HEAD AND NECK CANCER IN THE UK PATIENTS, HEALTHCARE PROFESSIONALS AND LANDSCAPE ANALYSIS

This report was produced with support from Merck who had no input into the content or development.



BACKGROUND AND APPROACH

The following presentation is a summary of analysis conducted on surveys of Head and Neck Cancer patient and healthcare professionals and the landscape in the UK.

Data sources:

- Patient Survey: Run in Q4 2021/Q2 2022 by Oracle Cancer Trust (156 patients and family members)
- Healthcare Professionals Survey: Run in Q1 2022 by the Head and Neck Cancer UK Coalition (43 respondents Healthcare professionals)
- 2011 and 2021 Census data
- Cancer data from England and Wales Regional Clinical Commissioning Groups/Health Board data (2013-2021)
- NHS Cancer Stage Data Analysis (2013-2019). Cancer sites used in this analysis were 1) oral cavity, hard palate and lip (inner aspect); 2) Oropharynx, base of tongue, tonsil, soft palate and uvula; 3) Larynx including anterior surface of epiglottis

Approach:

The data was analysed in by Impact Data Metrics: A data research company that uses proprietary technologies to provide detailed insights to clients.

Many thanks to the Merck Group for its funding and support for this project and to all those who contributed by providing their valuable insights.

TABLE OF CONTENTS

- Section 1: Patient and Caregiver survey summary
- Section 2: Healthcare professional survey summary
- Section 3: Head and Neck Cancer UK landscape summary
- Appendix:
- Patient Survey additional detail
- Healthcare Professional Survey addition detail
- For full reports behind this report please contact the Head and Neck Cancer UK Coalition
- Tamara Kahn @ tamara@oraclecancertrust.org

SECTION I

Demographics:

• 156 respondents from across the UK

1. What is your interest in head and neck cancer?

- 73% of participants were current or past HNC patients; 27% were friends/family members
- 40% of those surveyed were HPV positive
- Main treatment types were radiotherapy, chemotherapy and surgery
- Age of respondents almost normally distributed: 56% in the 46 to 65 years age band





Key Findings Diagnosis and Treatment:

- 85% had symptoms < 1 year before seeking medical treatment; 15% waited > 1 year = 1 in 6.
- Once diagnosed a very positive 76% received treatment in weeks, a further 23% within a few months and only 1% >1 year later
- A positive 70% highly rated the information and support they were provided <u>before</u> treatment started and 74% highly rated the information provided <u>during</u> treatment.
- The most frequently cited priorities for improving the diagnosis experience were:
 - 1. Getting to the right specialist faster
 - 2. More awareness at GP/Dentist
 - 3. Getting scans/tests sooner and quicker results
- 80% of those surveyed reported treatment side effects as either "severe" or "very severe". Treatment
 options were said to be "invasive and unpleasant".
- 51% of those surveyed reported recovery from treatment taking a year or longer
- The most frequently cited priorities for improving the treatment experience were:
 - 1. More/better information once diagnosed
 - 2. More person centred support
 - **3**. Post treatment support starting immediately

Key Findings Post Treatment:

- 56% highly rated the information and support they received <u>post</u> treatment. In general there was a much less positive sentiment in responses and experiences of post treatment support.
- Respondents did not feel aware or able to take up a full range of support services that they felt they would benefit from.
- 28% took up Speech Therapy, 26% Feeding Support, 13% counselling, 10% physiotherapy, 10% attended Peer-run support groups, 8% clinician-run support groups, 5% Psychotherapy.
- The most frequently cited priorities for improving the Post Treatment Support were:
 - 1. Support more available, accessible and long-lasting
 - 2. Faster and more targeted to individual
 - 3. Active signposting and access to peer support/support groups



Calls to Action

- Public awareness of Head and Neck cancer symptoms needs to be improved
- GPs and primary health professionals must be informed about Head and Neck cancers so they can support patients
- Post treatment support needs to be improved
- Of patients surveyed, majority did not feel aware of peer support groups

"I went to the GP with lumps in my neck. I was advised to watch and wait. After 6 months I was referred to the hospital and a tumour on the tonsil was diagnosed."

"Only symptom was a hard fixed lump under the jaw. No pain. Thought it was a swollen lymph node at first, when it was still there a few weeks later, I went to the GP who immediately put me on an urgent 2ww referral to ENT."

"My gp failed to.diagnose me I was a recovery nurse working in theatre I asked a ENT consultant to.have a look in work he removed my tonsils the next day and I had my cancer diagnosis 2 other folk in my village died as they where not diagnosed"

SECTION 2

SECTION 2: HEALTHCARE PROFESSIONAL SURVEY

- The healthcare professional survey was run by the Head and Neck Cancer Coalition in support of their response to the NHSE call for inputs into the 2022 10 Year Cancer Strategy Consultation.
- The survey contained 6 questions and respondents were asked to provide free text answers. For this part of the analysis, the answers were reviewed, summarised and a 'word/phrase tag' created.
- 43 respondents from across England with some geographic gaps
- 94% of respondents were directly involved in Head and Neck Cancer care across a range of specialties.





