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Non-Profit Organizations Advocating for Head and Neck Cancer Patients: A Scoping Review

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ABSTRACT

Purpose: To identify and characterize non-profit organizations (NPOs) from English-speaking countries providing advocacy to individuals with head and neck cancer (HNC) and critically analyze the multifaceted roles played by these NPOs for patients, caregivers, healthcare professionals, and researchers.

Methods: A scoping review was conducted through PubMed, Scopus, EMBASE, Web of Science, Google Scholar, ProQuest, and open databases. The data collected on the NPOs were: information on origin, founder background, cancer types addressed, mission, and information and services offered.

Results: Twenty-five NPOs were identified, predominantly from the US ($n = 10/40\%$) and UK ($n = 10/40\%$). Most NPOs ($n = 16/64\%$) were founded by survivors and/or their families. The websites provided diverse information, with over 84% ($n = 21$) covering risk factors, signs, symptoms, and screening/diagnosis. Common services included educational resources, newsletters, and patient support groups. Legal advice was also provided but less frequently. All NPOs promoted fundraising; the majority promoted awareness events, and 40% ($n = 10$) offered research grant opportunities.

Conclusions: NPOs are vital advocates for HNC patients, offering community support and empowerment. Healthcare professionals, by being aware of NPOs and their work, can enhance patient support. Additionally, researchers should view NPOs as essential sources for patient and public engagement, which is increasingly valued by funding agencies.

1 | Introduction

Cancer treatments, whether short-term or long-term, often come with a range of side effects. For survivors, prevalent challenges include the fear of recurrence or progression and experiences of depression (Götze et al. 2019). Their concerns extend to their family members who, although they are pillars of support, share in the anxieties experienced throughout the treatment and often seek more information about the disease and the necessary care to provide support (Götze et al. 2019; Dri et al. 2020). Recognizing the multifaceted nature of the cancer journey, a comprehensive approach that goes beyond specialized teams is essential. Head and Neck Cancer (HNC) is ranked as the seventh most common type of cancer worldwide in 2020, with approximately 890,000 new cases and 450,000 deaths, and individuals diagnosed with HNC often face communication challenges and a lack of representation of their struggles in society (Dawson et al. 2020). In this context, the

concept of advocacy is based on the idea of promoting empowerment for groups of individuals who are vulnerable in various aspects, such as HNC patients, by leveraging the power and influence of more influential groups or individuals to support their causes and give visibility to their challenges in various spheres (Dawson et al. 2020).

Non-profit organizations (NPOs) not only provide these support networks but also extend their roles far beyond. They serve as crucial funding sources, facilitate collaborations with research partners, and disseminate scientific information to patients and caregivers. In addition to educating patients about what to expect from therapy and how to manage side effects, support groups promote the sharing of experiences and mutual encouragement (Griffiths et al. 2009; Jablotschkin et al. 2022), empowering patients to make informed decisions about treatment and navigate the oncology care system (Ziegler et al. 2022). The community engagement fostered by these NPOs also helps break down barriers, countering the isolation that often accompanies the cancer journey. This scoping review aimed: (i) to identify and characterize NPOs that provide advocacy for individuals with HNC; (ii) and to analyze the multifaceted roles performed by these organizations for patients, caregivers, healthcare professionals, and researchers.

2 | Methods

2.1 | Protocol and Registration

The protocol is registered with the Open Science Framework at the following address: https://doi.org/10.17605/OSF.IO/PHYWF. The scoping review was conducted following the Preferred Reporting Items for Systematic Reviews and Meta-Analyses extension for Scoping Reviews (PRISMAScR) (Tricco et al. 2018).

2.2 | Eligibility Criteria

The inclusion criteria were based on the PCC strategy (Population, Concept, and Context), as follows: (P) Patients with HNC; (C) NPOs; (C) English-speaking countries.

The exclusion criteria were as follows: (1) Publications that do not have full texts available; (2) Publications that are not in English; (3) Publications focusing on NPOs related to tumors in other regions of the body; (4) Publications that do not mention any NPO; (5) Publications focusing on support groups that do not constitute a complete organization.

2.3 | Information Sources and Search Strategies

Electronic searches were conducted on August 17, 2024, in the following databases: PubMed, Scopus, EMBASE, and Web of Science. Gray literature was also searched on Google Scholar, ProQuest, and open Google. All available publications in these databases contained a combination of controlled and predefined medical subject terms (MeSH) and free terms related to HNC and NPOs, using Boolean operators (OR, AND) to combine the searches. The predefined terms were adapted to the syntax rules of each bibliographic database (Appendix S1).

