BEYOND CLINICAL OUTCOMES

UK patient experience in head and neck cancers

This report was written and funded by Bristol-Myers Squibb (BMS).

Endorsed by:

The concept of the survey was developed and funded by Bristol-Myers Squibb following a comprehensive review of survey types and questions. The survey itself was co-developed via a 3-way partnership between BMS, The Swallows Head and Neck Cancer Patient Support Group and the Mouth Cancer Foundation. The patient charities played a pivotal role in both shaping the survey questions and in the dissemination of the survey to patients through their social media channels, while BMS commissioned an independent market research agency, specialising in surveys, to host the survey and provide results as aggregated data tables.
Survey scope
The report is based on a survey carried out across the United Kingdom in June 2019 among 118 patients to better understand the patient experience after being diagnosed with head and neck cancer and the care that they received beyond treatment itself. The survey was conducted in accordance with the Market Research Society (MRS) Guidelines, the British Healthcare Business Intelligence Association (BHBIA) Legal & Ethical Guidelines, the Association of the British Pharmaceutical Industry (ABPI) Code of Practice and all UK Data Protection legislation.

Disclaimer
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The survey collected data over the period 1-20 June 2019.

The Swallows is a nationwide head and neck cancer support charity formed by patients who experienced a lot of difficulty swallowing after their cancer care treatment. It is a support group that organises monthly meetings in Blackpool and provides practical information for both patients and their carers. It also has a 24/7 support line service.

The Mouth Cancer Foundation is a charity that is dedicated to the relief of sickness and the promotion and protection of good health among those suffering or at risk of mouth, throat and other head and neck cancers. Founded in 2004, it is a professional support organisation dedicated to supporting people with mouth, throat and other head and neck cancers.
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FOREWORD

Chris Curtis
The Swallows Head and Neck Cancer Charity

When a person is diagnosed with head and neck cancer, their life changes dramatically. The locality of these types of cancer often mean that, after treatment, people have trouble with tasks that are typically taken for granted, such as speaking and swallowing. Losing the ability to speak can do profound damage to a patient’s ability to stay in employment and interact with friends and loved ones, while changes to a patient’s appearance can damage their mental health.

Getting the right support when these changes happen can be challenging, as the findings of this report show. That is why I founded The Swallows Head and Neck Cancer Charity, to provide help and support to fellow sufferers and their families in dealing with such life-changing effects. Our 24/7 support line is answered by patients and carers for patient and carers and forms a big part of the charity.

I was delighted to support the development of this report because it takes a closer look at patients’ experiences of getting treatment for head and neck cancer. Understanding what matters to people must be at the very heart of the care they receive. The responses clearly show that patients place great value on their quality of life, which is why information and support for the many difficulties they may face after treatment is so important.

This report calls on policy makers and healthcare professionals to realise that survivorship without good quality of life is not survivorship at all. Curing cancer will forever be important to our community; but ensuring that the side effects of treatment do not prevent patients from enjoying a good quality of life is crucial too.

So, we must all work together, speaking with one voice, to call for improvements in care that reflect what patients want and need. I look forward to working with the head and neck cancer community, as well as industry, the NHS and policy makers, to take forward these recommendations and ensure that the patient journey of tomorrow is better than that of today.

A big thank you must go to the Mouth Cancer Foundation for their part in the distribution of the survey and it shows how collaboration can benefit our head and neck cancer community.

Mahesh Kumar
Mouth Cancer Foundation

The incidence of mouth cancer is growing. People with cancer are living longer. Consequently, patients require more services for longer. People with cancer and their families need assistance from diagnosis through to treatment and beyond. Therefore, it is important that these services cater to patients' individual needs and provide the best possible care throughout the whole pathway.

The Mouth Cancer Foundation (MCF) was established to help people with mouth, throat and other head and neck cancers deal with the crisis of cancer. The charity gives resources, information and contact to people to support them during a difficult time, in a variety of ways. We also campaign for improvements in cancer care and are delighted that the NHS has announced that it will expand the HPV vaccination programme to include all boys in school year eight in England from September 2019, protecting both boys and girls from a number of cancers including head and neck. We hope the recommendations in this report will also be taken up to positively impact the patient experience.

