



THE HEALING FOUNDATION

Rebuilding the bodies, minds and lives of people with disfigurements

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○ Information for People Living with Conditions that Affect their Appearance

REPORT III

**A SURVEY OF PEOPLE WITH HEAD & NECK
CANCER, BURNS, PSORIASIS AND PARENTS OF
CHILDREN WITH A CRANIOFACIAL CONDITION**

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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
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1 Executive Summary

1.1 Introduction

- This survey report is the culmination of a three year research programme that has investigated the information needs and experiences of patients with conditions that cause disfigurement and visible loss of function.
- The survey aimed to capture the similarities and the differences of views and experiences, providing a voice for information needs that is seldom offered, and on behalf of conditions that are seldom heard.
- The four conditions that were included in the survey represent the diverse ways that disfigurement can arise: Disease requiring surgery (head & neck cancer); Disease where no surgical option exists (psoriasis); Accidents (burns); and Congenital conditions (craniofacial).

1.2 Methods of investigation

- The development of the survey was overseen by multiple stakeholders and drew from a large programme of interviews and focus groups across the country. The survey was rigorously tested through cognitive interviewing.
- The four conditions were sampled from five leading specialist centres across the country.
- The survey was in the field for four months and was returned by 443 patients. The overall response rate of 46% was considered good for an independent survey of this kind that elicited views from a sensitive patient population. The response rate compares favourably with official NHS survey programmes.
- Analysis for head & neck cancer respondents showed that non-response bias would not be an issue for this group.

1.3 Survey results

What information have patients received?

- Doctors are the key information providers and have given information on approximately a third of 20 information topics. However, for those with burns, the nurse is the key role having provided a far broader range of information than doctors – almost a third more.
- Those with psoriasis report having received almost 25% less information from their healthcare professionals compared to other condition groups.
- The parents of children with a craniofacial condition (hereafter referred to as 'craniofacial parents') and those with psoriasis have a much greater appetite for information and have searched for three or four times more information than people with other conditions. The most sought after information related to diagnosis and psycho-social topics.

- Healthcare professionals are failing to signpost patients to further information. Less than half of those with head & neck cancer and a quarter of those with burns said they had been given such guidance. Over three quarters of craniofacial parents and those with psoriasis who didn't receive guidance reported that they would have liked it. Crucially, amongst those who were provided with guidance, the overwhelming majority had followed it up.

What are the common sources of information?

- Healthcare professionals are the most commonly consulted sources of information - used by three quarters or more of all respondents. However, whilst 75% of those with head & neck cancer rated hospital doctors as a *very useful* information source, this was only the case for half of those from other condition groups.
- Other popular sources of information were family and friends and people with similar conditions.
- The internet was a very common source for craniofacial parents and for those with psoriasis; it was rated as *very useful* by approximately 40% of both groups and as one of the most trusted sources by almost a third. However, the internet was used by only a minority of those from other condition groups.
- The least popular sources consulted directly by respondents were national voluntary organisations and charities, commercial organisations, local support groups and public libraries.
- Healthcare professionals featured overwhelmingly in the top five most trusted sources for all respondents.

What are the most important topics of information?

- For those with head & neck cancer, the chances of recurrence (64%), radiotherapy (61%) and how surgery might affect functions such as speaking or eating (56%) were vital areas of information.
- Craniofacial parents registered the highest levels of importance to information topics overall. Key areas were: how surgery might affect their child's appearance (75%), how the condition might affect appearance (73%) and developmental issues (66%).
- Only one topic was rated as very important by the majority of those with burns – skin massaging and creaming (54%). Other important information topics for this group were skin grafts (48%) and environmental factors (46%).
- Those with psoriasis valued information on oral treatments (45%), triggers for the condition's onset (39%) and cream and emollients (37%).

The information gap

- The majority of those with burns found information that was important to them easy to find. However those with psoriasis and craniofacial parents were encountering greater difficulties.
- Across all condition groups, respondents found information of a psycho-social nature - dealing with emotions, relationships and managing social situations - some of the hardest topics on which to find information.

- Psycho-social information was a particularly severe information gap for those with psoriasis, where the highest levels of difficulty were recorded overall.
- The availability of counselling services was an information gap for craniofacial parents and for those with psoriasis. However, this was not an issue for those with head & neck cancer and burns.

What are the preferences for receiving information?

- The most popular delivery methods for information were either face-to-face or printed material. These were the top two choices for delivery of every information topic, with the preference for face-to-face being almost universal.
- However, a reliance on purely printed material as an alternative to face-to-face should be tempered by the knowledge that a substantial minority (20%) of respondents from all condition groups other than craniofacial chose not to receive information in a printed format for **any** topic.
- The internet was a popular medium for craniofacial parents and for those with psoriasis, but less so for respondents from other condition groups. Seeking alternative therapies and details of counselling services were popular choices for this medium.
- For the telephone, preferring to receive information of a more psycho-social nature was a common choice where support could be provided through a helpline to health professionals, perhaps when dealing with negative emotions such as depression and anxiety.
- The mass media was one of the least popular choices for receiving information for all condition groups. However, information on healthy living, environmental factors and alternative therapies were thought to work well via this format.
- Audio/visual information was also a minority choice, but thought appropriate for instructional material such as skin massaging and creaming (burns). Craniofacial parents also found it useful to help them and their children visualise how their appearance could be affected by their condition and treatment.
- The consultations of craniofacial parents were found to be the most audio-taped but overall levels were low across all condition groups. Asked if they would have liked to have had their consultations taped respondents gave a mixed response.
- Showing material such as photographs to help patients visualise what their appearance may look like after treatment was a common preference only for parents of a child with a craniofacial condition (48%). Whilst the majority of other respondents were against seeing visualisation material, those that had were almost universal in proclaiming it helpful.

Attitudes towards information

- Respondents from all condition groups showed a broad understanding of the intrinsic benefits of information. There was positive agreement that information helps them to formulate the right questions to ask, informs their decision-making, helps them to gain realistic expectations and a better understanding about their conditions.
- Assessment of the quality of the information they have received was more measured but still positive for respondents from all condition groups other than those with psoriasis. Respondents from this group were more equivocal and rated their information significantly lower than all other groups.

- Reflecting on the relationship with doctors and their provision of information produced a moderately high evaluation. Those with psoriasis were again the least positive.
- A third of craniofacial parents and of those with psoriasis felt that they had to push their doctors to provide them with information.
- Over a third of those with head & neck cancer and over 40% of those with other conditions agreed that doctors give them information only when the *doctor* thinks it is appropriate. This is a serious criticism of the power dynamic that can exist with information sharing in the doctor-patient relationship.

The impact of appearance on information needs

- High levels of general self-consciousness of appearance were found amongst those with head & neck cancer, burns and significantly so for those with psoriasis. Levels were higher than those found in the general population, whilst those for psoriasis were consistent with those found in other clinical conditions.
- There is a profound relationship between the psychological impact of a person's condition and their information experiences. Those with high levels of self-consciousness were more critical of the quality of the information they had received and were more negative about their doctors' provision of information.
- Those measuring high on self-consciousness were less likely to have received psycho-social information from healthcare professionals. These topics were viewed as very important, significantly more so than those measuring low on self-consciousness.
- Those measuring high on self-consciousness drew on a more diverse range of sources for their information needs and were more likely to prefer information to be made available through the internet and via audio/visual mediums.

Barriers to information

- Language was a barrier to information for only a very small number of respondents, where English was not their first language (1%). This group had to rely on relatives to interpret for them and the majority of this small group did not have access to information in a language they could understand.
- Those with burns were the most likely to report that the state of their condition acted as a barrier to information (11%). The majority stated that this had not been taken into account and that alternative information media were not offered (for example, audiotape or large print).
- Higher levels of home internet access were reported overall by our respondents than the national average, but this varied by condition. Craniofacial parents (90%) and those with psoriasis (83%) were the most connected.
- Nine out of ten of all respondents reported that they had enough opportunity to talk to a doctor when *they* wanted to. However, only half of craniofacial parents and those with psoriasis reported that this was *definitely* the case.
- Results for whether family or friends had the same level of access to information were more mixed; those with head & neck cancer and those with burns reported the higher levels of such access. A notable minority of craniofacial parents and of those with psoriasis reported that family and friends were not involved, or the respondents did

not want them to be involved, revealing this to be a complex area for healthcare professionals to navigate.

1.4 Conclusions

- This is the first time that a survey comparing the information experiences of patients with different disfiguring conditions has been attempted. The views of over 400 survey respondents builds substantially on previous qualitative work, when combined this then provides a wide assessment of the provision of information for disfiguring conditions.
- Several key messages emerged concerning the role of healthcare professionals in the signposting of information; the existence of information gaps; the format and delivery of information; and the impact that self-consciousness about appearance can have on information needs.

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 Summary Report of the whole project (Report IV), drawing out key conclusions and presenting recommendations. This report details the findings of the last stage of the research arising from a multi-condition survey.

2.2 Background and objectives

The number of people whose appearance has been disfigured by a medical condition or as the result of accidents is far from trivial. In the UK almost one in every 150 people has some form of disfiguring condition (Office of Population and Census Studies, 1988). For those that have been affected, not only can treatment be complex and long-term but even trying to cope with simple everyday tasks such as a shopping or a social event can be a profound ordeal. We are not a society that tolerates difference of appearance well. Even relatively minor disfigurements can provoke comments and behaviours that can be humiliating or threatening, increasing levels of self-consciousness and anxiety. This frequently creates an additional psychological burden for people who are already coping with sometimes extensive and prolonged medical treatment for their conditions.

The complex nature of most disfiguring conditions means that there is a much wider need for information beyond that for diagnosis, treatment and after-care, but also psycho-social, employment and benefit issues too. Furthermore, the involvement of multiple clinical disciplines in treatment adds an additional level of information need. Good quality health information is therefore essential for helping patients understand

and manage their conditions. Well informed patients are able to take an active role in making key decisions about their treatment and care, often reducing their levels of anxiety and fostering better relationships with healthcare professionals (Farrell, 2004). This is also a key area for Government policy, where the case for patient and public access to high quality health information has been made (Department of Health, 2004).

Our evaluation report (see Report II: Magee et al, 2006) has shown that there is a tremendous volume of information currently available to disfigured patients. The recent rapid rise in technology has also increased the potential formats by which information can be accessed or delivered on the internet, mobile phone, DVD and CD-ROM for example. However, quantity does not imply quality or the level of ease with which patients are able to retrieve or use information. Our qualitative report (see Report I: Cartwright & Magee, 2006) drew on the views and experiences of many patients and healthcare professionals across the country, and found acute information needs, but also a wide recognition that how and when information is given is as important as the content itself.

This earlier research helped develop and structure a number of questions that could be explored through survey methodology:

- What information has been received, where has it come from and what barriers exist?
- When patients are searching for information themselves, what sources do they use and what are the most trusted and useful sources?
- What information topics are the most important to patients and how easy or difficult have they been to find?
- What are the most popular ways that information can be made available to patients and are there different preferences for different types of information?
- How have patients and their doctors used information and what is their opinion of its quality?
- What has been the impact of appearance on information needs? Does a heightened level of self-consciousness affect information needs and experiences?

To our knowledge this is the first time that a single survey has been carried out on different conditions that affect appearance. The diverse nature of disfiguring conditions makes the process of capturing patient's views in a uniform design particularly challenging. However, meeting this challenge enables us to compare and contrast the information needs and experiences of this wider group, thereby allowing an important investigation into where commonality and difference may lie. The survey provides an opportunity to take the themes and issues that emerged from the qualitative material to a far larger group of patients. It has also been an opportunity for many with disfiguring conditions to give voice to their experiences. The survey is therefore valuable in providing a strong evidence base for highlighting areas where change and initiatives can be made to improve the quality of information provision for patients with these conditions.

2.3 The four conditions

The primary causes of disfigurement are either disease, accidents or congenital abnormalities. Disease itself comprises a diverse number of conditions that either

necessitate surgery or for which there is no surgical option. For the purpose of this survey we chose four conditions to represent the range of different conditions:

- Disease (surgical): head & neck cancer.
- Disease (non-surgical): psoriasis.
- Accidents: burns.
- Congenital: craniofacial.

The impact of each of these conditions on appearance can be profound and extensive. Some are less well known to the general public than others. By way of an introduction, a short synopsis of each condition providing background information is given below.

Head & neck cancer

Cancer can occur in over 30 different places in the head and neck area (excluding the brain) and are most common in the throat and mouth, along with the nose, ear and eye. Head and neck are the least widespread group of cancers, with approximately 7,000 new cases diagnosed in England each year, accounting for only 3% of the total number of cancers diagnosed.

Head & neck cancer is more common amongst men and those who are older. There is little inheritability of the disease; instead the risk factors are primarily lifestyle – smoking, alcohol, a poor diet and living in areas of deprivation.

Treatment is organised through a multi-disciplinary team that draws on a diverse and wide range of expertise. The majority of those diagnosed are already in an advanced stage of the disease, presenting a substantial and complex challenge to the managing team. Treatment can involve radiotherapy, surgery and chemotherapy, but will depend on the cancer site as well as on the extent of the disease.

The impact of the disease on basic functions such as eating, drinking, speech and normal social interaction can be profound. Prolonged rehabilitation with long term support is needed to achieve an adequate recovery. However, due to late presentation, the older age profile and lifestyle factors, there is a relatively poor survival prognosis.

- For further details see: <http://www.dahno.com>

Psoriasis

Psoriasis is one of the oldest recorded skin disorders. It is a non-contagious, incurable and chronic disease that affects over a million people in the UK. It occurs equally in men and women and is most commonly diagnosed when a patient is in their 20s, although onset can occur at any age. There is a strong genetic link but the onset trigger is often an outside event such as skin injury, stress or infection.

Although not fully understood, it is believed that psoriasis develops due to an over-reactive immune system, where the growth of skin cells is accelerated. Instead of the skin cells being shed as normal, they instead pile up causing a silvery white build up on raised, red patches or lesions.

The onset of symptoms can be unpredictable. Severity of the condition can range from small localised lesions to total body disfigurement and arthritis. Affected areas of skin can be inflamed and very itchy and are usually treated with topical creams, ointments and emollients. When severe or unstable, day care at a specialist dermatology department is usually required.

The psychological impact of psoriasis can be particularly pronounced, and public misperceptions that the condition is contagious or the result of poor hygiene can leave patients feeling stigmatised.

- For further details see: <http://www.skincarecampaign.org>

Burns

Burn trauma affects about 250,000 people each year in the UK. The majority of these are dealt with through A&E attendance but over 13,000 are serious enough to warrant hospital admittance.

Burns are skin damage caused by contact with fire, heat, electricity, radiation, or caustic chemicals and are amongst the most painful and disfiguring of injuries. Over 60% of burns occur between the ages of 15-64 and almost a third of these are work related. Men are more commonly burnt.

There are three categories of burn depending on how deeply it has affected the skin tissue: superficial, partial and full thickness. Those with severe burns need to be cared for in specialist burns units. Superficial burns can usually heal without leaving a scar in a couple of weeks, but deeper burns take longer and commonly require skin grafts. This is a plastic surgery technique that repairs injured areas of skin using healthy skin from an unaffected part of the patient's body. Full thickness burns tend to result in scars that can be difficult to treat and specialist treatment is aimed at minimising their impact.

Whilst 90% of burn injuries are preventable, people from lower socio-economic backgrounds are at greater risk from factors that are not easy to change. Poor housing, overcrowding, and other attributes of poverty are all major contributors to the risk of burn injuries.

Due to the traumatic nature of burns, adverse psychological reactions are common. Along with psycho-social issues associated with adjusting to a changed appearance, up to half of patients are also experiencing post traumatic stress symptoms a year after their original injury.

- For further details see: <http://bmj.bmjournals.com/cgi/content/full/328/7452/1366>

Craniofacial conditions

Craniofacial conditions are a diverse group of abnormalities in the growth of the head and facial bones and represent the most frequent type of human birth anomalies. For this survey we have focused on craniosynostosis, which affects 1 in 2,500 children in the UK. This condition causes a premature fusing of the skull bones, including those around the eye and upper jaw, which causes an abnormally shaped head and face as the growing brain pushes against those bones that have yet to fuse.