SECTION 2: HEALTHCARE PROFESSIONAL SURVEY

Key Findings

- Post treatment support was the most frequent factor cited to improve patient outcome.
- Awareness of symptoms was among the top 4 things healthcare professionals believed would allow patients to receive treatment faster.
- 41% of those surveyed believed that the best way to raise awareness for Head and Neck cancer is through media campaigns (eg. Similar to current approaches for heart/stroke). Other popular methods to raise awareness were public education- teaching in schools, a larger section on the Cancer Research UK website, ads with risk factors and warnings, training for GPs
- 20% of respondents suggested the need for better approaches to diagnosis. Eg. 20% advocated one stop clinics as something NHSE should pursue. Raising awareness among dentists was another area that was highlighted.

SECTION 2: HEALTHCARE PROFESSIONAL SURVEY

Calls to action:

- More investment and focus in awareness campaigns will encourage patients to come forward with symptoms
- Post treatment support must be improved
- More training for dentists and GPs in spotting Head and Neck cancers
- Advocacy and discussions with NHSE around availability of diagnostic facilities (so patients don't have to travel across the country for tests) possibility of one-stop clinics

SECTION 3

SECTION 3: HEAD AND NECK CANCER LANDSCAPE IN UK

Head and Neck Cancer UK Landscape

Data sources:

- 2011 and 2021 Census data
- Cancer data from England and Wales Regional Clinical Commissioning Groups/Health Board data (2013-2021)
- NHS Cancer Stage Data Analysis (2013-2019). Cancer sites used 1) oral cavity, hard palate and lip; 2) Oropharynx, base of tongue, tonsil, soft palate and uvula; 3) Larynx including anterior surface of epiglottis

Impact Data Metrics collated Head and Neck Cancer data from Clinical Commissioning Groups and ran demographic reports against this. This resulted in staging analyses and identification of <u>correlations</u> and <u>clusters</u> within the data.

- A correlation analysis looks for strength and/or direction of relationship between two (or more) variables. The direction of a correlation can be either positive or negative. Note: correlation does not imply causation.
- Clustering is used to identify areas that exhibit similar profiles overall. Using the same source data as correlation analysis, data from 113 Clinical Commissioning Groups/Health Boards was evaluated and segmented by stage of diagnosis and socio-economic factors resulting in 4 different cluster groups.

SECTION 3: CANCER STAGE COMPARISONS

Key Findings

- Head & Neck Cancers show a greater-level of diagnoses at Stage 1 and 4, compared with Stages 2 and 3.
- Where there have been high-profile awareness campaigns and screening programmes in place (e.g. Breast, Prostate, Skin), there is a greater level of early stage diagnoses, compared with later stage diagnoses.
- Time series data shows an overall increase in the numbers of Missing stage data across cancers in 2019.



There are slightly more early stage diagnoses in oral cavity, hard palate, and lip cancer, and more late stage diagnoses in oropharynx, base of tongue cancer etc. So, there are disparities in the different types of Head and Neck Cancers.

SECTION 3: CORRELATION ANALYSIS

Correlation Analysis Key Findings:

- For diseases with high profile awareness campaigns, there is higher correlation with early-stage diagnosis
- In Head and Neck Cancers there is a weaker correlation of diagnosis among ethnic communities, larger households, deprived households and economically inactive people. This indicates:
 - People of these characteristics and from these communities are less likely to receive a diagnosis.
 - There is a requirement to increase engagement with this part of the community.
 - There is less data available (even when weight adjusted) from these demographic communities and further research required around inequalities to understand this.
- Healthcare records have significant unknown or unknown stage data, suggesting gap in knowledge of HNCs
- There is noticeable disparity between early diagnosis and the data of White and White-Mixed ethnic communities and that of Non-White ethnic communities.
- There is less data on Non-White ethnic communities (Black, Asian and mixed). Worth understanding why this data is so limited and if these are falling into unknown categories.
- There is higher correlation of diagnosis in disabled/long term-sick

SECTION 3: CLUSTER ANALYSIS

Cluster Analysis



- Cluster analysis was undertaken to determine whether there are variations across England and Wales that delineated a diagnosis stage by these factors.
- It's purpose was also to identify geographic areas where it may be beneficial to focus awareness-raising effort base on these data.

SECTION 3: CLUSTER ANALYSIS

Cluster Analysis

4.4.1 Clusters by diagnosis stage 🖉



Mean of the number of patients in Clusters of Health Boards/CCGs by their stage of Diagnosis. Bars are the standard error of the mean of the population. Values in parentheses in the chart headers are the population within each cluster of CCGs.