From our experience of working with people with cancer, we know how valuable psychosocial services are. We have seen many times how professional counselling can improve quality of life in areas such as self-esteem, sense of control and the understanding of one’s diagnosis. As this report determines, people with cancer face a whole variety of challenges which they and their loved ones must tackle. Tailored emotional and practical support is incredibly important.

In addition, many patients encounter financial problems resulting from their illness. Patients benefit greatly from information on government entitlements and private resources to help them navigate financial concerns. We work with patients to provide individual counselling, an online support group, and help in obtaining financial assistance. The need for these services is clearly demonstrated in this report and we wholly support calls for all head and neck patients to be provided with core support after their treatment, which should include care for their physical and clinical needs, as well as financial guidance, social and mental care, and information access.

Whilst an important step, this report marks only the beginning. MCF is committed to working with industry and the Swallows Head and Neck Cancer Charity to see the realisation of the recommendations within this report which will ensure future patients benefit from the improvements in care they need.
EXECUTIVE SUMMARY

Head and neck cancers affect thousands of people across the UK. Despite its prevalence, there is a lack of understanding of the significant ongoing impact these cancers have beyond treatment. To gain an understanding of the impact on patients, Bristol-Myers Squibb (BMS), with the support of The Swallows and the Mouth Cancer Foundation, commissioned an independent market research agency to conduct a survey of people with head and neck cancer and collate data from the survey to understand what matters to patients and what improvements in their care should be made.

The survey focused on how head and neck cancer affected people living with it, and what they valued from cancer care as a result. It asked patients what areas of their care they believed could benefit from improvement and which areas are the best developed, including the practical access they had to appropriate resources and their involvement in their own care.

The results of the survey highlight that there are several key areas within the patient pathway that could be improved in order to support earlier diagnosis, optimal treatment outcomes and to reduce detrimental impact on quality of life.

There is a need to improve early diagnosis and healthcare professionals across the pathway, including GPs and dentists, can play a vital role in this.

The broader picture painted by the survey responses shows a desire by patients to be involved in decision making within their care. Shared decision making is key for reducing some of the stress and anxiety patients feel around their diagnosis. This report, therefore, makes the case for equipping healthcare professionals with the tools needed to support patients, as well as the importance of patient empowerment in asking for support from these professionals.

Historically, the cancer community has focused on extending patients’ lives and working towards an eventual cure for cancer. However, the head and neck cancer patients who undertook the survey highlighted the need for a renewed focus on quality of life.

Respondents identified the long-term burden that head and neck cancers can have, including a significant impact on quality of life post-treatment. To tackle this burden, preserving quality of life should be at the heart of integrated care.

Patients should be offered support with their physical and mental health needs and be made aware of the full breadth of resources available to support them to return to their day-to-day lives as best as possible.

It is clear there needs to be a coordinated effort to mitigate the detrimental impact of head and neck cancers. The wider oncology community should therefore work together to take forward this report’s recommendations with the goal of improving the lives of people with head and neck cancers.
WHO ARE THE UK’S HEAD AND NECK CANCER PATIENTS?

The burden of cancer in the UK is a growing challenge. Incidence rates are on the rise across all cancers combined and there has been a 12% increase since the 1990s, with another 2% increase anticipated before 2035.\(^1\)

However, for less common cancers, including head and neck cancers, which do not receive the same public attention and do not benefit from the same levels of public awareness, the rates of incidence have risen much faster. For instance, during the same time period, the incidence rates for head and neck cancers have increased by approximately 32%.\(^3\) While much higher, the incidence follows a similar trend across cancer, whereby the number of new cases continues to grow among the most deprived communities.\(^1,3\) The greater likelihood of people in these communities pursuing avoidable lifestyle factors increases the risk of their exposure to head and neck cancers.