Craniosynostosis usually occurs within the first year of life and is very unlikely to occur after the age of 2 or 3 years. In 80% of cases craniosynostosis occurs in isolation. However, there are almost 100 syndromes (more than one abnormality) that include craniosynostosis as a feature. Blindness, deafness, severe learning difficulties and facial deformities can be common problems in the more severe cases. In these complex cases there can be changes to the hands and feet such as webbing or where fingers or toes fail to develop separately. The bones of the face may also be underdeveloped causing vision problems when the eye sockets are too small, or problems with breathing when the passages behind the nose become too cramped.

The exact cause of craniofacial conditions is not known, but experts agree that it is due to both genetic and environmental factors. Genetics is thought to play a part in about 20-30% of cases. Other factors are pressures on the skull during pregnancy, reduced amniotic fluid or an abnormally shaped womb, and certain types of medicines or chemicals.

Treatment requires a multidisciplinary team of experts, the core disciplines being maxillofacial, plastic and neurosurgery, supported by anaesthetic, ENT, ophthalmic and specialist nursing colleagues. The surgery is intensive and protracted and combines maxillofacial reconstruction with neurosurgery. The child might often need to recover in intensive care having lost a significant amount of blood. Some children require more surgery as they get older to keep their facial bone structure in line with their development.

For parents of a child with a craniofacial condition it can be an emotional, stressful and often fearful experience, especially as the majority of cases are not diagnosed until after the child has been born.

- For further details see: <http://www.headlines.org.uk>

3 Methods of Investigation

3.1 Questionnaire design

The development of the questionnaire involved extensive input from patients in conjunction with a literature search and discussion of draft versions with our research advisory panel. The wider research programme involved carrying out a qualitative study comprising a series of focus groups and interviews with patients across the country about their information needs (see Report I: Cartwright & Magee, 2006). The results of this qualitative work were used to develop a substantial core of questions that were applicable to the information needs of all four conditions. This core formed the basis of each of the four condition questionnaires that were then augmented with condition-specialist items and context-specific wording.

The survey also incorporated a series of questions from the Derriford Appearance Scale (DAS) in order to measure the psychological impact that a person's condition may have on their appearance¹. DAS was developed at the Burns and Plastic Surgery Unit at Derriford Hospital and the University of Plymouth (Carr, Harris & James, 2000). The scale was designed to capture the emotional and behavioural issues related to appearance and thus provided the opportunity to gain an insight into the self-view of respondents across the different conditions.

The questionnaire was piloted in two waves through a series of in-depth cognitive interviews among patients from across the four conditions. All comments from the cognitive interviews were logged and analysed. On the basis of this analysis the questionnaire was revised and subjected to a second wave of cognitive interviews until only minor comments were being logged. A total of 12 cognitive interviews were carried out.

3.2 Sampling

The number of possible conditions that affect appearance is a prohibiting factor in designing a truly representative survey. Given this constraint, four conditions were chosen that reflected divergent aspects of disfigurement: head & neck cancer, craniofacial conditions, psoriasis and burns². A leading specialist centre for each condition was chosen in consultation with the Healing Foundation as our sampling site. The survey was therefore designed to capture the information needs and experiences of patients from these centres and whilst these results might be indicative of wider opinion - due to each centre's status in attracting patients from a wider area than their location - the sampling strategy was not designed to elicit representative data for all patients with these conditions.

Full documentation was provided to each site to enable them to draw their samples, which were then sent to the NHS Strategic Tracing Service (NSTS) for the checking of

¹ The survey of parents of craniofacial children excluded these questions.

² Burns are the result of trauma or injury, but to ease reporting will be referred to as a condition.

addresses and the removal of recently deceased patients to minimise any distress to bereaved relatives. Each centre was asked to draw a sample of 220 of their most recent patients³. There was a lack of any objective measure of disfigurement that was applicable across conditions and routinely collected on patient databases. This led to the following variation in criteria used to determine how the sample was drawn:

- **Head & neck cancer** – The sample was drawn from surgical lists where the type of operation would typically result in disfigurement. The sample drawn was in excess of our initial estimate as staff expected a large number of patients to be dropped through the NSTS process. However, it transpired that patient records were very up to date and the final sample was 277.
- **Psoriasis** – Patients were included in the sample if they had attended a recent psoriasis clinic at the centre, as attendance at these clinics implied severity of condition. The psoriasis site had the largest number of patients dropped by NSTS and had a final sample of 187.
- **Burns** – Two specialist centres were chosen due to an anticipated low response rate from this group. Information on the severity of the patient's burn injury was not available on the central patient database used to draw the samples and so proxy measures for severity were used. The sample was drawn at the first site from attendance at follow up clinics that targeted the most severe cases. At the second site length of stay was our proxy measure in order to filter out those with minor disfigurement. Recent patients, who had a hospital stay of seven days or more following their initial burn trauma, were selected to participate. The combined sample for the two sites was 319.
- **Craniofacial** – The sample was drawn from the specialist centre's active patient list of those where craniosynostosis is a feature of the condition. Only patients below the age of 15 years old were included. Unlike our other conditions, here the focus was on the information needs and experiences of the *parent* of a child with a condition that affects appearance. A sample of 220 was obtained.

3.3 Survey response

Survey mailing took place during the summer of 2006 and administration details are available in Appendix A. The survey was closed on 22nd September and full details of the response are given in Table 1. Overall, there were 443 respondents, representing a response rate of 46%, when adjusted for those that were ineligible due to inaccurate sample frame details. This represents a good response to an independent survey and compares favourably with recent official NHS survey programmes. For example, the 2005 PCT patient survey achieved a response rate of 47% and the mental health survey from the same year had a response of 41%.

Amongst the four conditions, the best response rates came from the two sites that dealt with the survey administration in a timely and efficient manner and were able to keep to the mailing deadlines – those with head & neck cancer (62%) and parents of children with a craniofacial condition (53%). The lowest response rates were from those with burns, where just under a third responded (32%), and those with psoriasis (39%), both of which suffered from major delays in survey administration.

³ Current inpatients and private patients were excluded from the sample at all sites.

Head & neck cancer was the only one of the four conditions able to provide the researchers with anonymised patient descriptive data from the sample frame. Non response analysis was carried out on both age and gender and there was found to be no statistically significant difference between responders and non-responders on age (63 compared to 61 years) and gender (64% of responders were male compared to 67% of non-responders). This provided confidence that non-response was not a potentially biasing issue for the results of this group.

Table 1: Survey response

Condition	Sample	Ineligible ^a	Opted out	Returned	Response
Head & neck cancer	277	17	19	162	62%
Craniofacial	220	3	5	114	53%
Burns	319	19	7	96	32%
Psoriasis	187	3	11	71	39%
Total	1003	42	42	443	46%

^a i.e. survey returned as undelivered or patient deceased. This figure does not include any patients who may have been ineligible but whose survey was 'not returned'. Likewise for those who opted out.

3.4 Reporting the data

The survey's primary focus is to report on the similarities and differences of the information needs and experiences between the four conditions. Survey results are therefore analysed and reported using a respondent's condition as the major break variable. The findings of the survey are organised around the following major topics:

- A biographical and condition profile of respondents.
- The information that has been received and where it originated.
- The most common sources for finding information.
- The ease of locating the most important topics of information.
- Preferences for receiving information.
- Attitudes towards information.
- The impact of appearance on information needs.
- Access and barriers to information.

4 Profile of Respondents

4.1 Biographical details

The questionnaire asked a series of questions to enable a detailed profile of the survey respondents to be compiled. Key biographical information is presented in Table 2.

Table 2: Biographical details (%)

	Head & neck	Craniofacial	Burns	Psoriasis
Age				
30 or younger	3	28	21	13
35 to 44	8	60	15	19
45 to 54	20	11	25	26
55 to 64	35	1	19	24
65 or older	34	0	20	19
Gender				
Female	32	85	35	34
Ethnicity				
White	97	90	92	86
Education				
No formal qualifications	32	6	39	21
Degree or higher	23	31	15	37
Current situation				
Employed	41	52	48	56
Retired from paid work	42	1	18	23
Unable to work due to disability/ill health	13	2	22	11
Looking after family, dependents	3	41	2	4
Other	1	4	10	6
Total number of respondents	162	114	96	71

Age

Respondents with psoriasis and burns have similar age profiles, with an average mean age of 52 and 50 years respectively. Those with head & neck cancer and parents of children with a craniofacial condition however are skewed in different directions. Over two thirds of those with head & neck cancer are above 55 years of age and are significantly older than all other conditions with a mean age of 60 years. By contrast, the craniofacial parents and carers who responded are significantly younger; 88% of this group are under 45 years old, with an average age of 38 years. The average age of their child with the craniofacial condition is 5 years old.

Gender

Eighty five per cent of respondents from the craniofacial sample were the mother or female carer of a craniofacial child. This was significantly different from the other three conditions where women respondents were in the minority and made up approximately a third of these groups. Men are more likely to be diagnosed with head & neck cancer and to suffer burns trauma. However, as non-respondent data was not collected for psoriasis, we are unable to speculate why these respondents are disproportionately male when the incidence rate is equal for men and women.

Ethnicity

There was little ethnic diversity amongst our conditions where a total of 34 respondents were non-white. This was particularly the case with head & neck cancer respondents, where 97% were white. Ten per cent of parents or carers of a child with a craniofacial condition (now referred to simply as 'craniofacial parents' from this point onwards) recorded an ethnicity other than white and this was similar to those with burns (8%). The largest ethnic diversity was amongst those with psoriasis (14%). Asian or Asian British was the largest non-white ethnic group amongst all conditions, and for psoriasis the next largest group were respondents of Middle Eastern origin.

Education

Craniofacial parents had a greater number of educational or vocational qualifications than any other condition, with only six per cent having no formal qualifications at all. Three quarters of this group had attained GCSEs (or equivalent), 42% had A levels (or equivalent) and 38% had a vocational qualification. Almost a third (31%) had received a degree - surpassed only by those with psoriasis where 37% were graduates. By contrast, burns respondents and those with head & neck cancer had lower levels of attainment, with 39% and 31% respectively reporting no formal qualifications. For those with burns, the level of A level and degree attainment was less than half that of craniofacial parents and of those with psoriasis.

Current situation

Given the older age profile of the head & neck cancer respondents, it is not surprising to find that 42% of them are currently retired, although a similar proportion (41%) are still employed. Those with psoriasis had the greatest number of respondents in employment (56%). Those with burns had the largest number of respondents unable to work due to disability or ill health (22%), twice that of the psoriasis group and significantly higher than for head & neck cancer (13%). The percentage of these three groups that were looking after family or dependents was very small compared to craniofacial parents where 41% were at home looking after their child.

4.2 Condition details

Questions that probed in greater detail about the respondents' conditions were also included in the survey. These results are available in Table 3.

Diagnosis

Craniofacial parents, those with head & neck cancer and those with burns had on average been recently diagnosed in the last five years or less. The average diagnosis for those with psoriasis was significantly longer: 28 years ago. As our sampling strategy was to maximise the inclusion of those whose condition has affected appearance, those with psoriasis were sampled from clinics at the centre that were run only for the most severe cases. This result reveals that severity tends to be among those who have had the condition for a prolonged period of time. The diagnosis age range for those with psoriasis was wide and ranged from four to 63 years. However, this range was normally distributed with a median value of 26 years that was close to the mean average.

Table 3: Condition details (%)

	Head & neck	Craniofacial	Burns	Psoriasis
Years since diagnosis/accident (mean ^a)	4 (3)	5 (4)	2 (2)	28 (26)
Had surgery for condition (%)	100	90	63	10
Number of operations for condition (mean ^a)	3 (2)	5 (3)	2 (1)	10 (10)
Years since most recent operation (mean ^a)	2 (2)	1 (1)	1 (1)	3 (1)
Necessity of surgery (% of those who had surgery)				
Essential for condition	88	59	89	100
Not essential, recommended by doctor	8	35	11	0
Not essential, requested by self	4	6	0	0
Total number of respondents	162	114	96	71

^a Median figure is presented in brackets

Surgery

All those with head & neck cancer have had surgery for their condition, which again has been influenced by our sampling strategy of using surgical lists for this group. Nine out of ten craniofacial children have had surgery. Those with psoriasis reported significantly less; only 10% had undergone surgery for their condition. However, for those with psoriasis that do undergo surgery they report a large average number of operations (10) being carried out. This is twice the number of those reported for craniofacial children, and those with head & neck cancer and those with burns report far fewer on average (three and two respectively).

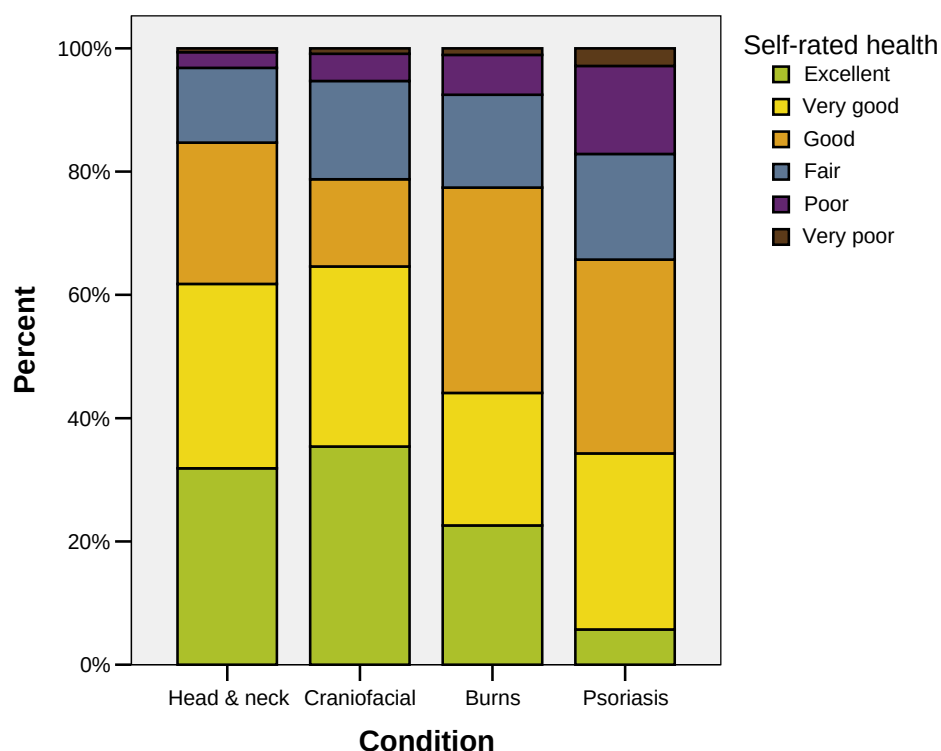
Those respondents who had undergone surgery were asked whether the surgery was essential for their condition and if it was *not* whether it was recommended by a doctor or requested by themselves. All psoriasis respondents who had had surgery stated that their surgery was essential. This was a somewhat surprising finding, as even treatment for severe psoriasis does not usually involve surgery. It is true, although rare, that psoriatic arthritis can develop in a small number of cases and that surgery is then an option. It could also be that some of the respondents were mistaking laser treatment for a surgical procedure.

Nine out of ten surgical cases were essential for those with head & neck cancer and with burns. However, this was less so for craniofacial children where only 59% of operations were essential and a third of operations were not essential but undertaken on the recommendation of the doctor/specialist. This reveals that for the craniofacial condition the decision to operate is less clear cut and subject to individual differences of the child's condition and level of severity. This is an interesting finding that reflects a clear difference between the four conditions, as the need for information will be all the more great when there is a 'grey' area concerning surgery. The difficulty of making decisions in these circumstances is echoed by an interviewee in the qualitative stage of our research who had to weigh up the risks of surgery against future social problems:

So we thought if they don't fix his head, he's going to get bullied at school.

