



Summary report of patient experience data: Head & neck cancer

VICS September 2025

The Victorian Integrated
Cancer Services are
supported by the
Victorian Government



Acknowledgements

The Victorian Integrated Cancer Services (VICS) are Victoria's cancer services improvement network. They build relationships between healthcare providers and other cancer care stakeholders to develop, implement and evaluate initiatives that improve the way our member health services provide care and support people affected by cancer. The VICS Optimal Care Summits program is an initiative of the VICS and administered by the North Eastern Melbourne Integrated Cancer Service (NEMICS). The VICS are supported by the Victorian Government. For more information, see www.vics.org.au.

Recommended citation

Baje N, McGannon F, Macleod A, Rodi H, Graham F and Nolte L. VICS Optimal Care Summits Summary Report of Patient Experience Data: Head & Neck Cancer. 2025. NEMICS, Melbourne, Australia.

Disclaimer

© Victorian Integrated Cancer Services 2025

This material VICS Optimal Care Summits Summary Report of Patient Experience Data: Head & Neck Cancer 2025 has been prepared by NEMICS and the VICS Optimal Care Summits program to inform and guide activities related to cancer service improvement within Victoria. The material and data are intended for Victorian Integrated Cancer Services (VICS) member organisations and health professionals to promote cancer services quality improvement within their health organisations.

All VICS materials – including data products, protocols, methods, analyses, documentation, and tools – are protected by copyright and remain the intellectual property of the Victorian Integrated Cancer Services (VICS) and the State of Victoria (Department of Health).

The State of Victoria (Department of Health) owns the copyright to the data. No part of this material may be reproduced, redistributed (including published in a research paper) or modified without the written permission of NEMICS and the Victorian Department of Health. Requests for permission to reproduce this material or data should be made to nemicsadmin@austin.org.au.

Table of contents

Abbreviations	3
Executive summary	4
Background	5
Aims	6
Methodology	6
3.1 CPES Data	6
3.2 Focus Groups	7
Findings	8
4.1 CPES Data	8
4.2 Focus Groups	31
Key findings	36
Implications	37
Appendices	38
Appendix 1: Discussion points for the focus group	38
Appendix 2: Definitions of all identified themes from free text responses and the OCP principles they align to	41
References	43

Abbreviations

Acronym	Full Text
CCV	Cancer Council Victoria
CPES	Cancer Patient Experience Survey
ED	Emergency Department
GP	General Practitioner
NEMICS	North Eastern Melbourne Integrated Cancer Service
OCP	Optimal Care Pathway
VAHI	Victorian Agency for Health Information
VICS	Victorian Integrated Cancer Services

Executive summary

Background: Head and neck cancer consumers have complex care needs. It is important to understand the experiences and views of these consumers to help improve health equity and shape improvement priorities.

Aim: To identify the experience and perspectives of people with head and neck cancer and their carers who have received or are receiving care for their cancer in Victoria.

Methodology: The analysis combined two data sources. First, the 2023 Victorian Cancer Patient Experience Survey (CPES) captured responses from 127 people with head and neck cancer who received inpatient care in 2022. The CPES, developed by the Victorian Agency for Health Information in partnership with the Department of Health and Ipsos Public Affairs, provides insights into patient experiences across the cancer care pathway. Second, seven focus groups were held with 17 patients and carers between July and August 2025. Discussions were structured around the Head and Neck Cancer Optimal Care Pathway, from prevention and early detection through to survivorship and end-of-life care.

Findings: Survey results indicated that most participants felt they were treated with dignity and respect throughout their care journey, with satisfaction levels ranging from 84% to 99% across treatment phases. However, only 55% expressed confidence in their GP's ability to manage ongoing cancer care, reflecting the same rate as the statewide average. Support for family and carers was inconsistent, with fewer than half of respondents reporting that staff asked about the needs of friends and family. Communication and care coordination, especially relating to surgical care, were the most commonly identified areas for improvement.

Focus group discussions provided richer detail on these themes. Many participants reported limited awareness of head and neck cancer prior to diagnosis, with symptoms such as ulcers, sore throats, or lumps often overlooked, leading to delayed presentation. While some experienced timely referrals, others described repeated dismissals before receiving a diagnosis. Treatment was described as intensive and frequently multimodal, leaving most with long-term impacts on swallowing, speech, weight, and fatigue. Emotional distress was common, and travel for treatment often compounded the burden of care. Post-treatment follow-up was generally available but tended to focus on tumour surveillance, with less emphasis on rehabilitation, survivorship, or holistic support. Recurrence and end-of-life care were particularly challenging, with late referral to palliative services and limited psychosocial support for patients and their families.

