flexibility, linking national information with information more tailored to the individual patient. This format will be more easily sustained in the future, and could easily be adapted to any hospital trust. The Head & neck team at the Oxford Radcliffe is acting as a pilot site for the project.

The **Cancer Services Collaborative 'Improvement Partnership'**⁷ is a national NHS programme that supports local cancer service teams. It has recently produced national electronic patient information pathways for many cancers including head & neck, breast and cancer. These pathways bring together information from a range of sources enabling patients, carers and clinicians to see what is currently available for each tumour from the early development of symptoms to diagnosis, treatment, rehabilitation, recurrence and bereavement. Links are provided to sections on a variety of national cancer websites.

The **SCAN (South East Scotland Cancer Network) Cancer Information Network** was developed for NHS Scotland by cancer professionals, patients and organizations throughout SE Scotland.⁸ Its aim is to provide web based information for patients, families, carers and health professionals on all aspects of cancer. It focuses on 9 major cancer types including head & neck, breast and skin cancers.

Mihealth is an innovative personalised on-line service for breast cancer patients developed by a team at Liverpool John Moores University in collaboration with patients and health care professionals from the Royal Liverpool hospital.⁹ The system was piloted at the hospital's Linda McCartney Breast Cancer Centre and a recently published

evaluation showed how successful it has been in helping patients to search for, manage and evaluate information.¹⁰ Very much the brain child of someone who was herself treated for breast cancer, Mihealth demonstrates the importance of personal commitment in maintaining the momentum behind these initiatives. In May 2006 a second pilot project started in Newcastle and Carlisle funded by the Royal Victoria Infirmary in Newcastle with a generic set of breast cancer information provided by CancerBackup and DIPEX. It is hoped that this pilot will prove that the system can be implemented in multiple locations and can ultimately be expanded to cover other conditions if funding can be identified.

BurnCentreCare is a new multi-media information package being developed at Pinderfields Hospital as part of a self-financed registrar research project.¹¹ It is designed to provide an information tool for burns patients and their families and currently consists of a book, DVD and website which all cover a wide range of subjects including reconstructive surgery, rehabilitation, physiotherapy exercises, after care and contacts for further support. Ethical approval has been granted to conduct a randomised control trial comparing patient attitudes to the 3 different formats. Future plans, dependent on funding, involve roll-out to other burn centres and an information package for district nurses.

New developments in reconstructive surgery inevitably create new information needs and nowhere is this more so than in the case of facial transplantation. In recognition of the fact that the normal informed consent process will not be adequate for such surgery with all the attendant physiological, ethical and psychological ramifications, the UK Facial Transplant Team has developed a tailor-made patient education process. To counter the danger that people will already have absorbed a lot of information from the media, which tends to define transplantation as an identity exchange, potential recipients will be given extensive information about:

- The technical aspects of the operation itself, the risks and the alternatives.
- The psychological challenges it will present.
- The implications of immuno-suppression.
- The coping strategies needed to manage aftercare.

To address the need for visual information, 3D laser volumetric scanning and photography of two different faces have been used to produce the computer model of a "new face". The team, which is based at the Royal Free, also produces a website providing information and the latest news about facial transplantation.¹²

Virtually all of the above information schemes are internet-based and an increasing number of NHS Trusts are developing more sophisticated websites which allow patients to download information leaflets on specific conditions, for example, North Bristol NHS Trust's cleft lip & palate unit¹³ and Salisbury NHS Trust Department of Burns and Plastic Surgery.¹⁴

Voluntary sector

In parallel to these developments in the NHS there is a range of new projects in the voluntary sector. Once again, funding is a major issue and there appears to be little opportunity for the exchange of ideas across the different charitable groups.

The Mouth Cancer Foundation was established in 2004 by Dr Vinod K Joshi, a specialist maxillo-facial prosthodontist.¹⁵ The website provides direct links to the relevant sections of existing cancer sites and includes patient experiences as well as an online support group. A registered charity since 2005, it relies on fundraising and donations to fulfill its objectives. Future plans include a "Survivor to Survivor" network, a telephone support line, a newsletter, and workshops covering treatment side effects, managing work and family, and new treatments.