2.4 | Selection Process

The selection of publications occurred in two phases. In the first phase, the reference management software EndNote was used to gather references and delete duplicates. In the second phase, titles and abstracts of all identified articles were read by a reviewer (L.F.C.). Subsequently, a full-text reading of the selected references was performed. Discussions with two researchers (C.B.C. and V.P.W.) were conducted during the selection and extraction process.

2.5 | Data Extraction

When available, the following data from the NPOs were extracted from each included article: the name of the NPO, country of origin, founder background (patient, caregiver, healthcare professional), year of creation, cancer type, quantitative measures of impact, mission, type of information provided (risk factors, signs and symptoms, adverse effects, etc.), use of inclusive language, services offered (patient support group, newsletter, research grants, etc.), and presence on other media platforms. Regarding the type of information and services offered, the data were categorized as "YES," "NOT AVAILABLE," or "YES, secondary access." The designation "YES, secondary access" refers to cases where the information or service was not immediately available on the main page but could be accessed via hyperlinks or references to external platforms. These references either redirected to partner institutions or to other online environments maintained by the same NPO, often with a distinct layout and expanded content, such as educational modules or detailed service information. In some cases, the NPO only mentioned the institution responsible for the service, without providing a direct link.

The publications that only mentioned a NPO, without exploring details about it, were used as references for the search for the NPO, either through open Google or directly on the website, if available in the article.

For the NPOs identified solely through open Google, the same data were extracted from the found websites. On these websites, if a partner institution that was also characterized as an NPO was identified, which had not been found in the publications until then, it was also included in the search through open Google searches.

After the initial data collection, efforts were made to contact certain institutions through their communication channels (e-mail or website) to obtain information that was not found, thereby enhancing the completeness of the data. Despite these efforts, some data remained unclarified.

2.6 | Synthesis of Results

The mapped data were synthesized descriptively. Categorical data were presented in absolute numbers and percentages.

3 | Results

A total of 840 publications were identified after conducting the searches in the selected databases. Of these, 689 articles were retrieved from the main databases, and after removing 130 duplicates, 559 publications remained. These were screened based on the title and abstract, resulting in 18 publications being selected for full-text review. In the end, eight publications were included in this study. From the gray literature, 151 articles were identified, of which 23 duplicates were removed, leaving 128 publications for screening. After title and abstract screening, seven publications were selected for full-text review, and 0 were included in the study. Thus, the total number of publications included was eight, which, in total, led to 10 NPOs. Additionally, through open searches on Google, more than 15 NPOs were found, totaling 25 NPOs. This process is outlined in the PRISMA flow diagram (Figure 1).

3.1 | Publications Citing NPOs

The following authors mentioned various NPOs that support patients with HNC: Chang et al. (2020) cited Thyroid Cancer Canada. Dawson et al. (2020) mentioned The Throat Cancer Foundation, which led us to The Ben Walton Trust for being referenced on its website. Dawson et al. (2020) also included Head and Neck Cancer Alliance, The Swallows Head and Neck Cancer Group, and Support for People with Oral and Head and Neck Cancer. Liu et al. (2020) highlighted the American Head and Neck Society. Additionally, Lee et al. (2016); Lubek (2018) and Overman (2009) cited the Oral Cancer Foundation, and Perros et al. (2012) mentioned the Butterfly Thyroid Cancer Trust. Finally, Yan et al. (2020) brought attention to both the Head and Neck Cancer Alliance and the Head and Neck Cancer Living Foundation.

3.2 | Open Google Searches

After analyzing the NPOs identified by the publications, the open Google search resulted in an additional 15 NPOs, namely: Adenoid Cystic Carcinoma Research Foundation, Head & Neck Cancer UK (HANCUK), Head and Neck Cancer Australia, Head and Neck Cancer Foundation (Australia), Head and Neck Cancer Foundation (UK), Head and Neck Cancer Foundation Aotearoa, Head and Neck Cancer Support Society, Lets Talk About Mouth Cancer, Mouth Cancer Foundation, Oracle Cancer Trust, Oral Cancer Awareness Foundation, Oral Cancer Cause, Salivary Gland Cancer UK, Thyroid Cancer Survivors' Association, and Thyroid, Head and Neck Cancer (THANC) Foundation.

3.3 | General Features

Twenty-five institutions providing support to individuals with HNC were identified (Table 1). The most common countries of origin were the UK and the US, both with 10 (80%) NPOs, followed by Australia with 3 (12%) NPOs and, finally, Canada with 2 (8%) NPOs. Patients diagnosed with SCC were the focus of the majority ($n = 19/76\%$) of the NPOs. Thyroid ($n = 4/16\%$) and salivary gland cancer ($n = 2/8\%$) also had specific NPOs.