Craniofacial parent

Figure 1: Self-rated health by condition



Health

Respondents were asked to rate the quality of their (or their child's) health during the four weeks prior to completing the survey as a general indicator of the impact of their condition (see Figure 1). The extent of a respondent's health could determine the extent to which they may see themselves as needing information or different types of information. Those with psoriasis reported the worst state of health, and stated health was significantly lower than those with head & neck cancer and craniofacial children. Amongst those with psoriasis, 17% reported *poor* or *very poor* health during the last four weeks, twice the level reported by those with burns and three times that for craniofacial children. By contrast, almost two thirds of craniofacial parents rated their child's health as *excellent* or *very good*, a figure similar to those with head & neck cancer. For those

with burns only 44% rated their recent health as *excellent* or *very good* and this dropped to 34% for those with psoriasis.

5 Survey Results

5.1 What information have patients received?

We asked respondents what information they had received about their condition and from whom they had received it. Table 4 below represents the percentage of 20 varied information items that respondents received from four different sources: a hospital doctor, nursing staff, any other health staff and/or they found information about these items themselves. The question was in a multiple response format, i.e. respondents could indicate that they had received information on a certain topic from more than one source.

Table 4: Source for 20 pre-selected topics on which respondents received information (%)

Information providers	Head & neck	Craniofacial	Burns	Psoriasis
Doctors	53	54	35	66
Nurses	39	43	64	21
Other healthcare professionals	22	18	18	5
Responders found information themselves	8	29	6	27

^a Percentages are based on those topics out of the 20 listed for which respondents did receive information. Topics on which information was not received were not included in the analysis.

From the results we find that doctors are the key information source, having provided over half of the topics on which information was received. However this is not the case for those with burns where the doctor only provided 35% of the information compared to 64% given by nurses. The nursing staff were also an important information provider for those with head & neck cancer (39%) and craniofacial parents (43%), but much less so for those with psoriasis (21%). Other healthcare professionals also provided information for respondents (other than those with psoriasis) on approximately one fifth of the topics covered.

It is possible that the results for those with psoriasis are influenced by the length of time since diagnosis, which was significantly further in the past than for those with other conditions. However, the nature of this condition means that diagnosis and treatment are ongoing issues that are frequently reviewed in the light of further symptoms. Perhaps what is more important to consider is that other conditions are more complex and draw upon a wider range of disciplines and specialists as part of the care team.

Looking at the information that respondents themselves found, we see that the most active searchers have been craniofacial parents (29%) and those with psoriasis (27%), who searched for three or four times more information than those with head & neck cancer (8%) and burns (6%). The motivation driving this appetite for information could be quite different between these two groups. It could be argued that for those with psoriasis there is a greater need for finding information themselves as they report having received up to 25% less information than other conditions from all their healthcare professionals combined. For craniofacial parents the motivation is less clear given that they have

received very similar levels of information to those with head & neck cancer and with burns. We can only speculate that there may be something specific to the condition, or simply because this is the only group looking for information on behalf of someone else (their child) that generates a desire to check for accuracy and diversity of opinion.

What information is it that craniofacial parents and those with psoriasis are keen to find? Is the information in areas where healthcare professionals have fallen short, revealing an unmet demand by the health service? Or is the information being searched for in addition to that already provided, revealing an appetite for scope or diversity of information and views or even concerns about quality?

Table 5 below presents the 20 information items grouped into five broad topic areas:

- **Diagnosis:** explanation about the condition, the future prospects and new research (three items).
- **Treatment:** options and alternatives, side effects, tests and treatment plan (five items).
- **After-care:** caring for themselves at home, medication, pain control, diet and therapy (six items).
- **Psycho-social:** self-help groups and dealing with emotions, appearance and the public (four items).
- **Economic:** returning to work or education, benefits and entitlements (two items).

As we have already seen in Table 4, there was a low level of self-motivated searching for information by those with head & neck cancer and with burns. For respondents from these two conditions the largest amount of information found within any of the topic groups was economic (15% and 18% respectively): that of returning to work (or education) and benefits and entitlements. Respondents with psoriasis and craniofacial parents were the more active searchers, and the most popular areas of information concerned diagnosis (34% and 54% of information was found on this topic respectively). Another popular topic was psycho-social where over a third of this information had been found by craniofacial parents and a quarter found by those with psoriasis. Craniofacial parents were also actively finding economic-type information (32%) compared to those from all other condition groups.

Table 5: Percentage of information received which was found by respondents themselves by topic area

Information areas	Head & neck	Craniofacial	Burns	Psoriasis
Diagnosis	12	54	5	34
Treatment	5	17	1	18
After-care	4	8	3	19
Psycho-social	8	39	7	24
Economic	15	32	18	18

With the exception of those with psoriasis, respondents from other condition groups were less likely to search for information on after-care themselves. However, this could be a reflection of the quality of information that was provided on this topic by healthcare professionals. Nursing staff most commonly provided after-care information and

supplied 50% of the information to those with head & neck cancer, 61% to craniofacial parents and 73% to those with burns. Our focus group research indicated a relatively high level of demand for after-care information once people had left the safe environment of the hospital. A quote from one patient illustrates that the lack of this type of information can be distressing:

Nobody really explained to me that the shit was going to hit the fan when you got home...nobody sat me down and said this is where you are going to need the support.

Amputee

Table 6: Most common information found by respondents themselves

Head & neck	Craniofacial	Burns	Psoriasis
Benefits and entitlements (19%)	Explanation of the condition (62%)	Benefits and entitlements (15%)	Explanation of the condition (39%)
Explanation of the condition (14%)	Future prospects for condition (42%)	Returning to work/ education (11%)	New research about the condition (37%)
Complementary/ alternative therapies (13%)	Benefits and entitlements (33%)	Living with appearance (8%)	Complementary/ alternative therapies (36%)
		Managing social situations (8%)	

For each condition, the top three most common information items that respondents found themselves are detailed in Table 6. Although respondents from some of the conditions revealed a relatively low level of self-motivated searching for the items overall, those items that were sought can be considered central to their information needs. For example, almost two thirds of craniofacial parents had searched for information themselves regarding explanation of their child's condition despite over 80% of them having received such information from doctors, and almost half from nursing staff.

Information guidance

As well as being providers of information, healthcare professionals are also in a position to point patients in the direction of further useful information. We asked respondents if any health professional had indeed provided guidance on *where* to find additional information about their condition. Table 7 shows significant differences between the experiences of respondents across all condition groups. Almost half of those with head & neck cancer (48%) had been given help to find additional information, but only a quarter of those with burns (26%), along with approximately a third of those with psoriasis (30%) and craniofacial parents (37%). This could be a reflection that there is simply more information concerning cancer to signpost patients to. However, these are disappointing results as it reveals that the majority of our respondents were left to their own devices when trying to find out more information about their conditions.

The importance of providing guidance is underlined by the finding that of those who were given advice, the overwhelming majority followed it up – as high as 80% in the case of craniofacial parents. We further asked those who *didn't* receive guidance whether they would have liked it and a strong division between the condition groups was found. Those with head & neck cancer were equivocal, roughly split 50/50, but a strident story

emerged from the other three groups. Over three quarters of craniofacial parents and of those with psoriasis stated that they would have liked guidance to have been provided by healthcare professionals. However, 64% of those with burns reported that they didn't need or want guidance even if had been offered to them.

Table 7: Guided to additional information (%)

	Head & neck	Craniofacial	Burns	Psoriasis
Yes	48	37	26	30
...and I followed it up	61	80	62	72
...but I didn't need or want it	39	20	38	28
No	52	63	74	70
...but I would have liked guidance	47	79	36	76
...and I didn't need or want it	53	21	64	24
Total number of respondents	147	106	82	60

Overall, these results reveal that healthcare professionals are not commonly providing signposts to additional information, and that for some conditions, such as craniofacial and psoriasis, there is actually a very large demand for this service. Conversely, amongst those with burns, and to a lesser extent those with head & neck cancer, there is a reluctance in advance to consider the benefits of pursuing further information. However, when patients from these conditions have been given such guidance, the overwhelming majority have followed it up. This would then imply that there are potentially strong differences in attitudes towards information between respondents from the condition groups, suggesting that a universalistic approach to information provision will not be successful for all patients, and that a more tailored approach to individual differences is required. It is therefore not necessarily an issue concerning quantity of information but rather it is about the abilities of healthcare professionals to guide towards quality information. It is not about healthcare professionals working harder, but instead working in more effective ways that can enable individual action by the patients themselves.

Summary

- Doctors are the key information providers and have given information on approximately a third of 20 information topics. However, for those with burns, the nurse is the key role having provided a far broader range of information than doctors – almost a third more.
- Those with psoriasis report having received almost 25% less information from their healthcare professionals compared to other condition groups.
- The parents of children with a craniofacial condition and those with psoriasis have a much greater appetite for information and have searched for three or four times more information than people with other conditions. The most sought after information related to diagnosis and psycho-social topics.
- Healthcare professionals are failing to signpost patients to further information. Less than half of those with head & neck cancer and a quarter of those with burns said they had been given such guidance. Over three quarters of craniofacial parents and those with psoriasis who didn't receive guidance reported that they would have liked it.

Crucially, amongst those who were provided with guidance, the overwhelming majority had followed it up.

5.2 What are the common sources of information?

When looking for information about their conditions there are many sources to which people can turn. Our survey detailed 15 such sources, ranging from different types of healthcare professionals to the media, charities and commercial organisations.

Table 8: Sources of information (%)

	Head & neck	Craniofacial	Burns	Psoriasis	Total
Hospital doctors	97	100	93	99	97
Nurses	95	97	99	88	95
GPs	88	92	75	97	88
Family/friends	68	81	73	65	72
Allied professionals	76	58	76	27	64
People with similar conditions	55	75	44	68	60
Internet/websites	47	92	27	72	59
Articles in newspapers/magazines	52	66	34	82	57
Pharmacist/chemist	40	51	43	68	48
Television/radio programmes	41	69	31	50	48
Psychologist/counsellor	30	50	44	18	37
National voluntary orgs/charities	35	50	15	32	34
Commercial organisations	28	34	23	33	30
Local support groups	28	47	18	14	29
Public library	25	43	15	28	28

Detailed in Table 8 are the percentage of respondents that have used these sources for information about their condition. Health professionals understandably are common sources, with three quarters or more of all respondents using hospital doctors, nurses and GPs. Seventy six per cent of both those with head & neck cancer and with burns were using allied professionals for information, but this was not a common source for those with psoriasis (27%). The most common non-healthcare professional source was family and friends (for two thirds or more of all respondents) and people with similar conditions, although this latter group was less popular as a source for those with burns (44%) and head & neck cancer (55%) than with craniofacial parents (75%) and those with psoriasis (68%). There were sharp divisions in the use of the internet and websites. This was a very common source for craniofacial parents (92%) and those with psoriasis (72%) but was used only by a minority of those with burns (27%) and head & neck cancer (47%). The low use of the internet by burn patients would not be surprising to the health professionals who took part in our focus group research and may well be a reflection of socio-economic status and educational levels.

Overall, the least popular sources of information were national voluntary organisations and charities, commercial organisations, local support groups and public libraries. With the exception of craniofacial parents, whose use of these was greater, these sources were only used by a third or less of respondents. The poor rating for voluntary organisations contradicts the findings of our focus group research, which indicated a strong dependence on this sector. This is not altogether surprising, as most of the focus group participants were recruited via various patient organisations. Nevertheless, the survey results should be treated with some caution. If respondents did not greatly value the information provided by these organisations it could be because they have never been directed to them (see Table 7) or because they fail to identify the organisation behind internet sites and other information sources. This finding does perhaps illustrate a need for the voluntary sector to advertise and promote its materials more effectively.

Table 9: Usefulness of information sources (%: 'very useful')

	Head & neck	Craniofacial	Burns	Psoriasis
GPs	33	9	22	14
Local support groups	30	15	0	0
Internet/websites	25	44	17	37
Public library	11	4	0	33
Hospital doctors	75	52	51	49
Articles in newspapers/magazines	5	19	0	11
People with similar conditions	36	44	24	16
Pharmacist/chemist	8	2	14	11
Psychologist/counsellor	40	11	13	0
National voluntary organisations/charities	29	38	8	14
Family/friends	52	20	44	7
Television/radio programmes	3	16	8	6
Nurses	62	50	66	33
Allied professionals	42	13	49	6
Commercial organisations	10	3	10	5

The survey also asked respondents to evaluate these information sources by rating their usefulness on a four-point scale (*not useful at all* (1) to *very useful* (4)). Table 9 shows the proportion of respondents finding the sources 'very useful' (a full break down of the results along with overall mean scores is available in Appendix B). Local support groups were a very useful source for almost a third of those with head & neck cancer (30%), but this was in stark contrast to other condition groups: 53% of those with burns and 44% of those with psoriasis stated that local support groups were not useful at all. This may reflect the current inactive state of many local burns support groups and the scarcity of local psoriasis groups. Of the healthcare professionals, GPs (33%), hospital doctors (75%) and psychologists/counsellors (40%) were very useful sources for those with head & neck cancer compared to other condition groups. This was particularly the case for craniofacial parents, where the mean useful scores were significantly lower compared to those with head & neck cancer for each of the five healthcare professionals. For craniofacial parents the most useful sources other than healthcare professionals was the internet and people with similar conditions (44% very useful for both).

Compared to other condition groups, nurses (66%) and allied professionals (49%) were the most useful to those with burns, and along with those with head & neck cancer family and friends were a key source (44% and 52% respectively) and mean useful scores were significantly higher than for craniofacial parents and those with psoriasis. Those with psoriasis rated almost half of all sources of information lower than other conditions. Those sources rated as not useful at all by this group were psychologists/counsellors (58%), television and radio programmes (41%), local support groups (44%) and commercial organisations (50%). However, commercial organisations were rated particularly poorly by all groups especially by craniofacial parents (78% not useful at all); the applicability of consumer products for this group is far less than for those with burns or psoriasis.

Trusted sources of information

Of the 15 different sources, respondents indicated which were in their opinion the most trusted overall. The top five most trusted sources according to each condition are detailed in Table 10.

Table 10: Most trusted sources of information

Head & neck	Craniofacial	Burns	Psoriasis
Hospital doctors (89%)	Hospital doctors (83%)	Nurses (87%)	Hospital doctors (89%)
Nurses (67%)	Nurses (64%)	Hospital doctors (72%)	Nurses (55%)
GPs (41%)	Internet (36%)	GPs (41%)	GPs (51%)
Allied professionals (19%)	People with similar conditions (30%)	Allied professionals (34%)	Internet (28%)
Family/friends (14%)	GPs (21%)	Family/friends (26%)	People with similar conditions (18%)

Three healthcare professionals feature prominently in the top five most trusted sources for all four conditions: Hospital doctors, nurses and GPs. Of these three, hospital doctors were overwhelmingly cited as the most trustworthy source of information for all conditions other than those with burns, where nurses were seen as the most trustworthy. Allied professionals were a trusted source for one out of five of those with head & neck cancer (19%) and for over a third of those with burns (34%). Family and friends and people with similar conditions were also popular trusted sources.

Of particular interest is the reporting of the internet as a trusted source by 28% of those with psoriasis and 36% of craniofacial parents. The internet has emerged over recent years as a major means of provision for health-related information from both professional and lay sources. Attitudes amongst healthcare professionals regarding the quality of internet-based material have been changing, reflected by the Department of Health's decision to embrace internet provision as part of its proposals to accredit health and social care information providers (Coulter et al, 2006).

For those with psoriasis, the sixth most trusted source was pharmacists (14%) whereas this was not recorded for those with burns and only by a very small minority of craniofacial parents and those with head & neck cancer. Psoriasis is generally treated at primary care level unless the condition has reached a level of severity that needs the interventions of a dermatological unit. The treatment of psoriasis involves the use of

topical creams, ointments and emollients which leads to a greater amount of contact time with pharmacists than other conditions. These results are perhaps indicative of a qualitatively different type of relationship with pharmacists for this group that has developed over time.