Conclusion: Together, the survey and focus group findings underscore the need for clearer and more tailored information, stronger GP and community awareness, timely diagnosis, earlier access to allied health and psychosocial services, and better coordinated approaches to survivorship and end-of-life care. While specialist teams were praised for their expertise and compassion, systemic gaps in communication, coordination, and support persist.

Key priorities include increasing awareness of head and neck cancer to support earlier detection, timely diagnosis and access to multidisciplinary cancer care, improving the clarity and consistency of information provided to patients and carers, embedding supportive care including psychosocial care, rehabilitation, and survivorship services throughout the care pathway, strengthening GP involvement in follow-up, and expanding access financial support services and palliative care. Addressing these gaps through coordinated collaboration between clinicians, community stakeholders, and health services will be essential to achieving more equitable, person-centred, and holistic care for people with head and neck cancer and their families in Victoria.

Background

The Victorian Integrated Cancer Services (VICS) Optimal Care Summits program is an initiative of the VICS which involves the examination of tumour-specific cancer care, experience, and outcomes measures against the standards and targets set out in the Optimal Care Pathways. [1] The Victorian Cancer Plan 2024-2028 [2] defines the program as an enabler for reducing variations in clinical practice and cancer outcomes. It aims to identify data informed patterns of cancer care and outcomes, variations in care, agree priorities for reducing unwarranted variations, and deliver quality improvement initiatives to reduce prioritised variations. The program involves a mixed-methods strategic consultation approach including tumour-specific expert advisory groups, strategic consultations, statewide surveys, and relevant stakeholder engagement throughout Victoria, as well as priority initiatives that are resourced by the VICS and other cancer organisations. Across 2025, the program explored unwarranted variations in head and neck cancer (HNC).

In 2023, 1,221 Victorians were diagnosed with HNC and 319 died from the disease, [3] representing 2.3% of all cancer deaths in Victoria.[4] HNC was the seventh most commonly diagnosed cancer and the fifteenth leading cause of cancer death in Victoria. The majority of new cases occurred in men (72%, n=883) compared to women (28%, n=343). Incidence rates were 23 per 100,000 in men and 8 per 100,000 in women, with lifetime risk estimated at 1 in 51 for men and 1 in 160 for women before age 75.[3] Median age at diagnosis was 64 years for men and 67 years for women. Encouragingly, five-year relative survival improved from 73% (2013–2017) to 75% (2018–2022). [3] Despite improvements, an evidence-to-practice gap remains a persistent challenge especially in complex cancer care. [5] The Optimal Care Pathways (OCPs) provide a framework for evidence-based consistent, safe, high-quality care for people with cancer. [1] However, gaps exist across cancer services in implementing these pathways. Understanding consumer perspectives is essential for identifying unwarranted variations, as patient and carer experiences provide critical insights into access, quality, and equity of care. Consumer engagement is recognised internationally as a cornerstone of patient-centred cancer services, [6]. [7] and their voices are vital in shaping priorities, informing service delivery, and reducing disparities in outcomes.[8]

To support this, the Victorian Cancer Patient Experience Survey (CPES) was developed by the Victorian Agency for Health Information (VAHI), in partnership Department of Health and Ipsos Public Affairs. The CPES aims to understand the cancer journey and experiences of Victorians undergoing cancer treatment at Victorian public hospitals. The CPES was first piloted in 2013 and again in 2015. In 2023, the updated survey was sent out to randomly selected patients who received cancer care at a Victorian public hospital in 2022. Participants were asked to answer questions based on their 2022 experience of care. In addition, a series of focus groups were completed by the VICS Optimal Care Summits team with Victorians who had a lived experience of head and neck cancer. This report draws on both the 2023 CPES and the focus group findings, with the aim of informing the VICS Head and Neck cancer summit and guiding future quality improvement initiatives across Victoria.

Aims

To identify the experience and perspectives of people with head and neck cancer and their carers who have received or are receiving care for their cancer in Victoria.

Methodology

3.1 CPES Data

Recruitment and data collection

Victorian cancer patients were randomly selected from a stratified list of cancer consumers prepared by individual campuses and invited to complete the survey via email, SMS, or letter. Data collection occurred between 13th March and 19th May 2023. The overall response rate for the survey was 32%, indicating that caution is needed in the interpretation of these results. Raw data for the head and neck cancer cohort was provided by VAHI, which included any survey participants who answered the question 'What cancer were you diagnosed with?' with 'throat/mouth' cancer or 'other', specifying other head and neck cancer related terms, e.g. 'nose', 'tongue', 'lip', 'thyroid', 'sinus', 'nasopharynx', 'neck', 'salivary gland'. These data were then aggregated to reflect the percentages across multiple choice responses.