The NPOs were created between 1984 (Head and Neck Cancer Alliance) and 2019 (Head and Neck Cancer Foundation, Australia). A progressive rise in the number of NPOs was observed between decades, with only one (4%) created in the 80s, followed by 5 (20%) in the 90s, 5 (20%) between 2000 and 2010, and 9 (36%) between 2010 and the present time.

Most NPOs were created by survivors and/or their family ($n = 16/64\%$), followed by clinicians in the field of HNC

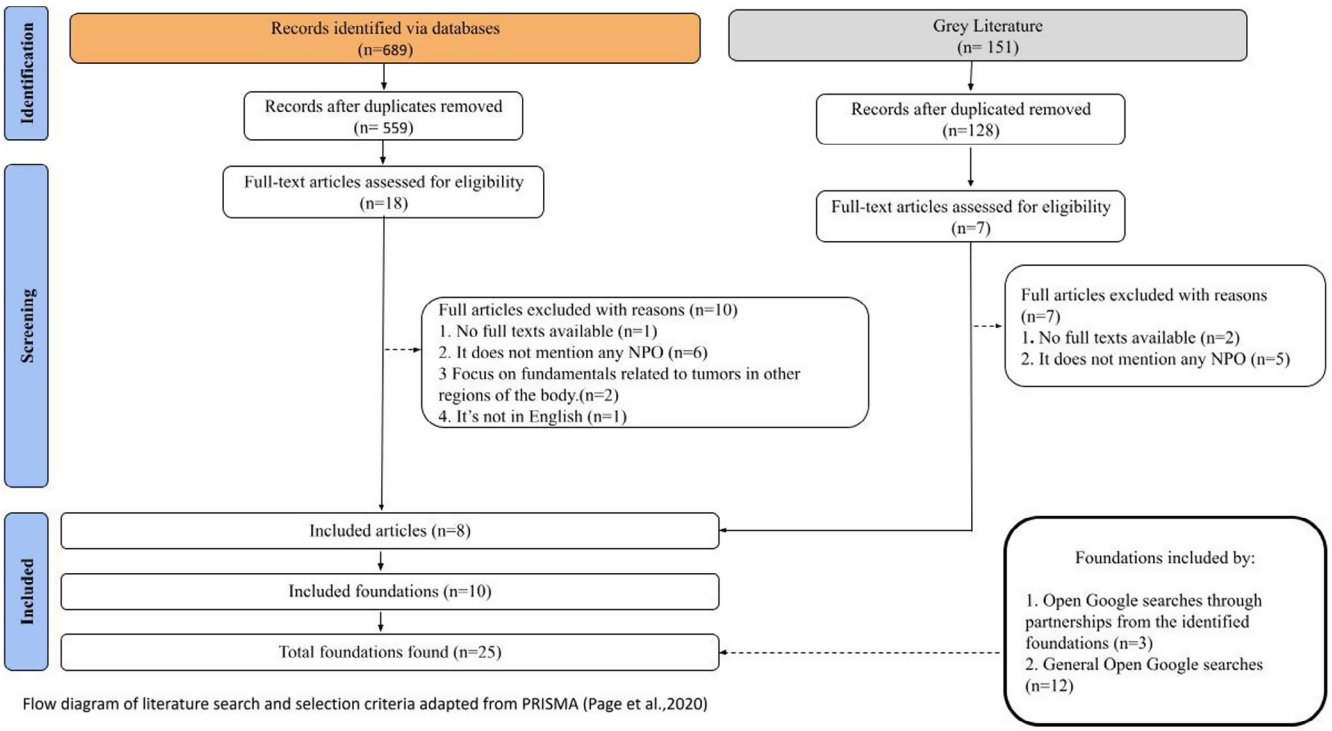

FIGURE 1 | Flow diagram of literature search and selection criteria adapted from PRISMA (Page et al. 2021).

TABLE 1 | HNC NPO's general features.