Summary

- Healthcare professionals are the most commonly consulted sources of information - used by three quarters or more of all respondents. However, whilst 75% of those with head & neck cancer rated hospital doctors as a *very useful* information source, this was only the case for half of those with other conditions.
- Other popular sources of information were family and friends and people with similar conditions.
- The internet was a very common source of information for craniofacial parents and for those with psoriasis; it was rated as *very useful* by approximately 40% of both groups and as one of the most trusted sources by almost a third. However, the internet was used by only a minority of those from other condition groups.
- The least popular sources consulted directly by respondents were national voluntary organisations and charities, commercial organisations, local support groups and public libraries.
- Healthcare professionals featured overwhelmingly in the top five most trusted sources for all respondents.

5.3 What are the most important topics of information?

The survey listed six information topics that were common for all respondents across each of the four condition surveys:

- How the condition might affect appearance
- Dealing with emotions (e.g. depression, anxiety)
- Dealing with personal relationships/friendships
- Managing social situations (e.g. staring)
- Availability of counselling services
- Healthy living (e.g. exercise, diet)

Further to these six, each survey had a series of unique items that were condition-specific. Respondents were asked how important or not it was for them to have information on these topics, and responses were measured on a five-point scale ranging from *very unimportant* (1) to *very important* (5).

The mean scores for each of these items was above the midpoint, and in most cases above or approaching four out of five (statistical details can be found in Appendix C). This reveals a high level of importance for these types of information amongst our condition groups. With the exception of 'dealing with personal relationships' there was a significant difference in the level of importance between the condition groups for each topic. To highlight this, Table 11 shows the percentage of response for each information item that was given as *very important*. Information about how the condition might affect appearance was judged very important by 73% of craniofacial parents and by a third of

respondents from all other condition groups. Managing social situations (50%) and dealing with emotions (48%) were also key areas for craniofacial parents and the rating was approximately 20% more than that given by respondents from all other condition groups.

Table 11: Importance of information topics (%: 'very important')

	Head & neck	Craniofacial	Burns	Psoriasis
How condition might affect appearance	34	73	33	35
Dealing with emotions	27	48	28	29
Dealing with personal relationships/ friendships	21	30	33	26
Managing social situations	15	50	19	28
Availability of counselling services	21	29	26	15
Healthy living	31	18	30	34

Table 12 details the condition-specific information items and the percentage rating each 'very important' (a full break down of these results is available in Appendix C). For those with head & neck cancer, the chances of recurrence (64%), radiotherapy (61%) and how surgery might affect their function (56%) were vital areas of information. More contentious was information on cosmetic surgery (13%) and alternative therapies (11%) where a greater percentage of people claimed that these were very unimportant areas (18% and 21% respectively).

Table 12: Importance of condition specific information topics (%: 'very important')

Head & neck	Craniofacial	Burns	Psoriasis
Chances of recurrence (64%)	How surgery might affect appearance (75%)	Skin massaging and creaming (54%)	Oral treatments (45%)
Radiotherapy (61%)	Developmental issues (66%)	Skin grafts (48%)	Triggers for the onset of my condition (39%)
How surgery might affect function (56%)	How the condition could be passed on (63%)	Environmental factors (46%)	Creams and emollients (37%)
Causes of condition (44%)	Sensory impairment (60%)	Care of donor site (36%)	Environmental factors (36%)
Chemotherapy (39%)	Special educational needs (58%)	How surgery might affect appearance (35%)	Steroids (32%)
How surgery might affect appearance (39%)	Breathing difficulties (52%)	Pressure garments (35%)	Light treatment (29%)
Prostheses (25%)	Speech therapy (50%)	Cosmetic surgery (26%)	Complementary/ alternative therapies (22%)
Cosmetic surgery (13%)	Cosmetic surgery (49%)	Complementary/ alternative therapies (23%)	Laser treatment (19%)
Complementary/ alternative therapies (11%)	Feeding (29%)	Prostheses (19%)	

Craniofacial parents registered the highest levels of importance for their condition-specific topics overall, with 75% or more of respondents stating that receiving information

on all topics other than breathing difficulties and feeding were important or very important. This represents an understandable widespread concern for their child's condition. The three information topics rated as the most important were how surgery might affect their child's appearance (75%), developmental issues (66%) and how the condition could be passed on (63%).

For those with burns, skin massaging and creaming (54%) was the only topic where the majority had rated it as very important. Information on skin grafts (48%) and environmental factors such as sun protection (46%) were also highly rated. Information on prosthetics, such as a false limb or facial part, was rated the lowest (19%) with half of those with burns claiming that this would be unimportant or very unimportant to receive information on, indicative perhaps that this was a minority topic of interest due to the nature of their injuries.

Those with psoriasis, as with burns above, were also more measured in their importance ratings. For this group the key information areas rated as very important by more than a third or more of respondents were oral treatments (45%), triggers for the condition's onset (39%), cream and emollients (37%) and environmental factors (36%). Information on alternative therapies (22%) and laser treatment were relevant to fewer respondents from this group.

Summary

- For those with head & neck cancer, the chances of recurrence (64%), radiotherapy (61%) and how surgery might affect functions such as speaking or eating (56%) were vital areas of information.
- Craniofacial parents registered the highest levels of importance to information topics overall. Key areas were: how surgery might affect their child's appearance (75%), how the condition might affect appearance (73%) and developmental issues (66%).
- Only one topic was rated as very important by the majority of those with burns – skin massaging and creaming (54%). Other important information topics for this group were skin grafts (48%) and environmental factors (46%).
- Those with psoriasis valued information on oral treatments (45%), triggers for the condition's onset (39%) and cream and emollients (37%).

5.4 The information gap

As we have seen from the previous section there is a strong appetite for information amongst the four condition groups. However, knowing what the most important information topics are is only part of the story. Without knowing whether this information has actually been received or not it is difficult to draw conclusions about the state of information provision. For each of the information topics we asked respondents how easy or difficult it has been for them to find this information (measured on a five-point scale: *very difficult* (1) to *very easy* (5)). The key issue for the previous section was to identify what are the most important topics of information. For this section, the challenge is to ascertain the extent of any information gap by establishing if these topics of information have been difficult to find or not.

Table 13 details the three information topics that have been the easiest to find amongst those that were rated as important by respondents. A full set of results for both core and

condition-specific topics are available in Appendix D. The majority of respondents within each condition were finding important information easy to locate with the exception of craniofacial parents where this was the case for only one topic – how the condition might affect their child's appearance. For those with head and neck cancer, five out of 15 information topics were judged easy to find by over 50% of respondents, the easiest being information on healthy living. Those with burns were able to find their information the most easy overall with eight out of 15 information topics found easily by the majority. Two of these - pressure garments and skin massaging - were given the highest ratings of any of the condition topics. Those with psoriasis reported fewer topics as being easy to find by the majority - only four of their fourteen items – the easiest of which was information on creams and emollients.

Table 13: Three important information topics that have been the easiest to find (%: 'easy' or 'very easy')

Head & neck	Craniofacial	Burns	Psoriasis
Healthy living (69%)	How condition might affect appearance (54%)	Skin massaging and creaming (84%)	Creams and emollients (64%)
Radiotherapy (61%)	Cosmetic surgery (49%)	Pressure garments (79%)	Light treatment (56%)
Availability of counselling services (58%)	Inheritance of condition (49%)	Skin grafts (66%)	Oral treatments (55%)

Turning to the other side of the rating scale, Table 14 presents the results for the information topics that were the most difficult to find. Even amongst those with head & neck cancer and those with burns where some positive results have just been described, there were a substantial minority (and a majority for one item in each condition) that rated some topics as *difficult* or *very difficult* to find. These key areas of difficulty were cosmetic surgery (52%) for those with head & neck cancer, and dealing with emotions (53%) for those with burns. For craniofacial parents and those with psoriasis the information gap was much larger – over two thirds of respondents from both condition groups reported that it was difficult to find out about counselling services. The level of difficulty faced by the majority of respondents in these two groups in finding psycho-social information was also of concern. This was especially severe for those with psoriasis where 74% reported difficulty finding information on dealing with emotions and 80% on how to manage social situations. Given that this analysis has only been carried out on those information topics that were rated as important by respondents, makes the findings particularly stark.

Table 14: Three important information topics that have been the most difficult to find (%: 'difficult' or 'very difficult')

Head & neck	Craniofacial	Burns	Psoriasis
Cosmetic surgery (52%)	Availability of counselling services (67%)	Dealing with emotions (53%)	Managing social situations (80%)
Managing social situations (48%)	Managing social situations (58%)	Dealing with personal relationships/ friendships (46%)	Dealing with emotions (74%)
Causes of condition (43%)	Dealing with emotions (55%)	Managing social situations (46%)	Availability of counselling services (71%)

In the additional comments at the end of the questionnaire, several respondents referred to failures in information provision in specific areas:

Radiotherapy should be explained to patients more clearly. Especially how bad it can be.

Head & neck cancer

Information on any specialist items (if available) such as cycle helmets: "off the shelf" ones don't always fit.

Craniofacial conditions

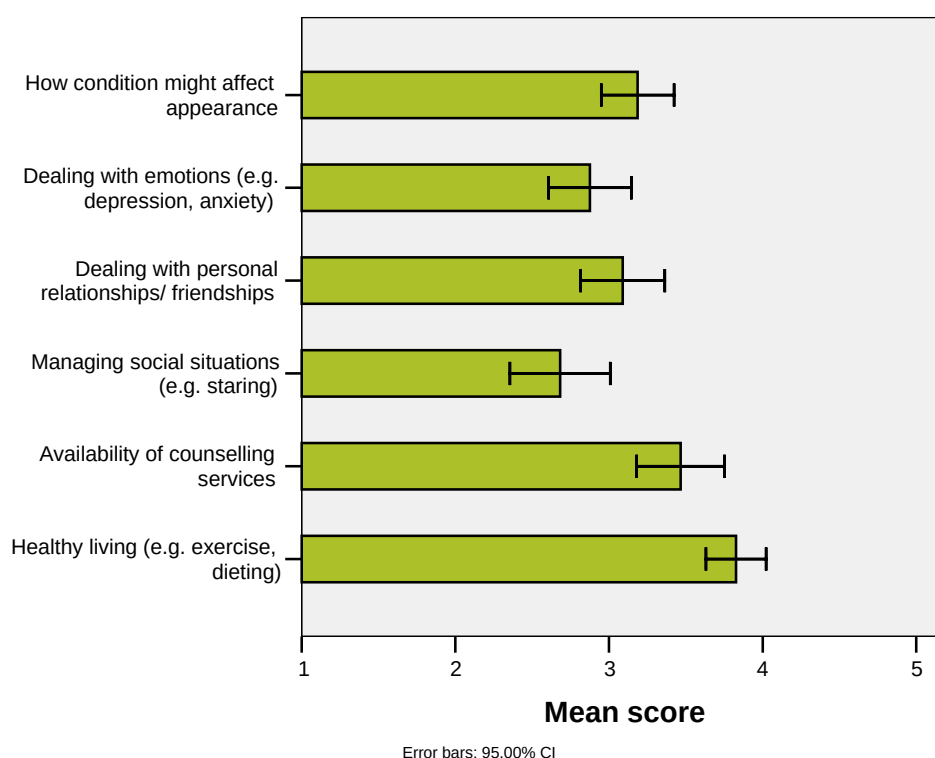
I would have liked far more information from whatever source about alternative therapies and natural healing methods including the link to diet.

Burns

Doctors offering different opinions due, I believe, to a lack of knowledge about different products available and in some cases unaware of product side effects.

Psoriasis

Figure 2: Ease of finding important information (Head & neck cancer)



The majority of the most difficult to find information topics reported in Table 14 are core topics that featured in each condition survey. The use of core topics allowed us to compare and contrast responses across the four condition groups. Figures 2 to 5 show the mean scores for these six common information topics. Disentangling the results by condition reveals that there are statistically significant differences between respondents from condition groups on five out of the six topics. Information for how the condition might affect appearance is somewhat easy to find with a mean rating above the midpoint

(3) and rated similarly by respondents from all condition groups. With regards to healthy living, craniofacial parents and those with psoriasis were finding it significantly more difficult than those with head & neck cancer to find this information.

The remaining four common information topics were all of a psycho-social nature: dealing with emotions, personal relationships, managing social situations and the availability of counselling services. The largest information gaps for these topics were found amongst those with psoriasis, where mean scores were the lowest overall and significantly lower than for those with head & neck cancer (statistical results can be found in Appendix D). With the exception of managing social situations, craniofacial parents were also finding it harder to locate these psycho-social materials with mean scores below the midpoint and significantly lower than those with head & neck cancer.

Our focus group research with healthcare professionals working in dermatology indicates that people with other dermatological conditions in addition to psoriasis may be having difficulty finding these information topics. Dermatology nurses felt that cancer patients receive better psychological support than those with skin conditions. In the additional comments, survey respondents across other conditions also expressed a need for more information on this aspect of their recovery, for example:

The emotional side of things wasn't touched on.

Craniofacial conditions

Figure 3: Ease of finding important information (Craniofacial parents)

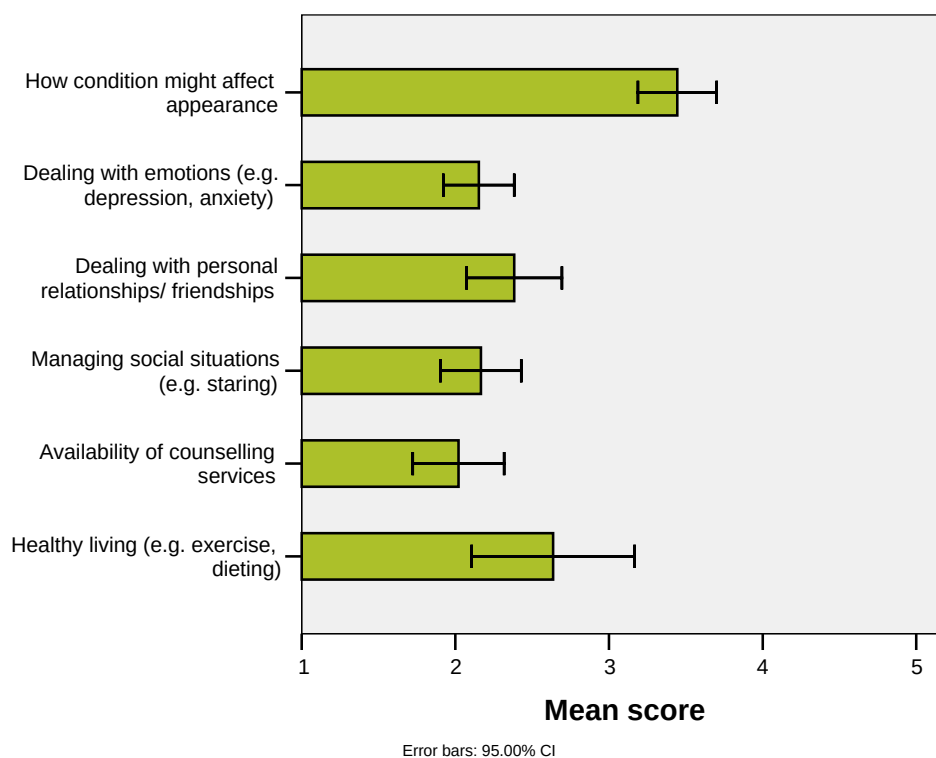


Figure 4: Ease of finding important information (Burns)