Positive response coding

Raw survey data were organised and re-coded to highlight positive responses within the data. The most desirable responses (e.g., 'Yes definitely') were included in positive response coding. Neutral answers (e.g., 'Not sure/cannot remember') were excluded from the denominator when calculating this value. Percentages included in this report have been determined through positive response coding.

Statistical comparisons

No significant differences could be calculated between the head and neck cancer cohort and the total statewide cohort, as raw statewide data was unavailable. Percentage differences are noted in this report. However, any identified differences may not be statistically significant. It should be noted that the head and neck cancer cohort is included within the state cohort when directly comparing the two cohorts. Not all participants provided a response to every survey question, and thus there is a varied response rate throughout the survey. Percentages within this report have been calculated using only the number of participants who answered a given question.

Free-text data

Free-text responses were collected for 17 survey items. Verbatim responses for each item were collated in an Excel file and common themes were identified using an inductive thematic analysis approach. As each response was open-ended, no restrictions were placed on how many themes could be used to code each response. Coded responses were then organised according to the seven principles outlined in the Head and Neck Optimal Care Pathway (2nd Edition). Responses that did not provide descriptions related to the experience of cancer care (e.g., when participants responded to the free-text survey item with statements like 'nothing', etc.) were coded as N/A and excluded from further analysis. Coded results were examined for themes that could provide further context to aspects of cancer care described by participants in their responses. Where relevant, steps outlined in the Head and Neck Optimal Care Pathway were noted for additional context.

3.2 Focus Groups

Recruitment

Recruitment for the focus groups was carried out through several head and neck cancer related organisations and advocacy groups. The VICS Optimal Care Summits team advertised an invitation to participate via their newsletters. Eligible individuals (adults living in Victoria with experience of treatment for head and neck cancer and their carers), volunteered to participate and completed a Qualtrics survey and provided their consent. None of the participants were known to the VICS Optimal Care Summits team prior to study recruitment. This study is ethically approved, VicTRI-19783.

Question development

The focus group questions (Appendix 1) were developed following a review of the relevant literature on consumer and cancer-related surveys. Key questions were identified and systematically mapped against the steps outlined in the OCPs, ensuring that each of the seven steps from prevention and early detection to end-of-life care were covered. To ensure the rigor and validity, the questions were subsequently peer-reviewed and refined through consultations with the 18 expert advisory group members and 3 consumer representatives from the North Eastern Metropolitan Integrated Cancer Service (NEMICS).

Data collection

Seven focus groups were held between June and August 2025 using Microsoft video conferencing software, Microsoft Teams. Each focus group lasted approximately 1.5 hours and was facilitated by two members of the VICS Optimal Care Summits team. The discussion covered the topic areas listed above. In circumstances where access to Microsoft Teams was identified as a barrier, the participant was contacted by a VICS Optimal Care Summits team member via the phone and the same questions were asked.

Each participant was contacted prior to the individual or group discussions and given a participant information sheet which included the list of questions including prompts to explore particular issues further (Appendix 1).

Video recordings of the focus groups from Microsoft Teams and individual phone call were transcribed by a VICS Optimal Care Summits team member; all identifying information was removed during transcription. Transcripts from video recordings were checked against the original audio recordings for accuracy. A draft of the transcript specific to each participant was anonymised and forwarded to them for comment.

Analysis

The transcripts were then analysed using via latent and semantic coding and then thematically analysed whereby patterns of meaning were generated from the data. Quantitative data from the discussions was extracted by a VICS Optimal Summits team member and analysed descriptively using Excel.

Findings

4.1 CPES Data

General findings

Age, gender, Aboriginal status, and interpreter status

A total of 127 people who participated in the Victorian CPES were diagnosed with a head and neck cancer in 2022. One participant identified as Aboriginal. Majority (72%) of participants identified as male, and 28% identified as female. Over half (54%) of participants were aged 50-69 years, 39% were aged 70+ years, and 7% were aged 16-49 years. Most participants (97%) mainly spoke English at home, one (1%) participant spoke Mandarin, one (1%) spoke Vietnamese, and two (2%) spoke a language not listed in the survey ('Other'). The majority of participants (96%) indicated that they did not need an interpreter at any point during their cancer care, one (1%) participant indicated that an interpreter was available at all/most of their appointments, one (1%) indicated that an interpreter was available at some of their appointments, and one (1%) indicated that an interpreter was never available during their appointments.

Quantitative data

Finding out what was wrong

Over half (53%) of participants with head and neck cancer waited less than two weeks from when they were referred by their GP to when they were seen by a specialist/clinic, compared to 45% across all cancers in the state. Of these, 75% felt their doctor explained their cancer diagnosis in a way they could understand, which is the same as the statewide average (75%), and 72% were satisfied with the format in which their diagnosis was explained, compared to 73% across the state. Additionally, 71% said they were given information about treatment options, which is similar to the statewide average (74%).