Name	Country	Cancer type	Year of creation
Adenoid Cystic Carcinoma Research Foundation	USA	Salivary Gland Cancer	2005
American Head and Neck Society	USA	SSC	1998
Butterfly Thyroid Cancer Trust	UK	Thyroid	2000
Head & Neck Cancer UK (HANCUK)	UK	SCC	2017
Head and Neck Cancer Alliance	USA	SSC	1984/2006
Head and Neck Cancer Australia	Australia	SSC	NA
Head and Neck Cancer Foundation	UK	SSC	NA
Head and Neck Cancer Foundation	Australia	SSC	2019
Head and Neck Cancer Foundation Aotearoa	Australia and New Zeland	SSC	NA
Head and Neck Cancer Support Society	Canada	SSC	2018
HNC Living Foundation	USA	SSC	2013
Lets Talk About Mouth Cancer	UK (Scotland)	SSC	NA
Mouth Cancer Foundation	UK	SSC	2004
Oracle Cancer Trust	UK	SSC	2011
Oral Cancer Awareness Foundation	USA	SSC	2007
Oral Cancer Cause	USA	SSC	2013
Oral Cancer Foundation	USA	SSC	1999
Salivary Gland Cancer UK	UK	Salivary Gland Cancer	2016
Support for People with Oral and Head and Neck Cancer	USA	SSC	1991
The Ben Walton Trust	UK	SSC	1996
The Swallows Head and Neck Cancer Group	UK	SSC	2010
The Throat Cancer Foundation	UK	SSC	2012
Thyroid Cancer Canada	Canada	Thyroid	NA
Thyroid Cancer Survivors' Association	USA	Thyroid	1995
Thyroid, Head and Neck Cancer (THANC) Foundation	USA	Thyroid	2003

Abbreviations: HNC, head and neck cancer; NA, not available; NPOs, non-profit organizations; SSC, squamous cell carcinoma; UK, United Kingdom; USA, United States of America.

($n = 7/33\%$). Some of NPOs were founded by survivors alongside clinicians ($n = 3/14\%$). More information on the founders can be found on Table S1.

3.4 | Information for Patients

The websites provided a wide range of information for patients, covering topics from risk factors and screening to open clinical trials and legal advice (Figure 2; Table 2; Table S2). It was observed that information on risk factors, signs and symptoms, and screening/diagnosis was the most commonly available, present on more than 84% ($n = 21$) of the primary websites. While only 16% ($n = 4$) of the NPOs directly provided a list of available clinical trials, a significant number of NPOs ($n = 10/40\%$) offered this information through secondary access. Legal advice was the least reported type of information, with 68% ($n = 17$) of the NPOs not providing it either directly or indirectly. Regarding the use of inclusive language, all the websites demonstrated a moderate level, presenting clinical and scientific information in a comprehensible yet thorough manner (Table S2).

3.5 | Services Offered

In addition to presenting educational content, the NPOs offered a variety of services (Figure 3; Table 3; Table S3). Based on the information provided on their websites, 92% ($n = 23$) of NPOs provided information on how to donate for fundraising, and 80% ($n = 20$) promoted awareness events. Other common services included downloadable educational resources and options to join newsletters or patient support groups (Table 3). Almost