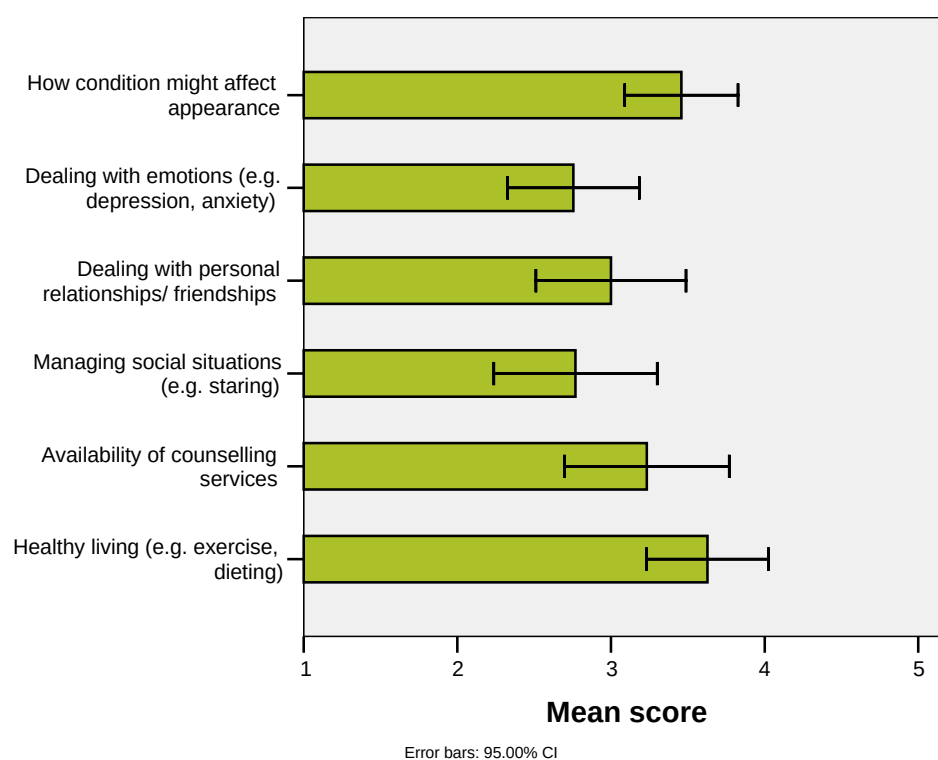
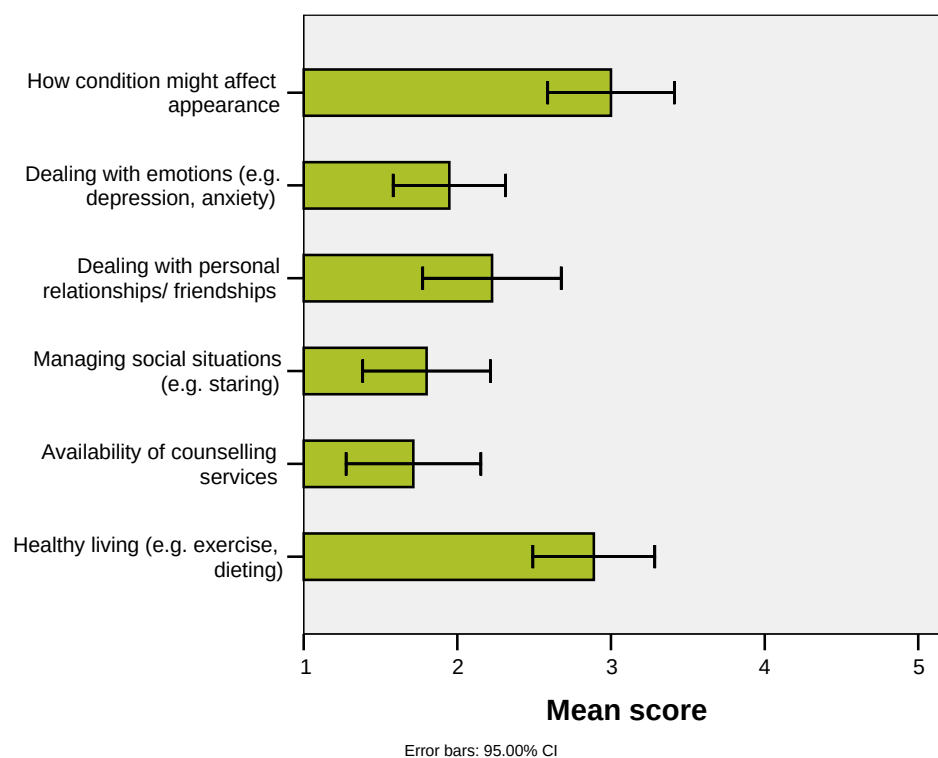


Figure 5: Ease of finding important information (Psoriasis)



Summary

- The majority of those with burns found information that was important to them easy to find. However those with psoriasis and craniofacial parents were encountering greater difficulties.
- Across all condition groups, respondents found information of a psycho-social nature - dealing with emotions, relationships and managing social situations - some of the hardest topics on which to find information.
- Psycho-social information was a particularly severe information gap for those with psoriasis, where the highest levels of difficulty were recorded overall.
- The availability of counselling services was an information gap for craniofacial parents and for those with psoriasis. However, this was not an issue for those with head & neck cancer and burns.

5.5 What are the preferences for receiving information?

The survey asked which of six common ways of receiving information about their condition respondents would prefer. The six broad choices were:

- **Printed:** e.g. leaflet or book
- **Mass media:** e.g. TV, radio, newspaper or magazine
- **Audio/Visual:** e.g. audio cassette, video, CD-Rom or DVD
- **Telephone:** e.g. direct line to a health professional or helpline
- **Face-to-face:** e.g. talking with a health professional
- **Internet:** e.g. website or email.

For each of the information topics respondents were asked to provide a first and second preference for delivery method. Table 15 gives an overview of this response by detailing the percentage of people who indicated that they would prefer the different delivery methods for at least one or more of the information items. The overwhelmingly popular choices for receiving information were either face-to-face or printed materials, and these findings are consistent with surveys that have looked at information preferences within other condition groups (e.g. multiple sclerosis, see Hepworth & Harrison, 2004). The preference for information to be delivered face-to-face was almost universal (91% or higher) and the choice for printed materials was between 19-34% more popular than for other competing media. However, amongst those with head & neck cancer, burns and psoriasis it is important to point out that a substantial minority - over 20% - chose not to receive information in a printed format for *any* topic.

For those who preferred not to have printed information, the most popular preferences were face-to-face and the telephone. This is not completely surprising when five and half million people in Britain have reading difficulties and 22% of the working population have a low level of literacy (Carey et al, 1997). Focus group participants also revealed their reluctance to read information.

I find that doing things face to face ...I can take a lot more in than if I have a leaflet or a pamphlet or something. Because as I say I tend not to read.

Head & neck cancer

Table 15: Preferences for delivery of information items (%)^a

	Head & neck	Craniofacial	Burns	Psoriasis
Printed	78	87	79	79
Mass media	29	28	37	28
Audio/Visual	28	39	27	19
Telephone	41	62	45	34
Face - to - face	91	95	95	91
Internet ^b	31 (44)	56 (62)	26 (41)	53 (60)

^a Percentages refer to those choosing the delivery method for at least one or more of the available information items

^b Percentages in brackets have as their base only those with home internet access.

The least popular choices for information delivery were through the mass media (although this was more popular with those with burns) and audio/visual (although this was more popular with craniofacial parents). The internet was a more popular preference, especially when the analysis focused on those with internet access at home. Over 40% of those with head & neck cancer and those with burns chose it as a delivery method and this rose to 62% of craniofacial parents and 60% of those with psoriasis.

Table 16: Most common information topic for each delivery medium

	Head & neck	Craniofacial	Burns	Psoriasis
Printed	Healthy living (68%)	Healthy living (73%)	Environmental factors (70%)	Complementary/ alternative therapies (62%)
Mass media	Complementary/ alternative therapies (15%)	Healthy living (15%)	Healthy living (19%)	Environmental factors (19%)
Audio/Visual	Managing social situations (14%)	How my child's condition might affect their appearance (19%)	Skin massaging and creaming (14%)	Environmental factors (12%)
Telephone	Availability of counselling services (29%)	Dealing with emotions (38%)	Managing social situations (36%)	Dealing with emotions (20%)
Face - to - face	Chances of recurrence (92%)	How surgery might affect my child's appearance (93%)	Pressure garments (83%)	How my condition might affect my appearance (83%)
Internet^a	Complementary/ alternative therapies (36%)	Availability of counselling services (37%)	Complementary/ alternative therapies (32%)	Availability of counselling services (47%)

^a Percentages refer to only those with home internet access.

Providing information to patients either face-to-face or via printed materials has historically been the most popular way of making information available, and our results confirm that this remains the preference within each of our condition groups. Indeed, face-to-face and printed materials were the top two preferences for each individual information topic. It is therefore of interest to look somewhat deeper and see which

information topics were the most popular for delivery through alternative mediums. These choices are set out in Table 16.

The mass media was seen as a good vehicle for presenting information about healthy living, environmental factors and complementary therapies. These are areas that could usefully be brought to life in magazine articles or local TV programmes providing interesting real-life stories or factual investigative material. For audio/visual the most popular suggestions were those that could maximise the visual potential of video or DVD, such as an instructional video covering skin massaging and creaming techniques for example. One survey respondent with head & neck cancer felt that a CD-Rom would be more reliable than a health professional:

CD-Rom information – especially if interactive – would be a good way to provide information as unfortunately with “people” things are often not covered.

Head & neck cancer

Craniofacial parents' preference for audio/visual information concerned how their child's condition might affect their appearance. The use of a DVD in this case could allow parents to compare their child with others with similar conditions, perhaps even with a gallery of photographic material to help visualise the effects of surgery and for them to watch documentary style stories of the experiences of other parents caring for a craniofacial child. Health professionals in the focus groups also recognised the potential of DVDs and videos:

I mean we're stuck with photos, but it has occurred to me that we should perhaps ..make a short video of the child, get permission for them to speak a bit and then get another dimension.

Craniofacial professional

Two common areas were popular for researching on the internet: complementary/alternative therapies and counselling services. Both areas lend themselves to the internet's hyperlink approach that aids searching for organisations' web pages that provide details about services along with important contact information. It has also become a popular resource for information that would be more time-consuming to find out about through other methods. For the telephone, information of a more psycho-social nature was a popular choice. Access to health professionals through a helpline would be an immediate way to gain information and support for dealing with negative emotions such as depression and anxiety as well as with ways of coping with adverse reactions from the general public.

Audio-taping

Respondents were further asked in more detail about two more specialist techniques for presenting information to patients – photographic material to help patients visualise how their appearance may be changed through different treatments, and the audio-taping of consultations. In a recent speech, Health Minister Rosie Winterton described how patients only remember on average 10% of the information given during consultations (DH, 2006). Any method that helps to improve the quantity as well as the quality of information during these sessions should be considered an important priority.

Our survey found that very little audio-taping had taken place across the four condition groups, although the consultations of craniofacial parents were clearly the more taped, with 12% taped compared to less than five per cent of the other condition groups. The issue of whether or not patients would actually prefer to have audio recordings made was divisive. The largest group in favour were craniofacial parents, where 46% would have liked to have been taped, but this was matched by 42% who were against having them taped. Across the other three condition groups it was the clear majority who were against taping, with 57% of those with head & neck cancer, 62% of burns and 79% of those with psoriasis.

Both health professionals and patients in the focus groups shared these reservations. Patients feared it might compromise the relationship they enjoyed with their clinicians and professionals were concerned about the legal implications:

I like to keep an open relationship with them ...it might put them on their guard more.

Craniofacial parent

Photographs

Health professionals in the focus groups frequently mentioned the use of photographs as a tool to inform patients and parents about the likely outcome of surgery. Burns patients wanted before and after photographs to help them visualise how their scars might heal. The survey probed whether respondents had been shown such photographs, and if they had, whether they had been useful to them.

Across the four condition groups the use of visualisation materials was reported as common practice only by craniofacial parents. Almost half of parents (48%) had been shown photographs to help them visualise how their child would look after treatment, and of this group there was only one parent who claimed that it was not helpful. Furthermore, looking only at those who had not been shown photographs (see Table 17) we found that 79% would have liked to have seen some. This is a positive result that reveals both the demand and importance for parents of this source of information.

Table 17: Use of photographs to visualise appearance (%)

	Head & neck	Craniofacial	Burns	Psoriasis
Have been shown photographs	12 (n=18)	48 (n=52)	8 (n=7)	10 (n=7)
...and it was helpful	94	98	100	86
...and it was not helpful	6	2	0	14
Have not been shown photographs	88 (n=127)	52 (n=57)	92 (n=80)	90 (n=60)
...but would have liked to have seen	44	79	41	47
...but did not want to see any	56	21	59	53

Amongst the other three condition groups there were far fewer cases of respondents having been shown photographs; approximately only 10% of respondents. Of those that hadn't seen any, the majority was against being shown them: between 53% and 59% within all three condition groups. However, what is interesting, and some caution must be exercised as these are the experiences of only a small number of respondents, is that despite reluctance for visualisation amongst these groups, those that had been shown

photographs overwhelmingly reported the practice as helpful. Given this positive result it would seem important for healthcare professionals to increase the practice whilst making additional effort to engage with the concerns of those who exhibit an initial reluctance.

A recent research review concerning the role of visual material in health communication has reported significant benefits for patients, particularly amongst those with low literacy levels (Houts et al, 2006). Visual material can be seen more formally as decision aids that can help health professionals and patients to reach conclusions whilst fostering joint decision-making. We are unable to tell from the survey results the context in which photographs are being shown. However, we do know that it is most common amongst craniofacial conditions and that this group also have the highest amount of non-essential surgery (41%).

Summary

- The most popular delivery methods for information were either face-to-face or printed material. These were the top two choices for delivery of every information topic, with the preference for face-to-face being almost universal.
- However, a reliance on purely printed material as an alternative to face-to-face should be tempered by the knowledge that a substantial minority (20%) of respondents from all condition groups other than craniofacial chose not to receive information in a printed format for **any** topic.
- The internet was a popular medium for craniofacial parents and for those with psoriasis, but less so for respondents from other condition groups. Seeking alternative therapies and details of counselling services were popular choices for this medium.
- For the telephone, preferring to receive information of a more psycho-social nature was a common choice where support could be provided through a helpline to health professionals, perhaps when dealing with negative emotions such as depression and anxiety.
- The mass media was one of the least popular choices for receiving information for all condition groups. However, information on healthy living, environmental factors and alternative therapies were thought to work well via this format.
- Audio/visual information was also a minority choice, but thought appropriate for instructional material such as skin massaging and creaming (burns). Craniofacial parents also found it useful to help them and their children visualise how their appearance could be affected by their condition and treatment.
- The consultations of craniofacial parents were found to be the most audio-taped but overall levels were low across all condition groups. Asked if they would have liked to have had their consultations taped respondents gave a mixed response.
- Showing material such as photographs to help patients visualise what their appearance may look like after treatment was a common preference only for parents of a child with a craniofacial condition (48%). Whilst the majority of other respondents were against seeing visualisation material, those that had were almost universal in proclaiming it helpful.