The Children's Fire and Burn Trust was established in 2000 with a mission to reduce the number of burn injuries to children through education and prevention, and support those who do sustain injuries in their rehabilitation and reintegration. As the charity has grown so have the number of enquiries received for clinical, psycho-social and practical information. Realising it was not equipped to deal with them, the Trust initially planned to set up a 24 hour help-line. However, not only was it confronted with the need to fund such a service, it also became apparent that getting agreement on the content of the information provided was extremely difficult. As our focus groups with health professionals highlighted, practices vary between different plastic surgery units and every consultant has a different methodology. The Trust is now hoping to raise funds to develop **'BiLL' the Burn Information Link Line**, a service that will sign-post people to the best information resources and advice available elsewhere.¹⁶

The need for a consumer guide to prosthetic limbs and components was first raised in our consultation with patients. In 2005 The Douglas Bader Foundation created **The UK Limb Loss Information Centre**, a central resource/information website for amputees, their families and friends, carers and healthcare professionals.¹⁷ Unfortunately the prosthetic products section, which may have met this need, still appears to be under development and is dependent on sponsors. However, a small research group in Scotland has now been formed with responsibility for taking the **Prosthetic Information for Patients (PIP)** project forward. At present it consists of representatives from the Murray Foundation, HealthQWest, the National Centre for Training and Education in Prosthetics & Orthotics, and an independent user.

Now that ethical approval has been granted for facial transplantation in the UK, a new charity, **The Face Trust**, has been formed to fund such operations and other innovative treatments of facial disorders and injuries. Its website provides information on surgical techniques, psychological aspects and immunosuppression.¹⁸

The Database of Individual Patient Experience (DIPEX) is an Oxford based charity launched in 2001. The website contains interviews with people about their experiences of particular illnesses and also provides information about each condition. The charity has to raise funds for each disease "module" separately (£100,000 per module) and ultimately aims to cover 100 major illnesses. It not only provides information to patients, their carers, family and friends, but also acts as a teaching resource for health professionals. After a series of successful funding applications several new modules are planned, although none directly related to conditions affecting appearance. To date only the breast cancer module addresses issues of disfigurement.¹⁹

It will be evident that the latest developments in patient information are much more sophisticated than the bulk of material collected in our initial information trawl. Most of them are internet-based and as such can offer a more tailored, flexible and multi-level information service than is available in simple print materials. This corresponds well with

the complex information needs we encountered in our group discussions with patients and parents. But sophisticated information is of no value if patients are not able to access it when they need it. The reliance on web-based information still excludes those patients who do not have on-line access or who find it difficult to navigate the internet. Even those who do have internet access may not easily find these websites if they are not guided to them by health professionals or patient organisations and this presupposes that they in turn are up to date with every new initiative. A more fundamental issue concerns the sustainability of some of these projects. Where they are dependent upon short term funding or research grants, there is a real danger that they will come and go without offering any long term benefit to patients and carers.

6 Best Practice in Information Provision

Our research has demonstrated that although there is an increasing amount of information available to people living with disfiguring conditions, many people are not receiving this information when they most need it. Even the most sophisticated and high quality information packages will fail if they are not integrated into the care pathway. This ultimately depends on the support of the clinicians treating people with disfiguring conditions. We have however identified a number of ways in which some healthcare and voluntary organisations are addressing this problem by offering guided access to information, staggering their information provision and organising specific events to facilitate the dissemination of information.

Cancer information centres

Evidence from our focus group discussions and the research review revealed that the timing of information is very important. Patients need to be taken through it at their own pace when they are best able to assimilate it. Cancer information centres, run by CancerBACKUP, Macmillan and Maggie's Centres, are based in or near to hospital sites. They hold a range of different materials from booklets and leaflets to videos and on-line access to web-based information. They are staffed by a mix of information and health professionals who can listen to patients' concerns and guide them to the relevant material. Importantly, patients visit the centres when they are ready and unlike busy clinicians, staff have time to support them in finding and interpreting information that meets their individual needs.