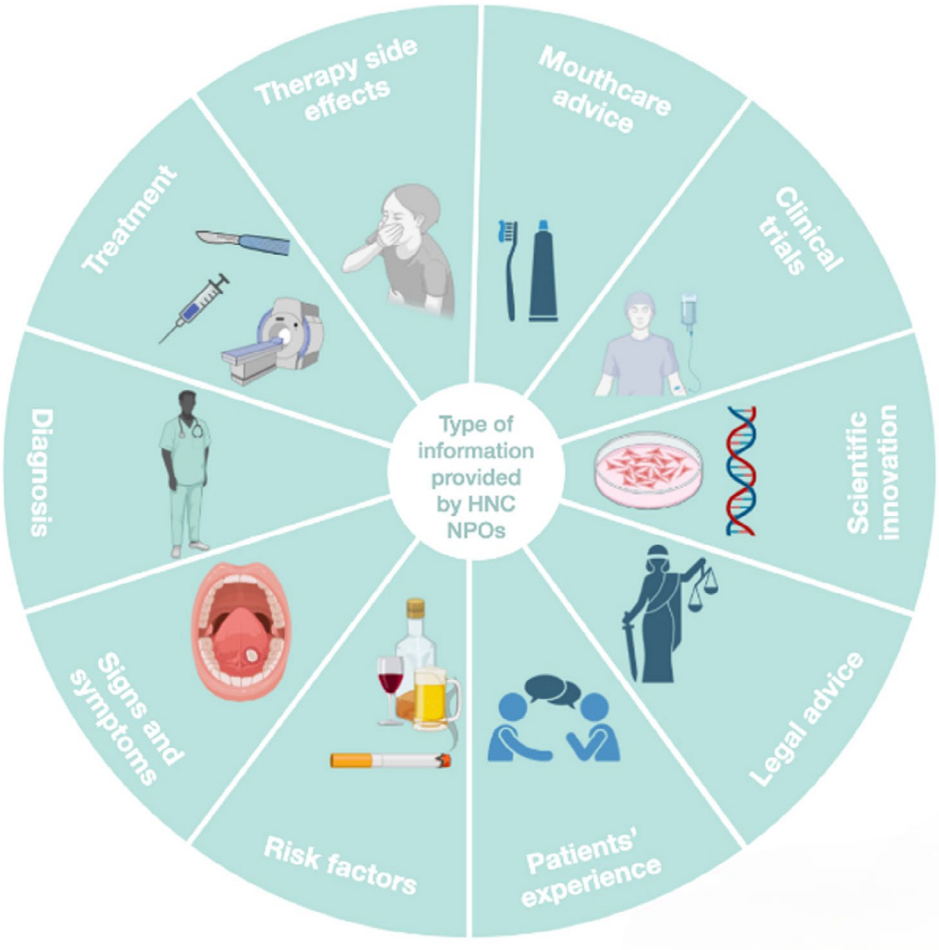

FIGURE 2 | Schematic representation of type of information provided to patients in HNC NPOs (pie chart slices do not correlate with frequency, for this information refer to Table 2).

half of the NPOs ($n = 10/40\%$) also offered research grant opportunities, ranging from academic scholarships to grants of up to $300,000, with a historic maximum of $600,000 (Adenoid Cystic Carcinoma Research Foundation—USA).

3.6 | Presence on Other Media Channels

Besides the majority of NPOs presenting an official website ($n = 24/96\%$), the NPOs were present on other media channels (Table 4; Table S4) such as Facebook (n23/92%), Instagram ($n = 21/84\%$) and Twitter ($n = 20/80\%$). Less commonly used were YouTube and LinkedIn ($n = 17/68\%$ and $n = 16/64\%$, respectively).

3.7 | NPOs' Impact

The section on "impact" aimed to explore how NPOs (non-profit organizations) report their activities and reach. However, standardized metrics were rarely available. In many cases, the categories used in this review—such as official members, patients supported, consumers, and awards & accolades—were deduced from available online information, which was presented inconsistently across organizations. To compensate for the lack of standardization in reporting reach, additional searches were conducted to identify the number of followers, subscribers, and members on social media platforms (when the NPO had such social networks). This data is provided in Table S5. Attempts were also made to contact organizations directly to gather more accurate data, and some, such as Salivary Gland Cancer UK, Adenoid Cystic Carcinoma Research Foundation, and Head & Neck Cancer UK, provided additional information to complement the publicly available data. Some NPOs report engagement in terms of research collaborations and general followers, while others, like HANCUK or the Head and Neck Cancer Alliance, provide more direct patient support figures. However, this information was unavailable for most ($n = 21/84\%$) HNC NPOs. Therefore, these indicators should not be interpreted as directly comparable measures of impact but rather as illustrative examples of the diverse ways NPOs operate and communicate their outreach (Table S6). From the available data, the impact could be estimated for NPOs such as the Oral Cancer Foundation, with over 13,000 official members; Head & Neck Cancer UK, which has supported over 2000 patients; the Mouth Cancer Foundation, with over 1 million consumers; and the Thyroid, Head, and Neck Cancer Foundation, whose websites receives 71,000 monthly visitors. Among awards, examples include the Excellence in Public Service Award, granted by the NIDCR at the National Press Club to the Oral Cancer Foundation (OCF). Additionally, OCF was named the Best Small Non-Profit Organization by Great Non-Profits in 2009.

TABLE 2 | Availability of information for patients on specific topics.

Information	Yes (*n*/%)	Yes—secondary access (*n*/%)	Not available (*n*/%)
Risk factors/prevention	21/84	2/8	2/8
Signs and symptoms	21/84	2/8	2/8
Screening/diagnosis	22/88	1/4	2/8
Treatment	19/76	2/8	4/16
Therapy adverse effects	16/64	3/12	6/24
Practical mouth care advice	10/40	4/16	11/44
Open clinical trials	4/16	10/40	11/44
Scientific innovation	13/52	1/4	11/44
Legal advice	7/28	1/4	17/68
Patient experiences	17/68	0/0	8/32

4 | Discussion

This scoping review aimed to investigate NPOs providing support to individuals with HNC and assess the variety of services and information they offer. The results highlighted the multifaceted nature of these NPOs, revealing that they offer a broad spectrum of information ranging from risk factors and signs and symptoms to nutritional and legal advice. They also provide critical services such as educational resources, support groups, and research grant opportunities. An inspiring finding from this study is that most NPOs were established by survivors and their families, emphasizing the crucial role of lived experience in addressing patients' needs.

