

# Information for people living with conditions that affect their appearance



This is a digest of a research study investigating the type of information patients with disfiguring conditions want, and what they currently receive.

The causes of disfigurement are wide-ranging and various, from congenital conditions to disease and trauma.

Disfigurement affects people of all ages and backgrounds, who need information and support to help them manage the physical, psychological and practical consequences.

The study produced four reports, of which the Summary includes further detail on the key findings and recommendations featured here.

## The Healing Foundation Patient Information Project

A three year research programme, commissioned by the Healing Foundation, conducted by the Picker Institute and funded by the GUS Charitable Trust

### Aims

- To assess people's needs for information
- To provide an overview of the information currently available
- To highlight gaps and weaknesses
- To make recommendations for improvement

### Methods

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



## Who is affected?

There may be around 400,000 people in the UK with a disfiguring condition that seriously affects their quality of life.

Each year --

- one in every 600-700 children in the UK is born with a cleft lip and palate (Cleft Lip and Palate Association)
- there are approximately 250,000 burn injuries (The National Burn Care Review 2001)
- there are nearly 8,000 new cases of head and neck cancer (Cancer Research UK/Office of National Statistics)

The conditions included in the research represent the diverse ways in which disfigurement can arise.

Focus groups and interviews were carried out with:

- Trauma and disease: amputees
- Trauma: burn injuries
- Disease: head and neck cancer; eye cancer
- Disease: vitiligo
- Congenital conditions: cleft lip and palate; craniofacial conditions

The survey respondents included:

- Trauma: burn injuries
- Disease: head and neck cancer
- Disease: psoriasis
- Congenital conditions: craniofacial conditions

### The kinds of patients taking part in the research

**Carol** suffered over 50% burns in a gas explosion in her block of flats and still has severe nerve damage pain. She gets a lot of her information from people who've had a similar experience.

**Bill** has vitiligo. He has experienced a serious loss of confidence and frequent embarrassment and thinks the internet has made it a lot easier to find information about his condition.

**Martha** knew nothing about cleft lip and palate when her daughter was born with the condition, but she was offered information from the Cleft Lip and Palate Association and found it very helpful.

**Kevin** had both legs amputated following a road accident. He felt that no-one prepared him for the difficulties he would face when he left hospital.

## Information questions

Information is essential to help these groups cope better with their condition, form realistic expectations about the outcomes of treatment, and make choices about their healthcare.

People living with conditions that affect their appearance can look to a multitude of health professionals who can offer information on conditions, treatment options, and rehabilitation. These include plastic, orthopaedic and maxillo-facial surgeons; dermatologists; oncologists; physio-, occupational and speech therapists.

Additional options for delivering information outside the clinical setting are rapidly evolving. It can be delivered in written, audio and video formats, on television and radio, and online.

Information is produced and offered by a huge variety of organisations. New health information initiatives are continually being developed.

But how easy is it to find the right information at the right time? How reliable is that information? Is it easy to understand? How useful is it to patients?

## Key findings

**Information needs** – and information deficits – are highest for the people most concerned about their physical appearance.

**Visual information can be highly valuable.** Most patients surveyed said they did not want to see photos of how they would look after surgery; yet those who did see such materials were overwhelmingly positive about it.

**The biggest deficit is in information about psychological and social aspects of disfiguring conditions:** all patient groups seemed to find it difficult to get information about counselling services, managing social situations and dealing with their emotions.

**Personal consultations with health professionals are the most important information source.** But professionals could both communicate better and signpost people to other information more.

**Peer groups are highly valued** for emotional reassurance and practical advice.

**Not enough information is accessible:** for example, for people with low literacy, sight problems or another first language than English.

*"I mean -- to find out about craniosynostosis on a website, without being told by a doctor, and just reading that on his discharge leaflet, I don't think that's right."*

Parent of a child with a craniofacial condition

## Sources of information

### Face to face:

- the most important source of information is the consultation with a health professional
- patients are often dissatisfied by it, commenting on professionals' poor communication skills
- clinicians are failing to signpost people to further information

### Peer support:

- meeting and talking with others in a similar situation is hugely important for sharing information and for finding reassurance, emotional support and practical advice

### Voluntary sector:

- information provided by charities and support groups was highly valued by focus groups – but there may be a bias because many had been recruited to the research via the voluntary sector
- by contrast, survey respondents placed voluntary organisations among the least popular information sources.

### The internet:

- not all patients will have access to the internet or find it easy to use
- those with burn injuries or head and neck cancer, for instance, said they use it less – which may be related to socio-economic status and age
- health professionals expressed concern about the reliability of online information.