Almost all participants (92%) felt that they were encouraged to ask questions regarding their diagnosis with their doctor, and 91% said that staff repeated treatment options following their diagnosis. Similarly, 88% of participants felt that they were treated with respect and dignity during diagnosis.

Questions related to being told how to access more information and being told who to contact for support yielded positive responses from only 43-52% of the head and neck cancer cohort, and only 49% of the head and neck cancer cohort said health professionals asked if family/friends need information or support during the diagnosis period. These survey items aligned with the statewide averages.

Deciding on treatment

Over three-quarters (76%) of participants were happy with the level of involvement they had in treatment decision making. Similarly, 75% of participants were explained the short-term side-effects of treatment before deciding on treatment, which is similar to the statewide average (79%). Only 55% were explained the long-term side-effects, which is below the statewide average (67%). Majority (82%) of participants were referred to services before commencement of treatment to address potential issues arising from treatment (e.g., reduced fertility, incontinence), and 88% were given information about what would be involved with receiving treatment. Only 57% of participants said that staff discussed the possibility of taking part in cancer research (clinical trials), which is below the statewide average (70%).

Surgery

Over half of participants (57%) underwent surgery as part of their treatment. Of these, 45% waited less than two weeks between being told they were ready for surgery and undergoing surgery, compared with 35% statewide.

Most participants reported experiences broadly consistent with statewide averages. Seventy-seven percent felt they received enough information about what to expect after surgery (vs 82% statewide). Similarly, 76% and 79% reported being given adequate information on managing surgical side effects and on what would happen after surgery, respectively, which were close to statewide figures. More than half (63%) felt staff explained things in a way they could always understand (vs 60% statewide).

High levels of satisfaction were reported with aspects of surgical care delivery: 82–84% of participants said staff managed side effects well, did everything possible to manage pain, and arranged appropriate follow-up care, which were all in line with statewide results. In addition, 65% said they were always able to receive help from staff within a reasonable timeframe during admission (vs 61% statewide), and 63% felt adequate arrangements were made for services needed after leaving hospital.

However, areas for improvement were noted. Only 39% of participants were given hospital contact details for follow-up concerns or questions, and just 42% reported being asked if family or friends needed information or support during the surgical process. These results, although consistent with statewide averages (43% and 46%, respectively), highlight important gaps in surgical related communication and carer engagement.

Several survey items indicated that people with head and neck cancer rated their surgical care lower than the statewide average. Among those who underwent surgery, only 40% reported being fully informed about costs, compared with 55% across Victoria. Similarly, just 33% of participants who experienced worries or fears about their condition or treatment felt these concerns were discussed with staff, below the statewide average of 50%. At discharge, 68% felt they received enough information to manage at home, which again was lower than the statewide figure of 78%.

Majority (84%) of participants felt they were treated with respect and dignity during surgical admission, and 97% rated care from surgical teams as either 'good' or 'very good'.

Radiotherapy

The majority of participants (83%) received radiotherapy as part of their treatment. Of these, 55% began treatment within two weeks of radiotherapy mapping.

Most participants (76–95%) reported receiving information before treatment on how to prepare, manage stress and anxiety, manage side effects, what to expect at the end of treatment, and recovery time. These results were comparable to statewide averages. Similarly, 83% felt staff checked their understanding of information, and 82% felt personal circumstances were considered when arranging appointments (vs 81% and 77% statewide).

During treatment, 89–95% reported that staff checked for side effects and provided help in managing them, consistent with statewide averages. Almost all participants (94%) received a phone number to call with questions, and 75–84% said staff asked about support needs for emotional wellbeing and transport to appointments. Nearly all participants (98%) said staff checked if they needed help with diet, eating, or physical movements—a result higher than the statewide average (87%).

However, only 38% reported being told about out-of-pocket costs prior to treatment, significantly lower than the statewide average (66%). Similarly, just 40% felt staff asked whether family or friends needed information or support, below the statewide figure of 50%. Despite these gaps, almost all

participants (99%) said they were treated with dignity and respect, and the vast majority rated their radiotherapy care as “good” or “very good.”

Chemotherapy

Two-thirds of participants (67%) received chemotherapy. Of these, 59% commenced treatment within two weeks of being deemed ready, compared with 55% statewide. Only 43% reported being informed about out-of-pocket costs, consistent with the statewide average (45%).