The literature searches for publications within this topic revealed a scarcity of publications investigating the NPOs that support patients with HNC. This gap in academic knowledge highlights the need for further research in this area, both to better understand the actions of these institutions and to disseminate their activities to patients, caregivers, and researchers. The adoption of open science practices, which make research results accessible to everyone, can benefit patients reading this study, as it addresses this gap by mapping the NPOs and creating opportunities for them to access their resources.

Twenty-five HNC NPOs were identified, all located in developed or developing countries, with 19 (76%) focused on SCC, the most common type of HNC (GLOBOCAN, 2024), four dedicated to thyroid cancer, and two addressing salivary gland cancers (one covering general salivary gland tumors and one specifically for adenoid cystic carcinoma). Comparing this number to that of NPOs for more common cancers is challenging due to a lack of comprehensive literature on NPO distribution. A recent study of NPOs with annual revenues exceeding $5 million found that breast and pediatric cancers had the highest number of NPOs (13 each), with breast cancer and leukemia NPOs generating the highest revenues—$460 million and $201 million, respectively (Kamath et al. 2019). Notably, no NPOs specifically dedicated to HNC were identified among the 59 types surveyed, highlighting significant disparities in cancer type funding (Kamath et al. 2019). Despite HNC being the seventh most common cancer worldwide, issues related to lack of interest and underfunding have been discussed for decades (Fribley et al. 2017). Along with this, information regarding the annual revenues of these NPOs is not easily found.

The relatively low number of NPOs for thyroid and salivary gland cancers (only 6 out of 25) is likely due to the rarer nature of these cancers. Patients with rare cancers face challenges due to the lower scientific consideration and financial support these tumors receive. Examples include incorrect or late diagnosis, lack of confidence in clinical decision-making by professionals, and a shortage of accessible therapies (Pillai and Jayasree 2017). In other words, their rarity often means there are significant gaps in knowledge, making ongoing research crucial for improving understanding of risk factors, diagnostic methods, and treatments (Locati et al. 2023). For instance, the Adenoid Cystic Carcinoma Research Foundation provides a list of open clinical trials to help patients find precise therapies. Other examples of good practices promoted by rare cancer-focused NPOs are the Second Opinion Program, which assists ALK+ lung cancer patients with financial constraints in obtaining second opinions from leading specialists, and a Scholarship Fund supporting students whose parents have been diagnosed with ALK+ lung cancer, both promoted by the ALK POSITIVE Foundation (Barton et al. 2023).

During the research, difficulties were found in locating some institutions mentioned in previous publications. Thyroid Cancer Canada, referenced by Chang et al. (2020), had its website down with no available information. Similarly, The Ben Walton Trust, mentioned on The Throat Cancer Foundation's website, did not have an accessible site, leading us to use data from The Throat Cancer Foundation. Although it was not possible to determine whether these organizations have ceased to exist or are undergoing website renovations, they were included in this research because they met the established inclusion criteria. The Thyroid Foundation of Canada, also mentioned by Chang et al. (2020), is an example of an NPO that supports not only individuals affected by thyroid cancer but also those with other thyroid conditions. For this reason, it was not further explored in this study. However, the work of institutions like this is of great importance and deserves to be investigated in future research.

Within this same context, it is essential to consider not only whether NPOs maintain official websites, but also whether these sites are regularly updated and actively managed. The consistency of online engagement and the breadth of services offered are key indicators of an organization's commitment to community. Based on these criteria—updated content, a wide range of services, and sustained website activity—some NPOs

FIGURE 3 | Schematic representation of the range of services offered to patients by HNC NPOs (pie chart slices do not correlate with frequency, for this information refer to Table 3).

TABLE 3 | Services offered by HNC NPOs.

Information	Yes (*n*/%)	Yes—secondary access (*n*/%)	Not available (*n*/%)
Patient support group	11/44	7/28	7/28
Newsletter	13/53	1/4	11/44
Research grants	10/40	0/0	15/60
Awareness events	20/80	0/0	5/20
Educational resource to download	14/56	5/20	6/24
Guide for professionals	12/48	4/16	9/36
Helpline	13/52	2/8	10/40
Option to donate	23/92	0/0	2/8
Shop	7/28	0/0	18/72

Abbreviations: HNC, head and neck cancer; NPOs, non-profit organizations.

TABLE 4 | HNC NPOs presence on other media channels.

