Giving a Voice to the Head and Neck Cancer Community

Innovation Can't Come Soon Enough for Head and Neck Cancer Patients

More than half of surveyed head and neck cancer patients (56%) agreed that they worry they won't live long enough to experience innovations in treatment.[1]

For people living with head and neck cancer (HNC), progression can mean more than the pathological advancement of cancer. It can bring greater uncertainty about what comes next, concerns about whether sufficient treatment options will remain and a worsening impact on everyday life.

Johnson & Johnson partnered with the Head and Neck Cancer Alliance (HNCA) to develop a survey giving people living with HNC and their caregivers a voice about their greatest concerns, what matters most to them and what gives them hope. The survey garnered more than 300 respondents (n=249 people living with HNC and n=54 caregivers*), revealing an urgent desire for continued treatment innovation and the hope that new approaches can bring.[1]

Patients Fear More Than Recurrence – What Options will Remain?

For patients with head and neck cancer, fear of recurrence or progression may be compounded by uncertainty about what happens next if their cancer returns. That uncertainty exists against a challenging treatment landscape, where less than 25% of patients with recurrent/metastatic head and neck squamous call carcinoma (HNSCC) responded to available subsequent treatment options.[1,2,3]

Nearly 8 in 10

surveyed patients (78%) agreed that they live in fear that their HNC will come back, including more than 1 in 3 (35%) who strongly agreed.[1]

3 in 4

of total surveyed patients (75%) agreed that they worry they won't have sufficient treatment options if their cancer progresses, along with 78% of those whose cancer has progressed, and 81% of caregivers*.[1]

Nearly Half

of surveyed patients (45%) whose HNC had progressed or recurred reported having limited treatment options.[1]

Progression Changes More Than the Cancer

Disease progression isn't simply a clinical turning point. For patients, it may represent a deterioration in everyday life. For caregivers, it can bring significant daily burden and feelings of isolation. The impact of HNC reaches far beyond the disease itself – and progression can deepen the toll on both patients and caregivers.[1]

82% of surveyed patients agreed that managing their cancer and treatment side effects impacts every part of their daily life.[1]

79% of surveyed patients agreed that they feel like people from outside their care team don't fully understand what they're going through, while **89%** of caregivers* agreed that no one else understands what it's like to provide care to someone with HNC.[1]

41%

of surveyed patients whose HNC progressed or recurred reported that their cancer and/or its treatment had a great deal or a lot of negative impact on various aspects of their life.

Top negative effects include:[1]

- Ability to eat **(69%)**
- Ability to swallow **(65%)**
- Energy levels/fatigue **(56%)**
- Ability to engage in social activities/interactions **(50%)**
- Job/career or ability to work **(48%)**
- Self-esteem/confidence **(46%)**

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Innovation Can Bring Hope

Even as surveyed patients expressed concern about what may come next, they also expressed hope in continued progress in HNC treatment and reported playing an active role in treatment decisions with their care teams.

92% of surveyed patients agreed that new treatment approaches give them hope for the future, while 94% agreed that they would be willing to try a new treatment option rather than use older treatments that may have shown limited effectiveness.[1]

85% of surveyed patients agreed they want to be (more) actively involved in exploring new treatment options with their care team.[1]

What Matters Most When Making Treatment Decisions

When asked about the importance of several factors when they are making treatment decisions with their healthcare provider, surveyed respondents identified these key priorities:

#1 Treatment Priority

Preserving capacity to speak was the top treatment consideration among those surveyed, with 96% of patients and 93% of caregivers* identifying it as very or somewhat important when making treatment decisions.[1]

93%

of surveyed patients reported that proven efficacy in treating their HNC is very or somewhat important when making treatment decisions, and 92% said the same about a long-lasting response in treatment.[1]

68%

of surveyed patients and nearly **3 in 5 surveyed caregivers*** (57%) reported that proven efficacy in another cancer indication is very or somewhat important when making treatment decisions.[1]

97%

of surveyed patients agreed that the most important thing to them is that their treatment keeps their cancer under control for as long as possible, including nearly 4 in 5 (78%) who strongly agreed.[1]

After Progression or Recurrence, What Matters Most?

When asked which aspects of a new/different treatment would increase their interest after progression or recurrence, surveyed patients most often identified:

69% Maintaining quality of life[1]

65% Proven efficacy in their cancer and/or another cancer[1]

58% Preserving capacity to speak[1]

53% Long-lasting response[1]

The Need for Progress is Personal

For people navigating HNC, the need for continued progress is deeply personal.

8 in 10

surveyed patients (81%) expressed interest in a new or different treatment following progression or recurrence of metastatic disease after initial or first-line treatment, and more than half (56%) were very interested.

92% of surveyed patients agreed that new treatment approaches give them hope for the future.[1]

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About the Giving a Voice to the Head and Neck Cancer Community Survey

The research was conducted online in the United States by The Harris Poll on behalf of J&J among US adults age 18+, of which 249 are patients who have been diagnosed with head & neck cancer and 54* are caregivers of adults who have been diagnosed with head & neck cancer. The survey was conducted July 18–September 4, 2026.

Raw data are not weighted and are therefore only representative of the individuals who completed the survey. All respondents for this survey were recruited from patient advocacy groups: Head and Neck Cancer Alliance (HNCA), Support for People with Oral Head and Neck Cancers (SPONC), CancerCare, and the Thyroid Head and Neck Cancer Foundation (THANC) through email invitations and social media channels.

The sampling precision of Harris online polls is measured using a Bayesian credible interval. For this study, the sample data is accurate to within ± 6.2 percentage points for patients and ± 12.9 percentage points for caregivers using a 95% confidence level. This credible interval will be wider among subsets of the surveyed population of interest.

All sample surveys and polls, whether or not they use probability sampling, are subject to other multiple sources of error which are most often not possible to quantify or estimate, including, but not limited to coverage error, error associated with nonresponse, error associated with question wording and response options, and post-survey weighting and adjustments.

Results based on small bases (n=50–99) should be interpreted as directional only.

References

1. Data on file. Johnson & Johnson.
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3. Fayette J, Licitra L, Harrington K, et al: INTERLINK-1: A phase III, randomized, placebo-controlled study of monalizumab plus cetuximab in recurrent/metastatic head and neck squamous cell carcinoma. *Clin Cancer Res* 31:2617-2627, 2025

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