Information prescriptions

Although the concept of information prescriptions does not apply specifically to patients with disfiguring conditions, they do provide one of the best ways of integrating useful information into the care pathway. Given directly to patients they essentially signpost them to sources of information that can support them in understanding and coping with their condition (including voluntary organizations, benefits advice, internet discussion groups, home care services and useful books and library locations). They are already in use in some primary care trusts and hospital trusts, for example, Guy's and St Thomas's who have run pilot schemes in elderly care, cardiology and stroke clinics and are planning a future pilot in dermatology. Prescriptions are given to patients by their clinicians who then take them to the trusts' Knowledge and Information Centre to be "dispensed". The Department of Health sees information prescriptions as a key part of its information strategy and is planning further pilots in cancer, mental health and care of the elderly.

Information to support psychological readjustment

The Outlook Disfigurement Support Unit based at Frenchay Hospital in Bristol produces a series of information sheets to help people who are experiencing emotional and psychological distress connected to appearance. They include suggestions for building self-confidence and assertiveness, learning to recognize and overcome distorted thinking, coping with anger and problem solving.

Information days/events

Various charities organise special events to enable patients, families and carers to exchange information and to question specialists and other health professionals:

- The Great Ormond Street branch of CLAPA (Cleft Lip and Palate Association) hold an annual "Meet your consultant day" at the hospital.
- The Burned Children's Club attached to St Andrew's Centre for Plastic Surgery and Burns organises family weekends when parents and carers can get together and share experiences in an informal way and question invited burn care professionals.
- The Skin Care Campaign, an umbrella organisation representing the interests of all people with skin diseases in the UK, arranges Skin Information Days. Open to patients, health professionals and families, their aim is to educate people about their skin and improve understanding, management and coping skills.
- Headlines – Craniofacial Support organises annual family weekends. A "Meet the Professionals" session enables people to talk individually with a range of clinicians and specialists.
- A pilot family weekend, supported by the Children's Fire and Burn Trust (CFBT) and the Fire Service National Benevolent Fund (FSNBF), and run by burn care professionals from Pinderfields, Manchester and Newcastle Burns Services, was held in November 2005. Parents/carers were offered information on coping strategies whilst the children benefited from meeting others with burn injuries. Funding has been secured to extend the programme to other parts of the country in 2006/7.

There are a variety of ways in which health professionals can ensure that people with conditions that affect appearance receive the information they need when they need it from the proactive approach of a structured information pathway to the more responsive style of the cancer information centres which gives patients a greater choice in what type of information they look for and when. An ideal solution would combine elements of both, but it will always rest on the professionals' ability to keep themselves up to date with new information sources.

7 Conclusions

The “information paradox”

Our request for samples of information materials indicated that the volume of information available to many people living with the various conditions that affect appearance is substantial. Furthermore, the Department of Health sees information as central to healthcare and has funded a number of initiatives that impact upon information provision for this group. Despite this, many of the people who participated in our interviews, focus groups and responded to our survey did not find it easy to access the information they considered important. Clearly, the information that does exist is not always getting to those who need it most. Moreover, the highest levels of difficulty were recorded by the most information hungry.

Information to support psycho-social adjustment

Although individual research participants identified a range of specific failures in information provision, the common theme running across all conditions was the difficulty of finding information of a psycho-social nature. This included information on the availability of counselling services, managing social situations and dealing with emotions. The survey analysis reinforced the findings of the focus group research and, whilst there was some variation between condition groups, the overall results revealed a large information gap. This was especially the case for those who considered this information to be important to them.

Signposting

The research highlighted that despite the increasing variety of sources available to patients, the health professional in the clinical setting remains the most important. But although such settings may be the depositories of much useful information, they are not always effective in conveying it to their patients. Our research indicated the extreme variability of clinicians' communication skills and fewer than half of survey respondents across all conditions received any kind of guidance from health professionals about where to find further information. Better signposting is crucial for those people who would like more information, but it does depend on clinicians' knowledge of what is available and their willingness to direct patients to other sources. Our consultation process suggested that some health professionals may be wary of standardised information and the internet.