- Cluster 1: Includes Cambridge, York, Birmingham, Frimley
 - Highest proportion of houses which are not deprived in any dimension
 - Second highest proportion of retired population
 - Least densely populated cities/towns
- Cluster 2: Includes Oxford, Liverpool, Bristol
 - Second lowest level of diversity
- Cluster 3: London
 - Higher levels of ethnic diversity
 - Higher number of larger households
 - Greater proportion of deprivation.
 - Has the greatest proportion of businesses in Financial Services, IT, and Professional Services.
- Cluster 4: Includes Southampton, Derby, Gloucestershire
 - Largest retired population
 - Highest number of people who are long term sick/disabled
 - Greatest agriculture industry

SECTION 3: HEAD AND NECK CANCER LANDSCAPE IN UK

Calls To Action:

- More Awareness campaigns will improve early stage diagnosis trend (currently HNC trending in the wrong direction)
- Specific area of engagement/awareness raising to focus on larger households and those with greater levels
 of deprivation.
- Diagnoses must be improved among ethnic communities, larger households, deprived households and economically inactive people
- More research should be done to understand why the inequalities data does not seem complete.
- Create focus on importance of reporting Head and Neck cancer stage of diagnosis to reduce the numbers falling in to the Missing/Unknown stage.

APPENDIX WITH MORE DETAIL

March 2023

1. What is your interest in head and neck cancer. Please select the option which best fits your current situation.

1. What is your interest in head and neck cancer?





2022 Patient Survey: What is your interest in Head and Neck Cancer?



2022 Patient Survey: What is your diagnosis? HPV positive or negative?





How long did you experience symptoms before you sought treatment?





How long did it take for you to be diagnosed from time you sought medical advice?



Narrative Analysis: Which part of the process failed.



Numbers above bars are the number of respondents answering in that category with the percentage in brackets below.

Numbers above bars are the number of respondents answering in that category with the percentage in brackets below. No y-label indicates question not answered.

What are your top 3 priorities for improving your experience of diagnosis?



2022 Patient Survey: What type of treatment did you have?



How would you describe the side-effects of any treatment you had?



How long did it take you to recover from treatment?



How would you rate the information and support you were given <u>before</u> treatment?



How would you rate the information and support you were given <u>during</u> treatment?



How would you rate the information and support you were given <u>after</u> treatment?



What should the top three priorities be for improving your experiences of treatment?

	More/better information once diagnosed
38 (17.	More person centred support
37 (17.:	Post treatment support starting immediately
23 (10.75%)	Better communication of and between drs/nurses/MDT team members/GP
19 (8.88%)	Safer and less invasive treatment advances
9 (4.21%)	Shorter waiting times
9 (4.21%)	Counselling and mental health support
8 (3.74%)	Closer treatment/ costs
5 (2.34%)	Access to specialist professionals
4 (1.87%)	Other
4 (1.87%)	Better information/awareness before
3 (1.4%)	Quality of life post treatment is focus
1 (0.47%)	Recurring cancer focus
1 (0.47%)	Peer support
1 (0.47%)	Earlier Diagnosis
1 (0.47%)	Allied Health Professionals
0 20 40	-

Narrative Analysis

What do you think should be our top three priorities be for medical research?





What type of support was available? Please select as many as relevant

Total = 25869 64 (26.74%) (24.81%) 40 (15.5%) 25 24 24 (9.69%) (9.3%) (9.3%) 12 (4.65%) Clinician-run support Peer-run Psychotherapy Counselling Physiotherapy Speech therapy Feeding support group support group

What should the top three priorities be for improving the support you received?

Support more available, accessible and long-lasting		41
Faster and more targeted to individual		28 (18.79%)
Active signposting and access to peer support/support groups		17 (11.41%)
Mental health support/counselling		14 (9.4%)
Easier access to clinicians and nurses.		11 (7.38%)
Support for families/caregivers provided		8 (5.37%)
Other		8 (5.37%)
Proactive checking in		6 (4.03%)
Focus more on Quality of life vs Survivorship		6 (4.03%)
More information provided before and after treatment		3 (2.01%)
Alternative therapy support provided		3 (2.01%)
Positivity in approach		2 (1.34%)
Personalised approach		2 (1.34%)
-	0	10 20 30 40

Narrative Analysis

Respondent profiles





What is your role and a Health Care Professional?



What is your awareness of Head and Neck cancers?

2022 Healthcare Professional Survey: What do you think could be done to improve awareness of HNCs generally?

2022 Healthcare Professional Survey: What one thing would help accelerate diagnostics for HNC patients with symptoms?

What is your awareness of Head and Neck cancers?

also increased . țumourviral dna ଞ raising awareness care early referral get dental can made gp ... gp ct mri age health better access see o face gp ^{mound} sec **sec** capacity inform secondary face face pet ct one stop gps risk mri pet circulating tumourviral mri slots dental care access post greater access bring dental seen clinic stop clinic stop clinics

In your H&N Cancer network, what one thing would you suggest to shorten the time between diagnosis and starting treatment?

In your H&N Cancer network, what one thing would yo suggest to shorten the time between diagnosis and sta treatment?

If you could change one thing in your H&N Cancer network to improve outcomes for patients what would that be?

If you could change one thing in your Ha improve outcomes for patients what wou

effects head side effects stop fast clinic nurse ONE Stop care diagnosis lower life oral dental care head ne K cns like o looks like care thin surge mes access lower stage access clinical access support cancer made