General risk factors for developing head and neck cancers vary depending on the type of tumour, however age, genetics and exposure to some lifestyle factors – including smoking and high alcohol consumption – can heighten a person’s chances of developing a tumour.\(^6\) An individual’s low natural immunity and infection with the human papilloma virus can also be factors in the development of head and neck cancers. However, another consistency is that patients in the most deprived quintile are not only more likely to develop head and neck cancers, but they also experience higher mortality rates as compared to those in higher economic quintiles.\(^4\)

While there are more than 30 areas of the body where head and neck cancers can develop, the most common include the mouth and lips, voice box, throat, salivary glands, nose and sinuses, and the nasopharynx.\(^7\) In the UK, there are approximately 11,900 new cases of head and neck cancer diagnosed annually, or a total of 3% of all new cancer cases,\(^2\) with incidence among men over double the rate as that among women.\(^3\) Though still relatively low in terms of overall cancer incidence, head and neck cancers account for 11 deaths every day (data from 2014-16)\(^2\) and while the mortality rate has decreased by 11% since the 1970s,\(^6\) this does not always translate into an improved quality of life. In fact, depending on the type of head and neck cancer, the 10-year survival rates vary from 19-59%\(^2\) and perhaps most concerningly, two of the three most common types of head and neck cancers, cancer of the mouth and pharynx, have risen at a rate of 20%, especially in the under 65 population.\(^4\)

The increase in incidence of head and neck cancers poses specific concerns as these cancers cause more deaths per number of cases than more commonly known cancers like breast cancer, cervical cancer, or melanomas.\(^7\)
How Does Head and Neck Cancer Impact Quality of Life?

When compared with some other types of cancer, head and neck cancers carry a long-term post-treatment burden that can have a significant quality of life impact, including pain and difficulty with eating, speaking, and drinking. The consequences of the disease and its treatment can have a significant detrimental impact on patients’ mental health and wellbeing, as well as on the quality of life of their family and friends.

Head and neck cancer patients may experience a wide variety of effects after treatment that have an impact on their ability to return to a normal way of life; both effects that are readily visible and effects that are more hidden.

From chewing and swallowing to speech difficulties, patients may require a breadth of support to cope with changes. Additionally, patients’ mental health may suffer due to the impact on their ability to manage day-to-day tasks and the severity of treatment. Over half of respondents to the survey reported dealing with negative thoughts (e.g. anxiety, stress, fear, and helplessness) as one of the most significant challenges during treatment.

When considering the non-clinical outcomes of head and neck cancer, these are primarily related to patients’ day-to-day lives and their ability to maintain a sense of normalcy, with communication, diet, and sleep being particularly affected.

Head and neck cancer can also diminish the quality of life of patients’ family and friends, particularly when patients are increasingly reliant on caregivers. Spousal distress rates can be comparable with those of patients themselves and reflect the variety of support that they may need to be incorporated into the patient support pathway.

<table>
<thead>
<tr>
<th>Percentage of patients reporting an issue with:</th>
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<tbody>
<tr>
<td>EATING A BALANCED DIET 32% INCREASE</td>
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<tr>
<td>ABILITY TO COMMUNICATE 37% INCREASE</td>
</tr>
<tr>
<td>TROUBLE SLEEPING 20% INCREASE</td>
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<tr>
<td>MEMORY LOSS 21% INCREASE</td>
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<td>MAINTAINING LIBIDO 21% INCREASE</td>
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Quite notably, patients who have undergone head and neck cancer treatment but are now in remission have nevertheless indicated that their anxiety levels remain quite high. In fact, prior to the receipt of any treatments, patients self-reported anxiety was at 52%. Whilst this figure fell following their most recent treatment, it fell to only 47%. The relatively minor change is consistent with other data, as captured by the Wolfson Institute of Preventative Medicine, which suggests that the higher levels of psychological distress among head and neck cancer patients is linked to the lower quality of life experienced by patients following treatment. This, in turn, is reflected in the type of symptoms that patients continue to experience after the completion of treatment, including dry mouth, changes in patients’ voice or speech, and trouble swallowing.
The continued problems and symptoms experienced by patients after treatment can have a significant and direct impact on the ability of patients to resume their normal day-to-day life. Simple things like swallowing are made difficult by soreness and pain, which can continue to manifest months after the completion of treatment, while physical disfigurement and after-effects such as bad breath can stimulate social anxiety. Nevertheless, patients feel that they need to go back to life as it was before diagnosis – a state that is often impossible or a very long process.