5.6 Attitudes towards information

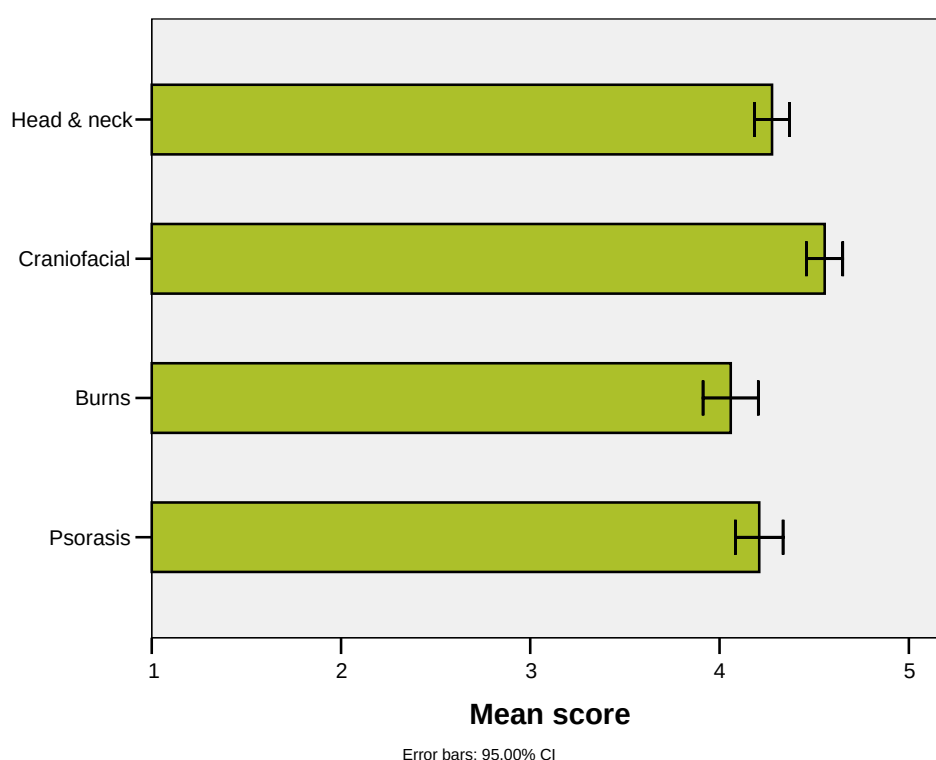
The survey presented respondents with a range of attitude statements providing them with the opportunity to express their views about any perceived benefits of information,

how doctors have chosen to provide them with information and on the overall quality of the information received. Responses were measured on a five-point scale *strongly disagree* (1) to *strongly agree* (5). Although individual questions provide a measure on a particular issue, a much more reliable method to tap underlying attitudes is to analyse the extent to which a number of questions are addressing a common attitudinal orientation or construct. In other words, if we combine a respondent's score on a range of questions that are all part of the same construct we will have a more robust measure than if we asked a single question. Further details about this process are available in Appendix E.

Information as a tool

Information can only be considered truly useful if it forms a guide to action, a tool that enables people to manage their lives (Mair & Kierans, 2006). Respondents were asked their views about five aspects of information that had emerged from interviews and focus groups regarding the use of information as a tool. Does information help respondents to formulate the right questions to ask, inform decision-making, gain realistic expectations, foster understanding about, and cope with, a condition that affects appearance? Figure 6 shows the mean score for these attitude statements according to each condition group. Overall the results are very high with respondents from each condition group rating this area over four out of five. This reinforces previous findings regarding the importance of information for these groups and reveals just how widely the potential benefits are understood. Even against a backdrop of such strong results there are still differences by condition group. The highest mean score was 4.56 from craniofacial parents, who were significantly more positive than respondents from every other condition group. The lowest mean score was from those with burns (4.06).

Figure 6: Information as a tool by condition

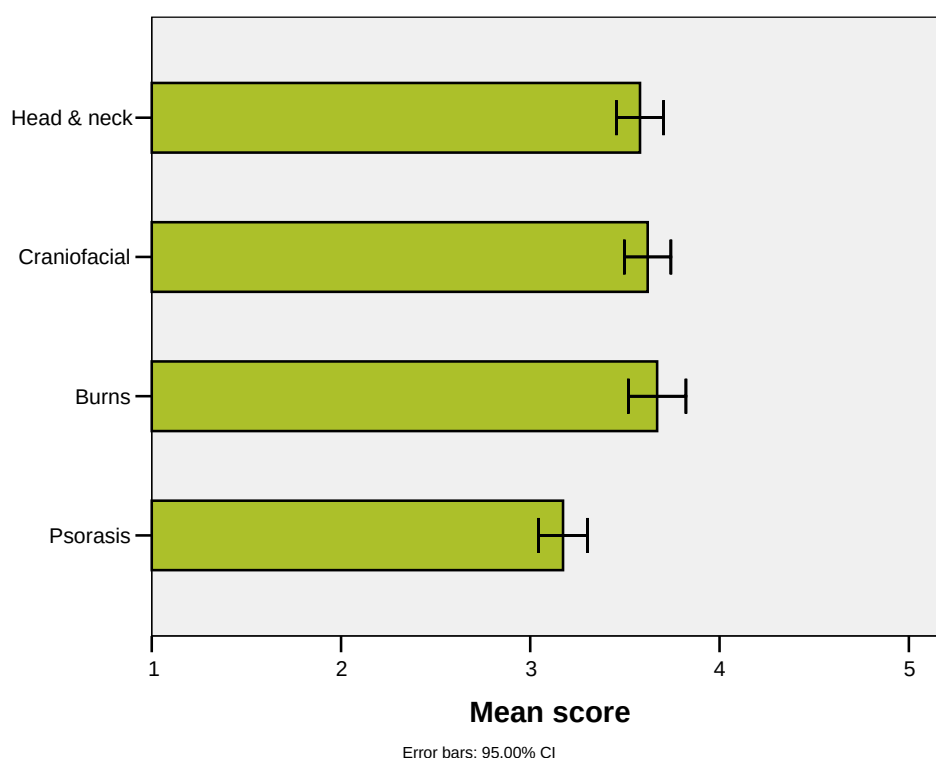


Looking at the individual attitude statements (a table of results is available in Appendix F), almost all craniofacial parents (96%), those with psoriasis (95%) and those with head & neck cancer (94%) agreed or strongly agreed that information helps them to ask the right questions in consultation, along with 83% of those with burns. The statement with the lowest level of agreement for all condition groups was whether information helped them to cope with their condition, but this still attracted high levels of response from 71% for those with psoriasis to 89% of craniofacial parents. Overall, there was a strong positive and consistent response from respondents within each condition group across the five statements.

Evaluation of quality of information received

Our results thus far have shown that information is valued as important; vitally so for some topics, and that respondents have a broad understanding of the intrinsic benefits of receiving information about their condition. Here we report on respondents' overall assessment of the quality of information they have received. Opinions were given on six aspects of information quality to ascertain whether information had been easy to understand, accurate and up to date, detailed enough, consistent and relevant to their needs.

Figure 7: Evaluation of information quality overall by condition



The average mean score for this group of items is shown in Figure 7 (see Table 18 for scale items). Overall quality was judged very similarly between those with head & neck cancer, burns and craniofacial parents with a mean score of approximately 3.6. This is a moderately high and positive result; however for those with psoriasis the average score of 3.17 was significantly lower than that recorded from the other three condition groups. The average score is also close to the midpoint showing that respondents with this condition are more equivocal about the quality of the information that they have received.

Amongst the four condition groups, those with psoriasis have on average lived with their condition for the longest time. It could be that for this group they are being asked to reflect on a greater amount of information over a period that has seen large changes in quantity, quality and delivery of information.

Table 18: Quality of information (%: 'agree' and 'strongly agree')

Overall info...	Head & neck	Craniofacial	Burns	Psoriasis
...has been easy to understand	68	72	66	50
...has been consistent ^a	58	50	46	33
...has usually been accurate	73	70	77	37
...has always been up to date	59	63	61	34
...has been detailed enough ^a	44	47	54	27
...has been relevant to my needs ^a	49	66	48	29

^a Item wording and data have been reversed for ease of interpretation .

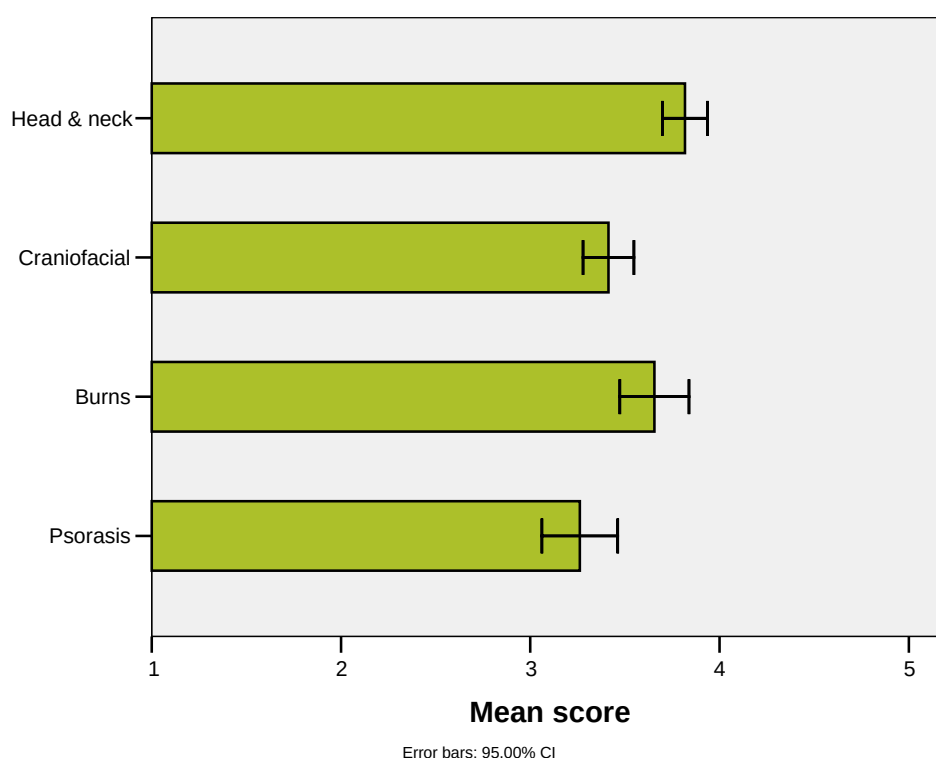
Amongst those with psoriasis agreement with the overall quality of information was relatively low, the highest individual response being only 50% agreeing (or strongly agreeing) that information had been easy to understand compared to two thirds or more from the other condition groups (see Table 18). The remaining five items saw agreement levels amongst psoriasis drop to around a third. By contrast, the lowest levels reported for other condition groups were 44% of those with head & neck cancer and 47% of craniofacial parents agreeing that information had been detailed enough, and just under half of those with burns agreed that information had been consistent and relevant to their needs.

The doctor - patient relationship

Earlier results have confirmed that doctors are a key healthcare professional when it comes to providing information. Doctors are trusted to work closely with patients to ensure that relevant information is given in a timely and appropriate fashion. Four statements that related to this information relationship were asked of our respondents and the average mean scores are shown in Figure 8 (see Table 19 for scale items). Results were once again moderately high and positive with all mean scores comfortably above the midpoint. Those with head & neck cancer were the most positive about their doctors with a mean of 3.82. This result was significantly higher than the views of craniofacial parents (3.41) and those with psoriasis (3.26) who gave their doctors the lowest rating. The mean for those with burns (3.66) was also significantly higher than for those with psoriasis.

Results for the individual statements (see Table 19) revealed that a third of those with psoriasis (35%) and of craniofacial parents (34%) agreed or strongly agreed that they had to push their doctors to provide them with information, along with a quarter of those with burns (23%). This figure dropped to 17% for those with head & neck cancer. Those with psoriasis were also less convinced that during their treatment doctors had chosen the right time to give them information. Only 49% were in agreement compared to over two thirds for craniofacial parents and those with burns and 82% for those with head & neck cancer.

Figure 8: The doctor-patient relationship by condition



A sizeable minority of respondents from all four condition groups were critical of the power dynamic that can exist within the doctor-patient relationship with regards to information. Over a third of those with head & neck cancer and over 40% of respondents from other condition groups agreed that doctors only give them information when the doctor thinks it's appropriate. However, despite these criticisms overall trust in doctors is high with 90% of those with head & neck cancer agreeing that they trust their doctor to know what's best.

Table 19: The doctor-patient relationship (%: 'strongly agree')

	Head & neck	Craniofacial	Burns	Psoriasis
During my treatment, doctors have chosen the right time to give me information	82	68	71	49
I never have to push doctors to get information ^a	60	36	53	39
Doctors give me information not just when they think it's appropriate ^a	40	25	28	21
Overall, I trust my doctors to know what's best	90	86	83	77

^a Item wording and data have been reversed for ease of interpretation .

The variability of the doctor-patient relationship is also reflected in the additional comments some respondents made at the end of the questionnaire. A few took this opportunity to commend their doctors:

Doctors and nurses always went to great lengths to explain everything I wanted to know.

Head & neck cancer

Others criticised them for using too much medical jargon, not appreciating the difficulties of assimilating information when seriously injured and failing to provide enough information:

Sometimes one feels like “just another on the list” with no real continuity or depth to the consultations at the psoriasis clinic. As a result the information and advice can become fragmented and limited to the knowledge gleaned from any given doctor on that particular day.

Psoriasis

Summary

- Respondents from all condition groups showed a broad understanding of the intrinsic benefits of information. There was positive agreement that information helps them to formulate the right questions to ask, informs their decision-making, helps them to gain realistic expectations and a better understanding about their conditions.
- Assessment of the quality of the information they have received was more measured but still positive for respondents from all condition groups other than those with psoriasis. Respondents from this group were more equivocal and rated their information significantly lower than all other groups.
- Reflecting on the relationship with doctors and their provision of information produced a moderately high evaluation. Those with psoriasis were again the least positive.
- A third of craniofacial parents and of those with psoriasis felt that they had to push their doctors to provide them with information.
- Over a third of those with head & neck cancer and over 40% of those with other conditions agreed that doctors give them information only when the *doctor* thinks it is appropriate. This is a serious criticism of the power dynamic that can exist with information sharing in the doctor-patient relationship.

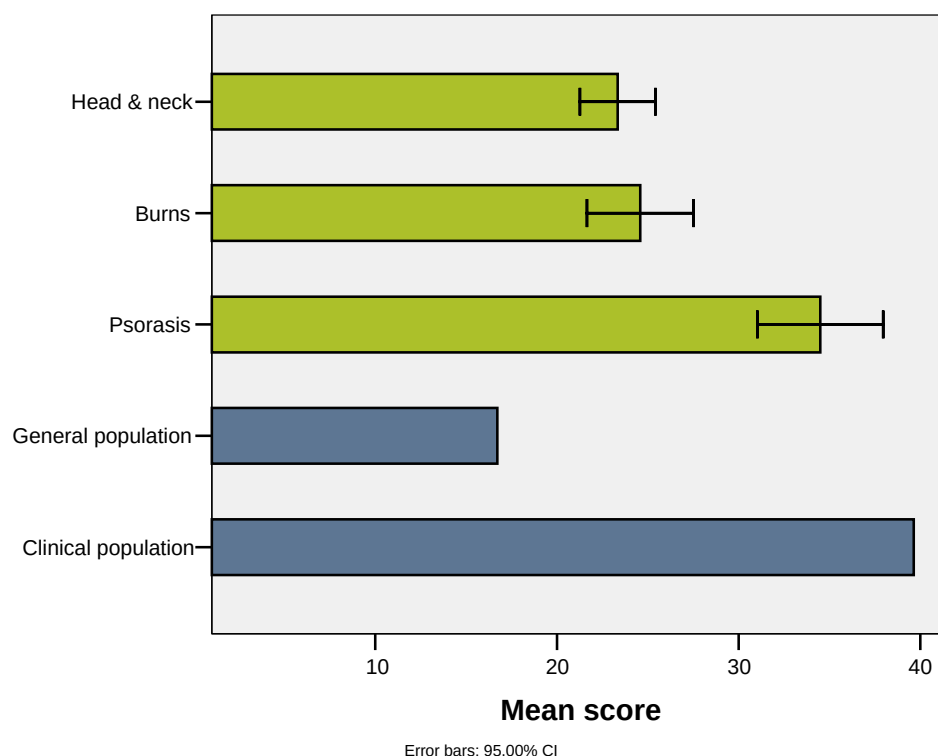
5.7 The impact of appearance on information needs

Up to this point we have explored the information experiences of respondents through the lens of their condition. It is likely that other aspects of their lives may also be important in understanding their views and experiences, such as their age, gender or level of education. However, it could be argued that the influence of these socio-demographic aspects are common to both disfiguring and non-disfiguring conditions. Central to understanding the information needs and experiences of those with conditions that affect appearance was to measure just how much *appearance* itself was a critical element of these views.

To measure the psychological impact that a person's condition may have on their appearance we used a series of questions from the Derriford Appearance Scale (DAS). Incorporating this psychological dimension in our survey enabled us to analyse if the information needs and experiences amongst our conditions were in any way influenced

by how respondents viewed their appearance. For example, do people with a more acute sense of their appearance have greater information needs, do they consult a wider range of sources on a diverse number of topics or have different preferences for how information is received?