Media channel	Yes (*n*/%)	No (*n*/%)
Youtube	17/68	8/32
Twitter	20/80	5/20
Instagram	21/84	4/16
Facebook	23/92	2/8
Linkedin	16/64	9/36

Abbreviations: HNC, head and neck cancer; NPOs, non-profit organizations.

stand out for offering a more comprehensive set of resources. Notable examples include the American Head and Neck Society, the Head and Neck Cancer Alliance, the Head and Neck Cancer Australia, the Oral Cancer Foundation, and the Thyroid, Head and Neck Cancer (THANC) Foundation, all of which demonstrate strong performance across multiple areas, including general information, access to clinical trials, research funding, and support through community groups.

Over 80% of the identified NPOs offer comprehensive information on risk factors, prevention, screening, diagnosis, signs, and symptoms related to HNC. Many of these organizations also provide details on treatment modalities, therapy

side effects, and practical mouth care advice, using inclusive language to ensure patients fully benefit from the information. The most commonly used treatments for HNC are surgical treatment, radiotherapy, and chemotherapy (Machiels et al. 2020). However, these treatments can result in sequelae such as functional impairments, esthetic defects, and other potential side effects, all of which can directly impact a patient's quality of life (Adkins et al. 2024; Brook 2021). Therefore, education during oncology treatment becomes essential. A study on nurses implementing educational plans found that these sessions significantly reduced patient anxiety, strengthened patient–nurse relationships, and provided crucial information about procedures and their potential side effects (Portz and Johnston 2014).

NPOs extended their reach beyond website visitors through various awareness campaigns. 80% of NPOs regularly organize events like running/walking activities or awareness months, during which they supply materials for others to conduct their own cancer awareness campaigns. For example, the Oral Cancer Foundation promotes Oral Cancer Awareness Month in April with options such as scheduled screenings at dental offices, office events, and public events in collaboration with local pharmacies. While these screening strategies are vital, Continuous Education Activities (CEA), which were not prominently featured in this search, are essential for long-term impact. One notable example is the "Red May" initiative in southern Brazil, which has been running since 2011. This campaign's education events have shown that 88.9% of dentists who frequently detect oral lesions attend these CEA sessions (Braun et al. 2021). Such initiatives are highly valuable and could be effectively promoted by NPOs working with general practitioners (GPs) and dentists in primary care settings, similar to public health systems like the NHS in the UK.

Peer support groups can significantly aid patients by connecting them with others who share similar experiences. In this study, it was found that 44% of NPOs offered direct access to these groups, while 28% provided indirect access, making it one of the most common services available. A systematic review of 18 publications investigating the effectiveness of mutual support among cancer patients concluded that peer support groups significantly improve psychological well-being and resilience, while reducing depression, anxiety, and fear of disease recurrence (Kiemen et al. 2023). Another review examining various types of support groups found that they positively influence psychological adaptation to cancer diagnosis and treatment by reducing feelings of isolation, encouraging healthy habits, and promoting positive psychological states. They also help patients reconsider their circumstances and improve their coping strategies (Hoey et al. 2008).

HPV-associated HNC are on the rise, especially among young people in North America and northern Europe (Chow 2020). Peer support dedicated to these groups can be beneficial. Specific support groups for younger patients, such as Young Tongues (Home—YoungTongues), provide a space for shared experiences and unique challenges faced by this age group. These groups help alleviate isolation, provide tailored information and resources for young adults, and offer emotional support targeted at the specific psychosocial issues of this audience. For example, the Mouth Cancer Foundation selected YoungTongues as one of the winners of the Support Group Award in 2022, recognizing the group's work in supporting young patients with HNC. However, few of the NPOs websites mention this valuable resource. There is an opportunity for other NPOs to include this in their additional resources.

Legal advice was the least addressed topic among NPOs, with only 32% providing this type of information directly or indirectly, and only 12% mentioning Financial Assistance under the "others" tab of Table S2. Considering that this is an extremely specific and specialized aspect, not all NPOs need to provide it; however, patients can be directed to available resources. Triage Cancer (https://triagecancer.org/, accessed on July 15, 2024) is a national NPO that provides free education on legal and practical issues affecting individuals diagnosed with cancer and their caregivers. A recent study analyzed the development of the Triage Cancer Conference, conducting a comprehensive program evaluation to assess its reach and impact. Its services extend beyond cancer patients and survivors to include caregivers, healthcare professionals, employers, and legal experts (Ghazal et al. 2024). This multifaceted approach aims to mitigate financial difficulties associated with cancer diagnosis and treatment. This initiative would not only strengthen the support network for those affected by cancer but also broaden the reach of educational and support services offered. All these considerations can encourage an expansion in the communication network among the mentioned NPOs, whereby one may provide information that the other does not possess, and vice versa.