When considering the surveyed patients – 81% were of working age when surveyed – a notable change occurred in employment status, with 23% fewer patients being in full-time employment after their most recent treatment, as compared to pre-treatment. Likewise, the number of survey respondents who were retired following their most treatment or unemployed and unable to work increased by 13% and 14% respectively.

While a small group may have been on the cusp of retirement, considering the significant quality of life impact of having gone through head and neck cancer treatment, it is clear some patients would have been unable to go back to work. This is especially likely for the 66% of patients who reported changes in their voice or speech, as well as the 49% who felt physically less attractive due to their disease or treatment, as both factors can serve as an impediment to good mental health.
WHAT IS THE PATIENT EXPERIENCE OF THE TREATMENT JOURNEY?

Early symptoms associated with many head and neck cancers are benign and can be reflective of much less serious conditions. Symptoms like bleeding in the mouth or headaches can cause patients greater concerns when they persist, and a healthcare professional’s intervention may be necessary. However, due to their nature, these symptoms can easily be dismissed as nothing serious and the role of healthcare professionals, especially GPs and dentists, becomes important in early diagnosis to support the optimal outcomes for patients.

This issue is exacerbated by the time constraints under which GPs operate, which often do not allow them to examine symptoms which may seem benign in greater detail, leading to missed opportunities for diagnosis and patients being prescribed treatments which address their symptoms rather than their condition. Anecdotal evidence by the Mouth Cancer Foundation highlights occasions where patients have needed to take an active role in pushing for further check-ups before they receive a definitive diagnosis by their GP.

Regular dental check-ups can support the earlier diagnosis of mouth cancer. Symptom checks for tumours, however, are not a part of every dental check-up and can lead to opportunities for diagnoses being missed. The cohort of the UK population who have a reactive approach to visiting a dentist when an issue arises, rather than proactively engaging in regular check-ups, will have less opportunities for their dentist to diagnose cancer.

Furthermore, the NHS recommendations on how often to visit a dentist are left to the discretion of the individual dentist and can vary from three months to two years, depending on an individual’s risk factors, history, and current oral health.

In addition, more deprived communities are both at a heightened risk for developing head and neck cancer and are twice as likely to be admitted to hospital for dental work, indicating that they are less likely to visit the dentists for regular check-ups. GPs are also visited less frequently by those in the most deprived quintile for preventative purposes and tend to experience greater numbers of long-term conditions, which then require more regular treatment-based visits, with someone aged 50 in the most deprived quintile visiting their GP as often as someone in their 70s in the least deprived quintiles.

While the role of healthcare practitioners (HCPs) is important for the early diagnosis of conditions, it also continues to be significant after diagnosis as treatment decisions are being made. With the rise of the informed patient and availability of information online, the importance of HCPs holding open conversations with patients about their condition, treatment options, and side-effects – both those clinical and beyond – is growing. For patients to be involved in co-decision making, patients need to have the right resources and support to make sound health decisions in the context of their everyday life and their specific health history.

When decisions were being taken about treatment, 58% of the surveyed patients felt very involved in the process. This signifies a good starting point in terms of institutional health literacy. It can be further improved, however, to ensure that the 16% of patients who did not feel very involved – or even not involved at all – are well integrated into shared decision-making (SDM). Likewise, further clarity is needed as to why 26% of patients only felt somewhat involved, and what action can be taken to improve this in the future.