Most participants (93%) waited less than 30 minutes at appointments, higher than the statewide average (83%). Information provision was generally strong: 82% were given advice on managing stress or anxiety, and 81% felt their personal circumstances were taken into account when scheduling, both higher than statewide figures (71% and 69%). Between 86–93% reported receiving information on preparing for treatment, managing side effects, emergency department access, and contacting the Symptom and Urgent Review Clinic, aligning with statewide averages. Additionally, 85% said staff checked their understanding of chemotherapy information (vs 80% statewide).

During treatment, 95% said staff checked for side effects, and 88% felt these were managed well, consistent with statewide averages. Similarly, 96% were asked if they needed help with diet or physical activity, 85% with emotional wellbeing, and 73% with transport needs. Almost all participants (99%) were provided with a phone number for questions, and 94% received an emergency card explaining their treatment, both in line with statewide averages.

Engagement with carers remained limited: only 49% reported that staff asked if family or friends needed information or support, though this was consistent with statewide figures. Overall, 99% said they were treated with respect and dignity, and 97% rated their chemotherapy care as “good” or “very good.”

Emergency Department experience

Over half (59%) of participants who attended ED during cancer treatment waited more than 30 minutes to be seen. About two-thirds (66%) of participants felt their condition was well managed in the ED, and 64% felt that ED staff had knowledge and skills to look after, both slightly lower than statewide averages (75% and 73%, respectively).

Follow up care

Follow-up care experiences were broadly similar to statewide patterns. Notably, 71% felt that appointments and tests were coordinated to minimise travel, which was higher than the statewide average (60%).

Over half (63%) were given a written follow-up plan, while 69% felt personal circumstances were considered when arranging appointments, and 70% said test results were always available to their GP. Only 55% felt confident in their GP’s ability to manage ongoing cancer care, comparable to statewide results.

At treatment completion, most participants received information about follow-up tests (83%), ways to stay healthy (79%), ongoing symptoms/side effects (72%), and check-up frequency (79%). However, fewer were given information on warning symptoms (65%), typical post-treatment experiences (64%), or available support services for themselves and their families (65%).

Information received

Across treatment, 69–84% of participants said they received information on impacts on daily activities, energy levels, and fertility, consistent with statewide averages. Only 59% recalled discussions about financial support programs, though this was higher than the statewide result (47%).

The majority (86%) felt able to ask health professionals questions, similar to statewide figures. Just under half (49%) said they could discuss complementary or alternative therapies, in line with statewide results (42%).

Compared with statewide averages, head and neck participants more frequently reported being offered supportive care services: psychologists (88% vs 73%), dietitians (95% vs 82%), speech therapists (96% vs 77%), pain specialists (74% vs 64%), financial services (67% vs 42%), and palliative care (100% vs 77%).

Participants also reported being asked about a range of practical and personal support needs. While responses around domestic chores (79%), family problems (74%), and support groups (70%) aligned with statewide averages, higher proportions said they were asked about childcare (86% vs 67% statewide) and finances (65% vs 45%).

Overall care

Most participants (97%) rated their overall care as “good” or “very good,” and 95% rated staff teamwork as “excellent” or “very good.” Nonetheless, 15% reported experiencing dissatisfaction to the extent that they wanted to or did lodge a complaint.

Experiences of continuity and communication were generally positive and aligned with statewide averages: 84% never received conflicting information, 88% felt all providers were informed of their treatment and progress, and over 90% said tests were not unnecessarily repeated or unavailable at appointments. Almost all participants (99%) said they never experienced discrimination based on cultural or ethnic background.

Coordination of care was also consistent with statewide results. The majority (88%) had a health professional they could contact with questions, and 87% felt treatment centres were informed about care they had received elsewhere. Two-thirds (68%) believed their GP was kept updated, and 65% were given the name of a Clinical Nurse Specialist (CNS). Most said their CNS was easy to contact (68%), listened carefully (91%), and communicated in a way they could understand (93%).

Your health today

At the time of the survey, 45% of participants rated their health at 81/100 or above, higher than the statewide result (40%). Between 43% and 97% did not report difficulties across core daily functioning areas. Most participants reported no issues with self-care (97%) and mobility (84%), the latter notably higher than the statewide cohort (68%). Rates of pain or discomfort (43%), anxiety/depression (62%), and limitations in usual activities (66%) were consistent with statewide averages.

Qualitative data

Qualitative data from the open-ended survey questions were present for between 17 and 97 participants, depending on the item. Each free-text response survey item captured between 4 and 6 principles from the OCP. Brief descriptions of OCP principles are described below, before results are presented by aspect of care as per the CPES. For detailed descriptions of each principle, please refer to the Optimal care pathway for people with head and neck cancer (2nd edition).

OCP Principles

Principle 1: Patient-centred care

Patient-centred care informs and involves patients in their care and respects and responds to the preferences, needs and values of patients, families and carers.