The association between non-profit organizations (NPOs) and professional societies or academies can offer mutual benefits. For NPOs, such collaboration may enhance their credibility, facilitate access to up-to-date clinical guidelines, and promote integration with the scientific community. For professional societies, partnering with NPOs represents an opportunity to broaden the reach of their initiatives, promote evidence-based health education, and strengthen engagement with patients and caregivers. However, the findings of this study revealed that few NPOs explicitly mention partnerships with such institutions. Notable exceptions include the Oral Cancer Foundation, which refers to the American Society of Clinical Oncology (ASCO), Association of Oncology Social Work (AOSW), National Comprehensive Cancer Network (NCCN), American Dental Association (ADA), American Head and Neck Society (AHNS), and International Association for the Study of Lung Cancer (IASLC); and Head and Neck Cancer Australia, which cites the Clinical Oncology Society of Australia (COSA), Royal Australian and New Zealand College of Radiologists (RANZCR), the United Kingdom's National Health Service (NHS), ASCO, and the National Tracheostomy Safety Project (NHS UK). A few other NPOs mentioned organizations that support research and the broader scientific community, although without clearly established institutional affiliations. These findings underscore the importance of encouraging structured partnerships between NPOs and professional societies as a means to foster stronger integration between science, clinical practice, and patient support.

Most of the NPOs ($n = 23/92\%$) of the analyzed NPOs offer a tab on their main website where consumers can make donations through various means. A systematic study evaluating

the effectiveness of patient-activists and allies in fundraising for Disease Advocacy Organizations found that groups directly affected by the disease, particularly those connected through friendship bonds, have higher fundraising potential. Additionally, the workplace environment proved more favorable for fundraising compared to private networks of friends, due to employees' commitment to their colleagues and employers, which can be converted into a pro-social asset (Walker et al. 2023). This finding is relevant for Awareness Months promoted by some NPOs, which enable companies to conduct their own awareness campaigns using materials supplied by the NPO. Fundraising opens opportunities for various initiatives, including research grants, which 40% of NPOs provide. The Adenoid Cystic Carcinoma Research Foundation (ACCRF) is an example of how targeted investment can transform research into rare cancers, with an average of eight research projects funded annually in recent years.

Beyond promoting grants, NPOs have something extremely valuable: the patients themselves. Patient and public involvement (PPI) is increasingly being incorporated into international government guidance to improve the relevance of research questions (Hoddinott et al. 2018). The research world is gradually changing, placing greater value on the voices of patients. Many funding agencies now seek this interaction to set research priorities, and NPOs can serve as a crucial link between researchers and patient groups, ensuring that patient needs and perspectives are incorporated into research strategies.

This study has some limitations worth mentioning. First, the analysis focused exclusively on English-language NPOs, which may have excluded relevant information available in other languages and resulted in an incomplete global overview. Second, new developments and additional NPOs may have emerged since the review was conducted, and these may not be reflected in the findings. Finally, NPOs that do not have a mention in the literature or any electronic address may not have been found.

5 | Conclusion

NPOs play a crucial role in supporting patients with HNC, primarily focusing on squamous cell carcinoma. Many of these organizations are founded by survivors or their families, which brings a personal and direct commitment to the cause. These NPOs are essential in educating, providing emotional support, advancing research, and strengthening the support network, especially given the scarcity of resources and the need for greater visibility for head and neck cancer. Finally, through online platforms and social media, they expand their reach, making support more accessible.

Author Contributions

Lucas Freitas Carnevali: methodology, investigation, data curation, formal analysis, writing – original draft. **Camila Barcellos Calderipe:** methodology, formal analysis, writing – review and editing. **Felipe Silveira Martins:** methodology, formal analysis, writing – review and editing. **Lauren Frenzel Schuch:** methodology, writing – review and editing, formal analysis. **Alan Roger Santos-Silva:** methodology, writing – review and editing, formal analysis. **Manoela Domingues Martins:** conceptualization, formal analysis, writing – review and editing. **Vivian Petersen Wagner:** conceptualization, methodology, formal analysis, supervision, writing – original draft.

Conflicts of Interest

The authors declare no conflicts of interest.

Data Availability Statement

The data that supports the findings of this study are available in the Supporting Information of this article.

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Supporting Information

Additional supporting information can be found online in the Supporting Information section.