Deprived communities are both at a heightened risk for developing head and neck cancer and are twice as likely to be admitted to hospital for dental work.
How involved the lead healthcare professional made patients feel when treatment decisions were made:xx

<table>
<thead>
<tr>
<th></th>
<th>%</th>
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<tbody>
<tr>
<td>Very Involved</td>
<td>58</td>
</tr>
<tr>
<td>Somewhat Involved</td>
<td>26</td>
</tr>
<tr>
<td>Not Very Involved</td>
<td>15</td>
</tr>
<tr>
<td>Not Involved At All</td>
<td>1</td>
</tr>
</tbody>
</table>

A key component of SDM is ensuring that the right mechanisms are in place to support patients, not just in terms of the information they are given, but also in ensuring that this information is well understood, both in the immediate term and in terms of the potential consequences.

As the process of SDM works best with the input of both clinicians and patients, this relationship must be fostered through open and transparent conversation. Healthcare professionals should ensure patients have sufficient time to ask questions and where necessary lead and encourage them to explore potential issues associated with their condition.xxiv Beyond discussions with their healthcare professional, patients should be provided with or directed to access information and support materials relevant to their condition.xxv Improving their own knowledge can be especially helpful to patients in dispelling myths about their condition and providing them with reassurance.

Patient involvement in decision-making should also include considerations of the specific patient’s preferences and therefore it should be acknowledged that some patients may not wish to be equally involved at every stage of their pathway. However, the survey results suggested an overall desire for greater information to be provided by clinicians, with 75% of surveyed patients wanting to have received more information from their healthcare professional at some stage of their patient journey.xxvii Beyond this, 25% of respondents indicated that they had only a low or moderate understanding of the information they received from their healthcare professional, suggesting the need for greater clarity in communication.xxviii

With 35% of surveyed patients indicating that they would have liked further information on treatment decisions, and 43% on post-treatment care, xxix there is a clear indication that the type of treatments available to patients, as well as their impact, need to be carefully conveyed to patients. For head and neck cancers, the specific treatment used will depend on a variety of factors, including the location and size of the tumour, the stage at diagnosis, and a patient’s general health.xxx In an optimal patient pathway, each of these would be carefully discussed with the patient before moving ahead with a decision.xxv

For the majority of head and neck cancer tumours, the primary purpose of treatment tends to focus on removing the cancer as far as this is possible.xxiv This involves surgery in most cases.xxxi Yet, among the survey respondents for whom surgery was the most recent treatment, 64% ranked the physical effects of the treatment as being in the top three significant difficulties they experienced.xxxii This surpassed all other categories, including the lack of energy, changes in physical appearance, and intensity of the treatment itself. While this is consistent across patients who received other types of treatment – including chemotherapy and radiotherapy, it highlights the distinction respondents made when asked to rank their challenges.xxxiii

Stage at which patients would have liked to receive more informationxxviii

<table>
<thead>
<tr>
<th>Stage</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Initial discussion</td>
<td>24</td>
</tr>
<tr>
<td>Diagnosis</td>
<td>34</td>
</tr>
<tr>
<td>Referral</td>
<td>16</td>
</tr>
<tr>
<td>Treatment</td>
<td>35</td>
</tr>
<tr>
<td>Post-treatment care</td>
<td>43</td>
</tr>
<tr>
<td>Post-discharge</td>
<td>30</td>
</tr>
</tbody>
</table>
Patient ranking of challenges encountered during any of their treatments

Taken together, it is evident that the commonality of challenges does not mean that all difficulties can be treated equally and some, especially those that can have a significant medium and long-term impact, may require specific attention. This may fall onto clinicians as part of their discussions with patients to include also robust information on the impact of treatment in the long-term, including the impact post-treatment on quality of life, particularly when considering a patient’s ability to return to normalcy in their day-to-day life. In fact, when specifically asked about the level of information patients received in relation to the challenges encountered during any of the treatments, 59% of the surveyed patients indicated that they did not receive the right level of information in preparation for the complications encountered.

Providing patients with information on what they can expect, in terms of clinical side-effects and the potential psycho-social impact should be explored. Not only did 81% of survey responders highlight the physical effects of treatment as a significant challenge they encountered following treatment, but 65% identified issues around dealing with lack of energy and tiredness and 55% struggled to deal with negative thoughts and feelings such as fear and stress. This highlights the need for patient information on both clinical and non-clinical outcomes, to help patients tackle the full range of challenges they may encounter.
There are key areas of the broader patient pathway that could be improved in order to support a reduction of incidence, earlier diagnosis, optimal treatment outcomes, and reduced detrimental impact on quality of life.
WHERE CAN IMPROVEMENTS BE MADE TO THE PATIENT EXPERIENCE?