Delivery

Information giving by health professionals can be a rather adhoc process. Policy makers are increasingly realising that a more systemised approach is necessary to ensure that everyone is given relevant, timely and consistent information. At the same time, our research demonstrates that people take on information in different ways and at different times. In order to meet the individual needs of people with disfiguring conditions, information systems must be flexible in terms of content, level of detail and format.

Quality

Although the quantity may be growing, the quality of information is still problematic. There are now many tools to help producers in both the NHS and voluntary sector to produce better materials. However, our telephone interviews demonstrated that limited resources do not always make it possible for them to follow all their recommendations. Despite the government rhetoric, cut-backs in NHS budgets restrict what trusts can provide. Although the large cancer charities have been able to develop very sophisticated methods of information provision, the smaller charities which represent the views of people with congenital conditions, for example, are much more limited in what they can offer.

Format

Face to face and printed materials continue to be the main ways that people receive information and therefore perhaps not surprisingly these were the ways that most survey respondents preferred. Both the consultation and the survey revealed a mixed response to the idea of audio-taping consultations. However, there was a demand for more visual information amongst participants in the consultation process and although the majority of survey respondents did not want to see photographs of what they might look like after surgery, those who had been shown such material were overwhelmingly positive about it.

The internet

Most of the new information initiatives are internet based. This can offer a more tailored and flexible approach to patient information. Our focus group research indicated that people are using the internet as an information source, and amongst those we surveyed there was a higher level of home access than the national average. We did find that some conditions were using it more than others and this could be a reflection of the different age and socio-economic profiles of the groups. Survey findings showed that amongst those with internet access there were substantial numbers reporting it to be both a useful and trustworthy source.

Initiatives lack support

Some information projects that were developed during the course of our research are now struggling to survive. Initially funded in plastic surgery and dermatology by the Action On programme, they now require additional support if they are to be further developed. Initial start-up funding is not enough for information services that have to be updated and maintained on a long-term basis.

Appearance concerns affect information experiences

Our research demonstrated the extent to which self-consciousness about appearance affects both the need for information and the satisfaction of those needs. It seems crucially important that health professionals recognise this link when providing information as those that are most sensitive about their appearance are likely to be disproportionately affected by an information gap.

8 Recommendations

1. In order to encapsulate best practice, we recommend that The Healing Foundation and its member organisations draw up a code of practice for health professionals working in the relevant fields regarding good communication with people living with conditions that affect appearance.
 2. Recent Department of Health initiatives (for example, information prescriptions) should begin to improve information provision in clinical areas related to disfigurement as in other areas. However, in order to ensure that these have maximum uptake we recommend that The Healing Foundation sponsors a series of condition-specific training programmes for health professionals and those within the voluntary sector responsible for the development of relevant information packages.
 3. We recommend that such training programmes should focus on:
 - Increasing awareness of existing materials and information initiatives.
 - The skills to produce high quality information materials.
 - The production of information materials to support psychological adjustment.
 - The production of visual materials to assist the management of expectations.
 - The skills to support patients in their approach to such visual material.
 4. We recommend that The Healing Foundation enter into discussions with The Patient Information Forum²⁰, The Association of Social Care Communicators²¹ and The Centre for Appearance Research regarding the design and implementation of these training programmes.
 5. We further recommend that The Healing Foundation and voluntary organisations supporting people with disfiguring conditions are encouraged to join The Patient Information Forum and/or The Association of Social Care Communicators in order to benefit from the further training and dissemination of best practice supported by these organisations.
 6. We recognise that The Healing Foundation itself is not an information provider. However, we recommend that it consider developing the Links section of its website to include voluntary sector organisations and new information initiatives.
 7. We recommend that The Healing Foundation establishes a “Fellowship for Information Initiatives”. Existing projects could apply for funding to extend their information schemes to a wider range of disfiguring conditions or research registrars could apply for grants to develop new initiatives. In the latter case, funding should be conditional upon a plan for the future maintenance of the project.
 8. We recommend that The Healing Foundation follows the example of the British Medical Association and funds an annual best patient information award.
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9. Finally, in order to highlight the importance of good information provision and to kick-start the above, we recommend that The Healing Foundation host a one day symposium to bring together information specialists, health professionals, voluntary sector representatives and people living with conditions that affect appearance to share best practice and ideas for future developments.

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