## Strengths and weaknesses in information provision

Hundreds of information materials are available, produced by a range of well-established organisations and specialist centres, and disseminated using a range of methods. Most of them are condition-specific; a smaller proportion addresses generic disfigurement issues. Both patients and health professionals are largely positive about them.

There does seem to be much duplication of effort. And there are still gaps.

Most of the information identified is print-based, which can be a problem for people with limited literacy. The lack of large print or audio-taped materials discriminates against people with sight loss.

Few information providers produce materials in languages other than English.

The extent to which users are involved in the development of information materials varies. More could be done to ensure material is regularly updated.

Not all information materials are as visible as they could be.

*“I said, ‘I take it you haven’t got any leaflets for the Vitiligo Society?’ She said, ‘Well, wait a minute’ and she dug around and said, ‘Yes, we have’....so I said, ‘Why haven’t you got them on display?’”*

Vitiligo patient

## Good practice – what the patients say

Patients like information materials that do not patronise the reader, are honest, but avoid negativity.

They want them to be pitched at the right level for the audience, written in plain English, avoiding jargon, and have a clear and simple layout, with appropriate illustrations.

The aims of the information product should be clearly stated; the information balanced; and the source of information given, but without overloading the reader with references. There should always be contact details for further information.

These patient groups want information about the treatment options, given in a way that prepares them for what may happen. They like hearing the stories of other people’s experiences, and they want reassurance about their own emotional reactions, and guidance on how to deal with them. Information for their family and friends is also valued.

*“I thought that one was appallingly bad... there was something about ...sports and hobbies, ‘a surprising number of activities are possible.’ Who are they to say it is surprising?”*

Amputee recalling hospital prosthetic service booklet



## Conclusions

### The delivery of information

The face to face consultation with a health professional is central to the delivery of information to patients. Yet it can be a very variable and ad-hoc experience. On the one hand a more systematic approach is necessary to ensure that everyone is given relevant, timely and consistent information. On the other, 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.

### The “information paradox”

Despite the large number of information materials identified and initiatives to support people with conditions that affect their appearance, too many people still seem to have problems finding and accessing the information they consider important.

### Signposting

One reason for the difficulty in finding further information may be the failure of many health professionals to offer guidance on how and where to find it. This is crucial for information-hungry patients, but it depends on the clinician’s own knowledge of what is available and their willingness to direct people to other information sources.

### Quality

The quantity of health information is undoubtedly growing, but its quality can be problematic. Limited resources, particularly amongst smaller charities, do not always make it possible for them to follow best practice. Some of the new initiatives for people with disfiguring conditions benefited from start-up funding but are now struggling to survive.

### Format

Face to face consultations and printed materials continue to be the main ways that people receive information, and therefore it was perhaps not surprising that these were preferred by most survey respondents.

However, there was a demand for more visual information. Amongst parents of children with craniofacial conditions, 48% found photographs helped them to visualise what their child would look like after surgery.

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.

Most of the new information initiatives are internet based. This can offer a more tailored and flexible approach to patient information. The focus group research indicated that people are comfortable using the internet as an information source. The survey findings showed that amongst those with internet access, substantial numbers reported it to be both a useful and trustworthy source.

### Appearance concerns affect information experiences

People with a higher level of concern about appearance have a greater demand for information, and are more critical of what is available. Health professionals need to recognise this link when providing information, as people who are most sensitive about their appearance will be disproportionately affected by an information gap.

### Information to support psycho-social adjustment

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.

*“You go through stages of wanting to know about different things... but if you could have incremental doses as you progress, that would be very useful.”*

Patient with burn injuries

## Where can I find out more?

Copies of the four reports can be downloaded from the following websites:

The Healing Foundation: [www.thehealingfoundation.org](http://www.thehealingfoundation.org)

Picker Institute Europe: [www.pickereurope.org](http://www.pickereurope.org)

The Picker Institute is an independent charity that works with patients, professionals and policy makers to promote understanding of the patient’s perspective at all levels of healthcare policy and practice. It undertakes a unique combination of research, development and policy activities which together make patients’ views count.

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making patients' views count

The Healing Foundation is a national fundraising charity championing the cause of people living with disfigurement and visible loss of function, by funding research into pioneering surgical and psychological healing techniques. Through research, we also raise awareness about the cause and provide information about the sources of support.

### The Healing Foundation

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Charity Registration no. 1078666



THE HEALING FOUNDATION

Rebuilding the bodies, minds and lives of people with disfigurements