Principle 2: Safe and quality care

Hospitals and health professionals are responsible for providing safe and quality care.

Principle 3: Multidisciplinary care

Multidisciplinary care is an integrated team approach that involves all relevant health professionals discussing all relevant treatment options and making joint recommendations about treatment and supportive care plans, taking into account the personal preferences of patients.

Principle 4: Supportive care

Supportive care is a vital part of any cancer treatment program. Supportive care deals with issues that emerge for patients, families and carers from the effects of the cancer diagnosis and its treatment. It is made up of all the services, information and resources patients may need to meet their physical, psychological, social, information and spiritual needs from the time of diagnosis.

Principle 5: Care coordination

Care coordination is the responsibility of every professional, both clinical and non-clinical, who works with patients, their families and carers.

Principle 6: Communication

Everyone employed in the healthcare system is responsible for ensuring the communication needs of patients, their families and carers are met.

Principle 7: Research and clinical trials

Research and clinical trials play an important role in establishing the efficacy and safety of diagnostic, prognostic and therapeutic interventions, as well as establishing the role of psychological, supportive care and palliative care interventions (Sjoquist & Zalberg 2013).

Other

Some responses referred to aspects of care that were not directly related to the OCP principles. Additional context related to the themes captured in this group are provided as relevant in the results.

Aspects of care

Free-text responses from fourteen items on the CPES were used to understand what patients perceived to be helpful or an area for improvement. Each section of the survey aligned with the seven OCP steps focusing on the various aspects of optimal care. Four additional free-text questions were also analysed to better understand any specific instances in which participants may have received particularly good or bad care.

Text responses that could not be coded due to a lack of clarity, or where respondents noted 'N/A' were excluded from the thematic analysis (n=41). However, any responses stating 'no further comments', 'unsure' or similar were not excluded from the analysis, as these statements still provide valuable insight into patient perspectives. Where any single response could be coded with more than one theme, each individual idea was separately coded. As such, the number of themes identified in free text responses may be equal to or greater than the number of responses for the corresponding survey item. Results from the analysis are presented in line with the seven OCP steps and survey question order.

Diagnosis

Between 80 and 97 respondents with head and neck cancer answered survey items related to diagnosis. Six of the seven OCP principles were identified in responses for questions related to diagnosis (Table 1). Respondents indicated that the most helpful things staff did during their diagnosis related primarily to the ways that information was shared with them (6: Communication) and the way that staff interacted with them (1: Patient-centred care), with 79% of statements describing helpful things staff did during diagnosis aligning with these two principles.

The way staff communicated and shared information when delivering information about the diagnosis and treatment options were noted as being particularly helpful during diagnosis by 41% of respondents. For example:

'Made sure that I understood all aspects of the diagnosis and treatment.'

Of similar importance was the delivery of compassionate care and respect by staff. This included the care, empathy and professionalism of staff when guiding patients through their diagnosis and treatment options. For example:

'Provide empathy and understanding, positive messages and constant reassurance.'

In some responses, the interconnectedness of person-centred care and communication were clearly noted:

'Explained my cancer and treatment options. Were highly respectful and caring at all times. Gave opportunities for questions.'

Table 1: Principles discussed in free-text questions related to diagnosis

Q11. What were the most helpful things staff did during your diagnosis? (n= 97 responses)			
OCP Principle	Experience	Themes	Count
1: Patient-centred care (n=47, 37%)	Positive	Compassionate care and respect	39
		Family/friend involvement	4
		Patient involvement	1
		Professionalism	3
2: Safe and quality care (n=6, 5%)	Mixed	Care quality	1
	Positive	Care quality	3
		Medication management	1
		Outcomes	1
3: Multidisciplinary care (n=4, 3%)	Negative	Clinical information sharing	2
	Positive	GP experiences	1
		Multidisciplinary care	1
4: Supportive care (n=1, 1%)	Positive	Supportive care access/referrals	1
5: Care coordination (n=10, 8%)	Positive	Follow-up care	3
		Timeliness	7
6: Communication (n=52, 41%)	Positive	Communication and information sharing	52
Other	Positive	Access to resources	3