Figure 9: General self-consciousness of appearance



In developing the scale (Carr, Harris & James, 2000), the instrument was tested on over 1700 patients who were either undergoing aesthetic surgery to improve appearance (breast, face etc.) or had clinical conditions that affected appearance (accident, congenital or disease) and on a general population sample of 1000. A subset of 16 questions called the 'General Self-Consciousness of Appearance' (hereafter referred to as 'self-consciousness') was identified as the most appropriate part of DAS and was included in our surveys for head & neck cancer, burns and psoriasis, but not for craniofacial as the children's version of DAS is still under development. The results are presented in Figure 9 and show that those with head & neck cancer and burns rated their level of self-consciousness similarly – scores of 23 and 25 respectively - whereas those with psoriasis have a significantly more acute sense of their appearance (35). Work on DAS has shown that the level of self-consciousness in a general population sample is approximately 17 and in clinical populations is almost 40⁴. Our results show that in all of our conditions there was a greater reported overall acute sense of appearance compared to that found in the general population.

⁴ In both the general population and clinical samples women scored significantly higher than men. Women accounted for almost 80% of the clinical sample whereas in our three conditions this figure was a third. The clinical population score for men was 37 and very similar to the score of 35 for those with psoriasis.

Using multiple regression we were able to analyse what aspects of our respondents, in addition to their condition, were correlated with their self-consciousness scores. We found that the following were associated with higher self-consciousness scores: a younger age, poorer health over the last four weeks, not being in current employment and being female. There was no relationship between level of education, number of years the respondent had been living with a diagnosis or whether they had had surgery for their condition. Altogether, these variables were responsible for explaining almost a third of how respondents scored the self-consciousness instrument, a highly significant proportion (full statistical details are available in Appendix G).

Whilst there are differences by condition and profile of our respondents that are associated with higher self-consciousness scores, what is the impact of self-consciousness of appearance on information needs? Do people with higher self-consciousness scores have different information experiences or preferences for example? We found no relationship between self-consciousness and views on the perceived benefits of information, meaning that regardless of whether respondents are self-conscious of their appearance or not they still value the importance of information about their condition. However, the higher their level of self-consciousness the lower their evaluation of the quality of information they have received. Furthermore, those with higher self-consciousness scores are more likely to evaluate the quality of their doctors' provision of information more negatively.

This is evidence that health professionals need to be acutely aware of not just the person's condition but also the psychological impact of the patient's condition. How the respondent has internalised the effects of their condition on their appearance is an important indicator of their information needs. Whilst these survey results are cross-sectional rather than longitudinal (i.e. we are unable to assess which direction causation lies) they do show that even after controlling for a range of important variables to do with a respondent's profile, there remains a significant impact of a respondent's sense of self on their experience of the provision of information.

Additional analysis of the information needs of those sensitive to appearance will be made available in a separate paper. A summary of the main findings are detailed below. Those with a higher level of self-consciousness about appearance are significantly:

- More likely to have searched themselves for information on topics concerning psycho-social well-being, tests & investigations and after-care.
- Less likely to have received information about psycho-social well-being from nurses and other healthcare professionals, and less likely to have received information about after-care from healthcare professionals other than doctors and nurses.
- Much more likely to prefer information to be made available to them through the internet or audio/visual means.
- More likely to draw on a diverse range of information sources beyond healthcare professionals, especially: the internet, public libraries, printed articles, pharmacist and mass media. However, whilst those with higher self-consciousness are more likely to be using these sources they are no more likely to find them useful than those with lower self-consciousness scores. The only association between self-consciousness score and usefulness of an information source was for hospital doctors and the relationship was negative, i.e. those with higher self-consciousness scores found hospital doctors less useful as an information source.

- More likely to rate the six core information topics as important, especially those of a psycho-social nature. However, despite these topics being of much greater importance, there is no larger information gap for those high on self-consciousness. It is not that the information is any harder to find, it is just more important for those sensitive to their appearance to find it. This means that any information gap in general for these items will have a disproportionate impact on those that are measured higher on self-consciousness.

Summary

- High levels of general self-consciousness of appearance were found amongst those with head & neck cancer, burns and significantly so for those with psoriasis. Levels were higher than those found in the general population, whilst those for psoriasis were consistent with those found in other clinical conditions.
- There is a profound relationship between the psychological impact of a person's condition and their information experiences. Those with high levels of self-consciousness were more critical of the quality of the information they had received and were more negative about their doctors' provision of information.
- Those measuring high on self-consciousness were less likely to have received psycho-social information from healthcare professionals. These topics were viewed as very important, significantly more so than those measuring low on self-consciousness.
- Those measuring high on self-consciousness drew on a more diverse range of sources for their information needs and were more likely to prefer information to be made available through the internet and via audio/visual mediums.

5.8 Barriers to information

When providing information to patients it is important to consider the different barriers that could prevent the information from being accessed or received. Language is an obvious example, and for some patients where English is not their first language, provision may need to be made for printed material that has been translated or for access to an interpreter. The patient's condition itself may be a limiting factor where ability to read or hear is impaired. There are also the healthcare professionals themselves, and whether their consultation style encourages patients to engage productively, and whether family and friends are also given the opportunities they need to become informed. These and other barriers to information are discussed in more detail below.

Language

Language was not a barrier to information for the overwhelming majority of respondents. The survey began by asking respondents if their first language is English, which was the case for 96% of all respondents. There were just five respondents who reported that they needed help understanding English, three with head & neck cancer and two with burns. Of these five only one head & neck cancer respondent reported that information was given in a language that s/he couldn't understand. However, all five did have to rely on a relative to interpret for them at hospital and GP appointments.

Condition

With the exception of craniofacial parents, respondents were asked whether their condition had ever affected their ability to access information, for example because of burns to their hands or problems with their vision. This was most common for those with burns (11%), but less so for those with head & neck cancer (4%) and psoriasis (6%). Those who reported that their condition did affect their access to information were additionally asked if this had been taken into account when information was offered to them, for example using documents written in large print or audiotapes. Of those that reported access problems, two out of four head & neck cancer respondents had been offered additional information and two out of five of those with burns. Neither of the two psoriasis respondents had been offered additional information.

Internet access

The internet has become an important resource and gateway for health-related information. According to recent government figures (ONS, 2006), 57% of UK households now have access to the internet, up from 46% in 2002. Overall, our sample reported a higher level of internet access at home of 65%. This figure rose to 73% when access at work or at their hospital/health centre was taken into account.

There is a large statistically significant level of variation across the condition groups. Craniofacial parents reported the highest levels of access (90%), closely followed by those with psoriasis (83%), whilst head & neck cancer and burns had the lowest levels of internet access (63% and 60% respectively). However, this should not be regarded as a finding intrinsic to the condition groups themselves rather as being indicative of demographic variations between these groups already reported in the profile section. Similar to the ONS data, across our sample there are significant differences between internet access and level of education, employment, gender and age.

Doctors

Healthcare professionals are a crucial source of information and we asked respondents whether during their treatment they had enough opportunity to talk to a doctor when *they* wanted to. The overwhelming majority agreed this was true, in fact levels of over 90% were reported by respondents within each condition group. There was a large variation in response when we looked at those who reported that they had *definitely* had such an opportunity, thereby excluding those who stated they had had access only to *some extent*. Three quarters of all those with head & neck cancer were *definitely* given enough opportunity to talk to a doctor along with 63% of those with burns, however this was less so for craniofacial parents (56%) and those with psoriasis (54%).

Within all condition groups there was only a very small minority that claimed they had *not* had enough opportunity to talk to a doctor (three to seven per cent), and the burns group was the only condition where a small number of respondents stated that they had not wanted or needed information (three per cent).

It is also important for family members to feel that their information needs are supported by healthcare professionals so that they in turn can provide support to their relative. Respondents were similarly asked if a family member or close friend had wanted to talk to a doctor about their condition and whether they had enough opportunity to do so. This

was *definitely* or *to some extent* the case for the majority of those with head & neck cancer (91%) and burns (78%), but less so for craniofacial parents and those with psoriasis (52% for both). Amongst these two conditions approximately a quarter reported that no family or friends were involved (26% for both); and a further 14% of craniofacial parents and 12% of those with psoriasis stated that their family or friends did not want or need any information.

A further five per cent from these two conditions did not want their family or friends talking to a doctor. This was in contrast to those with head & neck cancer and burns where the overall percentages for these three categories were significantly less (5% and 18% respectively). These findings are indicative of the balancing act healthcare professionals need to perform when dealing with the information needs of patients and their family.

Summary

- Language was a barrier to information for only a very small number of respondents, where English was not their first language (1%). This group had to rely on relatives to interpret for them and the majority of this small group did not have access to information in a language they could understand.
- Those with burns were the most likely to report that the state of their condition acted as a barrier to information (11%). The majority stated that this had not been taken into account and that alternative information media were not offered (for example, audiotape or large print).
- Higher levels of home internet access were reported overall by our respondents than the national average, but this varied by condition. Craniofacial parents (90%) and those with psoriasis (83%) were the most connected.
- Nine out of ten of all respondents reported that they had enough opportunity to talk to a doctor when *they* wanted to. However, only half of craniofacial parents and those with psoriasis reported that this was *definitely* the case.
- Results for whether family or friends had the same level of access to information were more mixed; those with head & neck cancer and those with burns reported the higher levels of such access. A notable minority of craniofacial parents and of those with psoriasis reported that family and friends were not involved, or the respondents did not want them to be involved, revealing this to be a complex area for healthcare professionals to navigate.

6 Conclusions

This is the first time a survey of this kind has been undertaken. There are many more conditions that affect appearance than those we have surveyed and some caution over the generalisability of our findings would be prudent, particularly as our leading centres may not be representative of the views found amongst these conditions across the country. Nonetheless, the survey has successfully given voice to the information concerns of those whose appearance, or child's appearance, has been affected by four very different conditions. The 443 patients and parents who responded have enabled us to build substantially on the findings from the focus groups and interviews and thereby offer a much wider assessment of the information experiences of people living with conditions that affect appearance. A drawing together of the different strands of the research programme along with recommendations are available in the project's overall report (see Report IV: Magee et al, 2006).

This survey report has presented analysis revealing many similarities and many differences between patients and parents of children with disfiguring conditions. Several key messages have emerged that can be considered of some importance when looking to improve information provision. These concern the signposting of information, the existence of information gaps, the format and delivery of information and the impact that self-consciousness of appearance can have on information needs. These points are summarised below.

The role of the health professional

Despite the increasing variety of information sources available to patients, health professionals continue to be the main source across all the condition groups surveyed. This being so, it is of some concern that, as in the focus groups and interviews, respondents expressed varying levels of dissatisfaction with the information service they provide. This was particularly so amongst those with a greater appetite for information, namely the parents of children with a craniofacial condition and people with psoriasis. Most notable is the finding that health professionals across all condition groups are failing to adequately signpost patients to additional sources of information. This is of some concern particularly when we found that the overwhelming majority of those respondents who had received this help then went on to follow it up. Given the vulnerability of patients and the vast amounts of information and sources available, searching for information can be a daunting and fraught experience. Expert guidance to additional information is therefore both needed and valued.

Information gaps

We found only a moderate information gap amongst those respondents with burns and those with head & neck cancer. Amongst these two groups a greater number of respondents reported that it was easy to find important information topics than it was difficult. However, this was in stark contrast to craniofacial parents and those with psoriasis where some of the highest levels of difficulty were recorded. The survey analysis strongly reinforces the message from focus group findings that information on psycho-social adjustment is far more difficult to find than other types of information. This was

true for all our condition groups, but especially so for those with psoriasis who were having a significantly harder time coming across this type of material.

Format and delivery

Although the most popular information delivery methods were either face-to-face or printed material, a significant minority of respondents preferred not to receive any information in print. With the exception of the parents of children with craniofacial conditions, the majority of respondents did not want materials to help them visualise how they would look after treatment. However, those that had been given photographs or pictures found them helpful. This suggests that more could be done to produce such materials and support people in their use of them. Other alternative formats, such as audiotape and large print, appeared to be scarce, and the small minority of respondents whose first language was not English did not report access to information in their own language. The complexity of information needs was demonstrated by our findings concerning how different sources were preferred for different purposes.

Appearance concerns and information needs

The inclusion of questions from the Derriford Appearance Scale allowed us to highlight significant relationships between self-consciousness about appearance and information needs. Significantly high levels of self-consciousness were found among respondents with psoriasis and it is this group of patients who rated the quality of their information lower than all other conditions. It should be emphasised that this is not about degree of disfigurement, but about the psychological impact of a different appearance. When controlling for a respondent's condition along with other important background details, we found that those with higher self-consciousness have a much more critical attitude towards the quality of information they have received. Crucially, there was no difference in information gaps associated with higher measured self-consciousness, it is just significantly more important for them to find it – particularly information of a psycho-social nature. It is therefore much more likely that lack of information for those sensitive to their appearance will have a much greater impact. A patient's level of self-consciousness is a critical area about which healthcare professionals should be aware.

Summary

- This is the first time that a survey comparing the information experiences of patients with different disfiguring conditions has been attempted. The views of over 400 survey respondents builds substantially on previous qualitative work. When combined this then provides a wide assessment of the provision of information for disfiguring conditions.
- Several key messages emerged concerning: the role of healthcare professionals in the signposting of information; the existence of information gaps; the format and delivery of information; and the impact that self-consciousness about appearance can have on information needs.

References

- Carey, S., Low, S. & Hansbro, J. (1997). *Adult literacy in Britain*. London: ONS.
- Carr, T., Harris, D. & James, C. (2000). 'The Derriford Appearance Scale (DAS-59): A new scale to measure individual response to living with problems of appearance'. *British Journal of Health Psychology*, 5: 201-215.
- Cartwright, J. & Magee, H. (2006). *The Views and Experiences of Patients Living with Disfiguring Conditions & Health Professionals Involved in their Care*. London: Healing Foundation.
- Coulter, A., Ellins, J., Swain, D., Clarke, A., Heron, P., Rasul, F., Magee, H. & Sheldon, H. (2006). *Assessing the Quality of Information to Support People in Making Decisions about their Health and Healthcare*. Oxford: Picker Institute Europe.
- Department of Health. (2004). *Better Information, Better Choices, Better Health: Putting Information at the Centre of Health*. London: Department of Health.
- Department of Health. (2006). *Tomorrow's patients will have information prescribed alongside medicines*. Press release: 18/10/2006 (<http://gnn.gov.uk>).
- Dillman, D. (2000). *Mail and Internet Surveys: The Tailored Design Method*. New York: John Wiley & Sons.
- Farrell, C. (2004). *Patient and Public Involvement in Health: The Evidence for Policy Implementation*. London: Department of Health.
- Hepworth, M. & Harrison, J. (2004). 'A survey of the information needs of people with multiple sclerosis'. *Health Informatics Journal*. 10: 49-69.
- Houts, P.S., Doak, C.C., Doak, L.G. & Loscalzo, M.J. (2006). 'The role of pictures in improving health communication: A review of research on attention, comprehension, recall, and adherence'. *Patient Education and Counseling*, 61: 173-190.
- Magee, H., Heron, P., Cartwright, J. & Askham, J. (2006). *Information for People Living with Conditions that Affect their Appearance: Report IV, Overview and Recommendations*. London: Healing Foundation.
- Magee, H., Heron, P., Cartwright, J. & Askham, J. (2006). *Information for People Living with Conditions that Affect their Appearance: Report II, Review and Assessment of Existing Information*. London: Healing Foundation.
- Mair, M. & Kierans, C. (2006). *Evaluating 'mihealth Liverpool': Assessing the Effectiveness of New Health Information and Communication Technology in Providing Support to Patients with Breast Cancer Receiving Treatment in Liverpool*. Liverpool John Moores University: Centre for Public Health.
- Office of Population and Census Studies. (1988). *Report 1. The Prevalence of Disability Among Adults*. London: HMSO.
- ONS (2006). *First Release: Internet Access*. London: ONS.