Surveillance of and support for patients cannot be limited to any one stage of the patient pathway, and optimally the pathway should span beyond the point of diagnosis to also encompass prevention and post-treatment care. Working across patient advocacy groups, Government, the NHS and industry, the commitment to deliver on the full spectrum of care and support should be shared by all stakeholders. This support will also need to be provided across the country to avoid the current disparities in access.

Rate at which patients reported being offered specific services:xxix

<table>
<thead>
<tr>
<th>Service</th>
<th>Rate</th>
</tr>
</thead>
<tbody>
<tr>
<td>Named nurse who could be contacted</td>
<td>77%</td>
</tr>
<tr>
<td>Dedicated healthcare professional</td>
<td>70%</td>
</tr>
<tr>
<td>Emotional &amp; psychological support</td>
<td>46%</td>
</tr>
<tr>
<td>Specialist dietician or nutritionist</td>
<td>79%</td>
</tr>
<tr>
<td>Domestic carer support</td>
<td>7%</td>
</tr>
<tr>
<td>Transport to and from appointments</td>
<td>25%</td>
</tr>
<tr>
<td>Financial guidance</td>
<td>19%</td>
</tr>
</tbody>
</table>

For instance, while 100% of survey respondents who were offered domestic carer support found that these services either met or exceeded expectations, only 7% were offered such support.xxix Likewise, 44% of respondents indicated that their named nurse, who could be contacted for care-related concerns, exceeded expectations, but 23% of respondents were not provided with this support.xxix All head and neck patients should be provided with core support after their treatment, which should include care for their physical and clinical needs, we well as financial guidance, social care, and information access.ix

Greater improvements are also needed in the availability of emotional and psychological support for head and neck cancer patients. The survey found that emotional and psychological support was offered to just 46% of respondents, with 17% of respondents who were offered support indicating that the services they were offered were below their expectations.xxix

Based on the survey data and the existing gaps that patient respondents have identified, as well as the broader head and neck cancer environment, there are key areas of the broader patient pathway that could be improved in order to support a reduction of incidence, earlier diagnosis, optimal treatment outcomes, and reduced detrimental impact on quality of life. To achieve this, the wider oncology community should consider the following recommendations:

- **Shared decision making and health literacy** are vital for reducing some of the stress and anxiety associated with cancer diagnosis and subsequent treatment. Healthcare professionals should have access to appropriate tools and training to ensure that they are prepared to speak to a wide variety of patients. Patients, through information-sharing, should feel comfortable to rely on their healthcare professional, as well as the supporting team, for addressing questions and concerns.

- **Multi-disciplinary teams** that are engaged throughout the patient journey must also be fully integrated to ensure patients receive holistic support and are aware of the broader impact of their cancer and treatment, beyond the direct clinical impact. These teams should continue to be engaged in patient support post-treatment to ensure that the return to day-to-day life is as smooth as possible for patients.

- **Dentists and GPs** can play a significant role in improving early diagnosis. It is crucial that primary care staff are able to spend enough time with patients to detect early symptoms of head and neck cancers and are appropriately upskilled to accurately recognise them.

- In the provision of services for head and neck cancer patients, the impact of treatment on quality of life should fundamentally be included in an **integrated care package** to ensure that patients are well equipped to return to their day-to-day lives, supported in terms of their physical and mental health needs, and aware of the full breadth of resources available.
REFERENCES


xi. BMS-sponsored survey Question #10.

xii. BMS-sponsored survey Question #11.

xiii. BMS-sponsored survey Question #12.


xx. BMS-sponsored patient survey Question #3.


xxii. BMS-sponsored patient survey Question #4.

xxiii. BMS-sponsored patient survey Question #5.