(n=3, 2%)			
N/A	Positive	Thanks/satisfaction	2
(n=3, 2%)	Neutral	No further comments	1
Total themes identified			128
Q12. What could be done to improve the diagnosis experience? (n= 80 responses)			
OCP Principle	Experience	Themes	Count
1: Patient-centred care (n=6, 7%)	Positive	Compassionate care and respect	4
		Family/friend involvement	1
		Professionalism	1
2: Safe and quality care (n=4, 5%)	Mixed	Care quality	2
	Negative	Care quality	1
		Hospital environment	1
3: Multidisciplinary care (n=3, 3%)	Negative	Clinical information sharing	1
		GP experiences	1
		Multidisciplinary care	1
4: Supportive care (n=2, 2%)	Negative	Supportive care access/referrals	2
5: Care coordination (n=7, 8%)	Negative	Care closer to home	1
		Care coordination	2
		Follow-up care	1
		Timeliness	3
6: Communication (n=22, 25%)	Negative	Communication and information sharing	19
	Positive	Communication and information sharing	3
Other (n=2, 2%)		Public health recommendations	2
N/A (n=41, 47%)	Positive	Thanks/satisfaction	2
	Neutral	No further comments	38
		Unsure	1
Total themes identified			87

Table values adjusted to nearest whole number where needed and may not equal 100%

Most respondents did not have suggestions for what could be done to improve the diagnosis experience (n=38). Where suggestions were made, these focused on aspects of communication and information sharing that respondents felt were lacking. Suggestions for improving communication and information sharing during diagnosis described a desire for additional information about potential short and long-term side effects, more contact with specialists, and making sure the advice and information provided was understood. For example:

'More explanation on specific side-effects likely to be experienced during treatment.'

'Multidisciplinary communication in terms of what my care need were/will be and transparent in informing me to my understanding.'

Two respondents specifically highlighted how challenging they found the lack of communication in the period between diagnosis and referral to a specialist:

'For me, it was the huge 'hole' between diagnosis and referral to a specialist. In total about 4 weeks for me. That was a challenging period to navigate in a vacuum.'

When I was told I had a cancer, I couldn't [hear] what was said after that. It was [quite] overwhelming. I was at outpatient clinic but was unable to get another appointment to ask more questions. I was told I will be contacted from <hospital> within a week. That was the longest week. Having someone to ask questions about my diagnosis would have lessened my worries.

Two respondents described receiving little to no communication about their diagnosis prior to treatment:

'It was not until I got to <hospital> that I was given treatment options.'

'It wasn't until I was referred to hospital that the full extent of my cancer was explained fully.'

One respondent also described feeling as if their needs were being dismissed by staff:

The support person at <hospital> was more focussed on her agenda than my needs.

Treatment decision-making

Between 69 and 88 respondents with head and neck cancer answered survey items related to treatment decision-making. Six OCP principles were found in free text describing aspects of treatment decision-making that participants found most helpful (Table 2). Participants most frequently referred to Principle 6: Communication, with clear explanations, information sharing, and responding to questions considered most helpful to treatment decision-making.

'Clear and precise explanations showed me through the treatment rooms explained the purpose of the machines.'

A smaller proportion of respondents also described engaging with staff who were helpful and who had a positive or professional attitude as helpful during treatment decision-making (Principle 1: Patient-centred care).

'The most helpful [thing was] staff gave me reassurance that the type of cancer was curable.'

Less frequently referenced OCP principles included 2: Safe and quality care, 3: Multidisciplinary care, 4: Supportive care, and 5: Care coordination (Table 2).

Table 2: Principles discussed in free-text questions related to treatment decision-making

Q23. What were the most helpful things staff did in relation to treatment decisions? (n=88 responses)			
OCP Principle	Experience	Themes	Count
1: Patient-centred care (n=33, 28%)	Negative	Patient involvement	2
	Positive	Compassionate care and respect	20
		Family/friend involvement	3

		Patient involvement	6
		Professionalism	2
2: Safe and quality care (n=16, 14%)	Mixed	Care quality	2
	Negative	Care quality	1
	Positive	Care quality	8
		Clinical skills/knowledge	1
		Medication management	1
		Outcomes	1
		Pain management	2
3: Multidisciplinary care (n=3, 3%)	Negative	Multidisciplinary care	1
	Positive	Clinical information sharing	2
4: Supportive care (n=2, 2%)	Positive	Supportive care access/referrals	2
5: Care coordination (n=8, 7%)	Negative	Timeliness	1
	Positive	Care coordination	2
		Timeliness	5
6: Communication (n=50, 43%)	Positive	Communication and information sharing	50
N/A (n=4, 3%)	Positive	Thanks/satisfaction	2
	Neutral	No further comments	1
		Unsure	1
Total themes identified			116

Q24. What could be done to improve your experience in relation to treatment decisions? (n=69 responses)

OCP Principle	Experience	Themes	Count
1: Patient-centred care (n=4, 5%)	Negative	Compassionate care and respect	2
		Professionalism	1
	Positive	Compassionate care and respect	1
2: Safe and quality care (n=4, 5%)	Negative	Care quality	1
		Clinical skills/knowledge	1
		Hospital environment	1
	Positive	Care quality	1
3: Multidisciplinary care (n=1, 1%)	Negative	Multidisciplinary care	1
4: Supportive care (n=1, 1%)	Negative	Supportive care access/referrals	1
5: Care coordination	Negative	Care closer to home	1