Appendix

A. Survey administration

The surveys were packed by Picker staff and sent to each specialist centre to be labelled with the patients' details. Each mailing consisted of a copy of the survey, a signed cover letter from a leading consultant at the site introducing the research, a language sheet for those respondents who wished to answer the survey in a language other than English and a reply-paid envelope. The cover letter reassured patients that the survey was anonymous, entirely voluntary and that individual results were confidential. Respondents were provided with a freephone telephone number to discuss any concerns or requests for further information that they may have.

The first mail out was the beginning of May 2006, however only three of the five sites were able to keep to this deadline. A protracted R&D management approval process at one site and serious problems with staffing at another delayed the mailing by over a month. Further delays to the final reminder occurred at one site when staffing sickness prevented the mail out. More problematically, at a further site the final reminder was 'lost' in the postal system. As our ethics approval limited us to only two patient contacts⁵, and as the final reminder had technically been sent, we were unable to send out a replacement reminder. Fortunately, survey returns from this mailout did eventually arrive, albeit nine weeks later. However, we were unable to assess whether this represented returns from the whole or part of the 'lost' batch.

⁵ Ethics approval for the research required that we only send an initial mailing and a final reminder due to perceived potential vulnerabilities of our target groups. Current best practice to maximise the response rate for surveys is for three contacts with potential respondents (Dillman, 2000). As such, we anticipate that this would have had an impact on our final response rate when compared against other patient surveys that incorporate this standard methodology.

B. Usefulness of information sources

Table B.1: Usefulness of information sources (%: Head & neck cancer)

	Not useful at all	Somewhat useful	Useful	Very useful
GPs	30	15	22	33
Local support groups	25	15	30	30
Internet/websites	19	23	33	25
Public library	53	25	11	11
Hospital doctors	3	5	17	75
Articles in newspapers/magazines	27	37	31	5
People with similar conditions	14	21	30	36
Pharmacist/chemist	37	31	24	8
Psychologist/counsellor	24	13	22	40
National voluntary organisations/charities	29	22	20	29
Family/friends	8	16	24	52
Television/radio programmes	40	37	20	3
Nurses	3	6	29	62
Allied professionals	4	14	39	42
Commercial organisations	59	15	17	10

Table B.2: Usefulness of information sources (%: Craniofacial parents)

	Not useful at all	Somewhat useful	Useful	Very useful
GPs	56	25	11	9
Local support groups	48	19	17	15
Internet/websites	1	26	30	44
Public library	57	32	6	4
Hospital doctors	4	11	33	52
Articles in newspapers/magazines	21	37	23	19
People with similar conditions	7	18	31	44
Pharmacist/chemist	68	16	14	2
Psychologist/counsellor	30	34	25	11
National voluntary organisations/charities	24	18	20	38
Family/friends	31	29	21	20
Television/radio programmes	24	33	28	16
Nurses	5	22	23	50
Allied professionals	17	25	45	13
Commercial organisations	78	11	8	3

Table B.3: Usefulness of information sources (%: Burns)

	Not useful at all	Somewhat useful	Useful	Very useful
GPs	33	7	37	22
Local support groups	53	20	27	0
Internet/websites	30	13	39	17
Public library	75	8	17	0
Hospital doctors	6	15	27	51
Articles in newspapers/magazines	34	21	45	0
People with similar conditions	11	18	47	24
Pharmacist/chemist	24	32	30	14
Psychologist/counsellor	21	16	50	13
National voluntary organisations/charities	38	31	23	8
Family/friends	3	18	35	44
Television/radio programmes	31	27	35	8
Nurses	1	10	22	66
Allied professionals	1	10	40	49
Commercial organisations	35	30	25	10

Table B.4: Usefulness of information sources (%: Psoriasis)

	Not useful at all	Somewhat useful	Useful	Very useful
GPs	18	41	27	14
Local support groups	44	22	33	0
Internet/websites	7	17	39	37
Public library	39	22	6	33
Hospital doctors	4	18	29	49
Articles in newspapers/magazines	7	48	34	11
People with similar conditions	11	32	41	16
Pharmacist/chemist	26	39	24	11
Psychologist/counsellor	58	25	17	0
National voluntary organisations/charities	19	19	48	14
Family/friends	23	35	35	7
Television/radio programmes	41	35	18	6
Nurses	3	35	28	33
Allied professionals	28	39	28	6
Commercial organisations	50	32	14	5

Table B.5: Usefulness of information sources (mean score)

	Head & neck (A)	Craniofacial (B)	Burns (C)	Psoriasis (D)	Sig	MC ^a
GPs	2.58	1.72	2.49	2.36	***	A,C,D>B
Local support groups	2.65	2.00	1.73	1.89	*	A>B,C
Internet/websites	2.64	3.16	2.43	3.07	***	B>A,C
Public library	1.81	1.57	1.42	2.33	*	D>B
Hospital doctors	3.64	3.33	3.24	3.22	***	A>B,C,D
Articles in newspapers/magazines	2.15	2.41	2.10	2.48	NS	
People with similar conditions	2.88	3.12	2.84	2.61	*	B>D
Pharmacist/chemist	2.03	1.49	2.32	2.20	***	
Psychologist/counsellor	2.78	2.16	2.55	1.58	**	A>B,D; C>D
National voluntary organisations/charities	2.49	2.73	2.00	2.57	NS	
Family/friends	3.20	2.30	3.20	2.26	***	A,C>B,D
Television/radio programmes	1.87	2.36	2.19	1.88	*	B>A
Nurses	3.49	3.20	3.54	2.92	***	A,C>B,D
Allied professionals	3.19	2.53	3.35	2.11	***	A,C>B,D
Commercial organisations	1.78	1.35	2.10	1.73	*	C>B

* $p<.05$, ** $p<.01$, *** $p<.001$

^aSignificant multiple comparisons between conditions (Bonferroni)

C. Importance of information

Table C.1: Importance of information (%: Head & neck cancer)

	Very un - important	Un - important	Neither	Important	Very important
How my condition might affect my appearance	5	6	22	33	34
Dealing with emotions	4	9	23	37	27
Dealing with my personal relationships/ friendships	4	7	34	34	21
Managing social situations	11	11	38	25	15
Availability of counselling services	5	10	28	36	21
Healthy living	2	4	17	46	31
How surgery might affect my appearance	5	4	21	30	39
Causes of my condition	2	4	11	38	44
Radiotherapy	3	1	10	25	61
Chemotherapy	18	4	21	17	39
How surgery might affect my function	3	1	5	35	56
Prostheses	25	4	29	17	25
Chances of recurrence	1	1	5	28	64
Cosmetic surgery	18	16	30	22	13
Complementary/alternative therapies	21	16	31	21	11

Table C.2: Importance of information (%: Craniofacial parents)

	Very un - important	Un - important	Neither	Important	Very important
How the condition might affect appearance	3	0	4	20	73
Dealing with emotions	5	1	15	32	48
Dealing with personal relationships/ friendships	6	6	30	29	30
Managing social situations	2	4	16	28	50
Availability of counselling services	6	7	28	31	29
Healthy living	10	15	36	21	18
How surgery might affect appearance	3	2	5	15	75
Cosmetic surgery	4	3	18	27	49
How the condition could be passed on	4	2	5	26	63
Developmental issues	5	0	4	25	66
Special educational needs	6	3	14	20	58
Speech therapy	6	2	16	27	50
Feeding	11	15	21	24	29
Breathing difficulties	11	9	14	14	52
Sensory impairment	10	2	7	22	60

Table C.3: Importance of information (%: Burns)

	Very un - important	Un - important	Neither	Important	Very important
How my condition might affect my appearance	4	12	17	33	33
Dealing with emotions	8	7	24	34	28
Dealing with my personal relationships/friendships	10	8	31	18	33
Managing social situations	17	13	31	19	19
Availability of counselling services	10	12	25	27	26
Healthy living	9	6	21	34	30
How surgery might affect my appearance	14	14	17	20	35
Prostheses	38	12	22	8	19
Cosmetic surgery	12	17	22	23	26
Complementary/alternative therapies	19	17	24	17	23
Skin massaging and creaming	1	1	10	34	54
Pressure garments	7	5	13	41	35
Skin grafts	6	6	10	30	48
Environmental factors	4	4	12	34	46
Care of donor site	20	8	19	18	36

Table C.4: Importance of information (%: Psoriasis)

	Very un - important	Un - important	Neither	Important	Very important
How my condition might affect my appearance	3	7	17	38	35
Dealing with emotions	6	9	25	31	29
Dealing with my personal relationships/friendships	6	6	35	26	26
Managing social situations	4	13	37	16	28
Availability of counselling services	13	7	46	18	15
Healthy living	4	4	21	37	34
Complementary/alternative therapies	9	13	31	24	22
Environmental factors	3	0	16	45	36
Light treatment	7	10	20	33	29
Steroids	3	3	18	44	32
Laser treatment	17	16	33	16	19
Triggers for the onset of my condition	9	4	12	36	39
Creams and emollients	1	1	7	53	37
Oral treatments	4	1	15	34	45

Table C.5: Importance of information (core topics: mean score)

	Head & neck (A)	Craniofacial (B)	Burns (C)	Psoriasis (D)	Sig	MC ^a
How condition might affect appearance	3.87	4.61	3.79	3.94	***	B>A,C,D
Dealing with emotions	3.73	4.18	3.67	3.69	**	B>A,C,D
Dealing with personal relationships/ friendships	3.62	3.70	3.57	3.62	NS	
Managing social situations	3.23	4.21	3.11	3.51	***	B>A,C,D
Availability of counselling services	3.59	3.71	3.47	3.13	*	A,B>D
Healthy living	4.00	3.23	3.70	3.91	***	A,C,D>B

* $p<.05$, ** $p<.01$, *** $p<.001$

^aSignificant multiple comparisons between conditions (Bonferroni)

D. Ease of finding important information

Table D.1: Ease of finding information rated as 'important' or 'very important' (%: Head & neck cancer)

	Very difficult	Difficult	Neither	Easy	Very easy
How condition might affect appearance	4	27	30	22	16
Dealing with emotions (e.g. depression, anxiety)	15	26	27	21	11
Dealing with personal relationships/ friendships	7	22	39	16	15
Managing social situations (e.g. staring)	11	36	34	9	9
Availability of counselling services	8	16	18	36	22
Healthy living (e.g. exercise, dieting)	3	8	20	42	27
Impact of surgery on appearance	8	24	23	24	22
Causes of my condition	23	20	15	21	21
Radiotherapy	8	15	17	23	38
Chemotherapy	13	13	38	19	19
Impact of surgery on function	11	16	20	28	24
Prostheses	5	10	33	33	19
Chances of recurrence	8	24	35	19	14
Cosmetic surgery	17	35	26	13	9
Alternative therapies	14	28	34	10	14

Table D.2: Ease of finding information rated as 'important' or 'very important' (%: Craniofacial parents)

	Very difficult	Difficult	Neither	Easy	Very easy
How condition might affect appearance	10	14	22	28	25
Dealing with emotions (e.g. depression, anxiety)	33	26	32	8	0
Dealing with personal relationships/ friendships	26	30	26	19	0
Managing social situations (e.g. staring)	39	19	31	8	3
Availability of counselling services	41	27	24	6	2
Healthy living (e.g. exercise, dieting)	27	14	32	23	5
Impact of surgery on appearance	9	19	27	25	20
Cosmetic surgery	13	11	27	32	17
Inheritance of condition	15	13	23	31	18
Developmental issues	16	22	35	16	11
Special education needs	20	16	43	18	3
Speech therapy	14	20	24	33	9
Feeding	21	17	36	19	7
Breathing difficulties	11	25	28	26	11
Sensory impairment	7	8	42	32	11

Table D.3: Ease of finding information rated as 'important' or 'very important' (%: Burns)

	Very difficult	Difficult	Neither	Easy	Very easy
How condition might affect appearance	10	8	35	17	29
Dealing with emotions (e.g. depression, anxiety)	22	31	16	11	20
Dealing with personal relationships/ friendships	17	29	14	17	23
Managing social situations (e.g. staring)	23	23	19	23	12
Availability of counselling services	17	20	13	23	27
Healthy living (e.g. exercise, dieting)	9	14	12	35	30
Impact of surgery on appearance	6	29	24	15	26
Prostheses	0	33	17	33	17
Cosmetic surgery	25	15	25	25	10
Alternative therapies	19	19	19	19	25
Skin massaging & creaming	0	6	10	29	55
Pressure garments	0	7	14	28	51
Skin grafts	7	10	17	29	37
Environmental factors	5	15	18	26	37
Care of donor site	3	13	22	22	41

Table D.4: Ease of finding information rated as 'important' or 'very important' (%: Psoriasis)

	Very difficult	Difficult	Neither	Easy	Very easy
How condition might affect appearance	20	15	24	29	12
Dealing with emotions (e.g. depression, anxiety)	46	28	15	5	5
Dealing with personal relationships/ friendships	39	23	23	10	6
Managing social situations (e.g. staring)	52	28	8	12	0
Availability of counselling services	62	10	24	5	0
Healthy living (e.g. exercise, dieting)	24	11	24	31	9
Alternative therapies	39	21	11	25	4
Environmental factors	10	21	19	42	8
Light treatment	2	20	22	39	17
Steroids	8	18	31	35	8
Laser treatment	44	11	22	11	11
Condition triggers	38	30	21	9	2
Creams & emollients	7	8	21	52	11
Oral treatments	8	14	24	41	14

Table D.5: Ease of finding important information (core topics: mean score)

	Head & neck (A)	Craniofacial (B)	Burns (C)	Psoriasis (D)	Sig	MC ^a
How condition might affect appearance	3.19	3.44	3.46	3.00	NS	
Dealing with emotions	2.88	2.15	2.76	1.95	***	A>B,D; C>D
Dealing with personal relationships/ friendships	3.09	2.38	3.00	2.23	**	A>B,D
Managing social situations	2.68	2.17	2.77	1.80	**	A>D; C>D
Availability of counselling services	3.47	2.02	3.23	1.71	***	A,C>B,D
Healthy living	3.83	2.64	3.63	2.89	***	A,C>D,B

* $p<.05$, ** $p<.01$, *** $p<.001$

^aSignificant multiple comparisons between conditions (Bonferroni)

E. Attitude scales

Factor analysis was used to test for the appropriateness of items to be joined together into scales. The scales were then tested for internal consistency using Cronbach's Alpha. Alpha coefficient scores above .70 are desirable and the higher the coefficient the more confident we can be that the average score from the combination of the items forming the scale is representative of the population from which it is sampled. The Alpha coefficient scores are provided below.

Table E.1: Alpha coefficients for scales

Scale	Alpha
Information as a tool	.80
Evaluation of quality of information received	.78
Doctor-patient relationship	.74
General self-consciousness of appearance	.95

F. Information as a tool

Table F.1: Information as a tool (%: 'agree' & 'strongly agree')

	Head & neck	Craniofacial	Burns	Psoriasis
Information helps me ask the right questions in consultations	94	96	83	95
Information helps me to make decisions about treatment	85	95	78	91
Information helps me to gain realistic expectations about the future	90	90	76	89
Information helps me cope with the condition	83	89	75	71
Information helps me understand the condition	90	97	79	93

G. General self-consciousness of appearance

Table G.1: Multiple regression results predicting general self-consciousness of appearance

	β	R ² (adj. R ²)	F
Condition group ^a			
Head & neck cancer	0.116		
Psoriasis	0.359**		
Biographical details			
Age	-0.439***		
Female	0.127*		
No formal education qualifications	-0.048		
Graduate	-0.054		
Currently employed	-0.155*		
Condition details			
General health during past four weeks	-0.213***		
Years since diagnosis	-0.004		
Surgery has been carried out for condition	0.057		
Model		.33 (.30)	12.99***

^aBurns is the reference condition

* $p < .05$, ** $p < .01$, *** $p < .001$

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