(n=2, 3%)		Timeliness	1
6: Communication (n=18, 24%)	Negative	Communication and information sharing	16
	Positive	Communication and information sharing	1
	Neutral	Communication and information sharing	1
N/A (n=45, 60%)	Positive	Thanks/satisfaction	6
	Neutral	No further comments	39
Total themes identified			75

Table values adjusted to nearest whole number where needed and may not equal 100%

Most respondents did not have suggestions for what could be done to improve the treatment decision-making experience (n=39). Where suggestions were made, most comments described areas for improvement related to communication and information sharing (Principle 6: Communication). Specifically, respondents wanted greater detail on what to expect from the treatments, including more information on possible side effects of treatment, including potential long-term side effects. For example:

'More explanation re options. More discussion about side effects.'

I'm not sure, I opted for two surgeries to try [and] avoid chemotherapy and radiation, but in the end had to have the chemo and radiation regardless. Maybe it could have been explained to me more clearly, that the chemo and radiation was non-negotiable.

'Told more about caring for my voice/vocal chords [sp.] after surgery.'

Suggestions for improvement that reflected other OCP principles were less frequent, but still highlighted mixed perceptions of the compassion and respect provided by specialists, consultants and registrars:

'Not a lot my oncologist was incredibly helpful & empathetic.'

'The multidisciplinary team meeting that I attended (where various members of the team see you within a period of about an hour or so - Surgeons, Radio-oncologists, Dieticians etc) was horrific.'

The surgical consultants and their registrars were horrible - speaking as if you were simply a case study and not even in the room. This needs to change! (note that some clinicians were fantastic, it's just that overall the process is flawed)

Surgery

Between 43 and 50 respondents with head and neck cancer answered survey items related to surgery. Themes related to five of the OCP Principles were highlighted as helpful during a hospital stay for surgery (Principles 1, 2, 3, 5, and 6, see Table 3). Respondents highlighted the importance of compassionate care and respect, high quality care by staff, and communication and information sharing during their surgical stay (Principles 1: Patient-centred care, 2: Safe and quality care, and 6: Communication). For example:

'Caring, kind, checking in on me, explaining how I would feel & to say if I needed any extra pain medication.'

Always professional, introducing themselves, what their position was what they would be doing, caring and attentive. Checking all the time how I was, keeping me informed [about] what they were doing and informing me of what may happen. Assurances, assurances, assurances. Can't speak highly enough of <hospital>

Less frequent comments described patient experiences with follow up care from health professionals (Principle 5: Care coordination) but were usually provided in context with other positive experiences related to care quality. For example:

'Excellent care. Pain management. Immediate response to any concerns. Staff available as soon as I needed them.'

Table 3: Principles discussed in free-text questions related to surgery

Q50. What were the most helpful things staff did while you were in hospital for surgery? (n=50 responses)			
OCP Principle	Experience	Themes	Count
1: Patient-centred care (n=25, 35%)	Positive	Compassionate care and respect	21
		Family/friend involvement	1
		Professionalism	3
2: Safe and quality care (n=27, 36%)	Mixed	Care quality	1
	Positive	Care quality	16
		Clinical skills/knowledge	3
		Hospital environment	1
		Outcomes	1
Pain management	5		
3: Multidisciplinary care (n=1, 1%)	Positive	Clinical information sharing	1
5: Care coordination (n=5, 7%)	Positive	Care coordination	1
		Follow-up care	2
		Timeliness	2
6: Communication (n=13, 18%)	Positive	Communication and information sharing	13
Other (n=1, 1%)	Negative	Food access	1
N/A (n=1, 1%)	Neutral	No further comments	1
Total themes identified			72

Q51. What could be done to improve your surgery experience? (n=43 responses)			
OCP Principle	Experience	Themes	Count
1: Patient-centred care (n=5, 9%)	Negative	Compassionate care and respect	3
	Positive	Compassionate care and respect	1
		Professionalism	1
2: Safe and quality care (n=17, 31%)	Mixed	Care quality	1
	Negative	Care quality	2
		Clinical skills/knowledge	2
		Early discharge	1
		Hospital environment	3
		Medication management	2
		Outcomes	1
		Pain management	1
	Positive	Care quality	3
Pain management		1	
3: Multidisciplinary care (n=1, 2%)	Negative	Clinical information sharing	1
5: Care coordination (n=4, 7%)	Negative	Follow-up care	1
		Telehealth	1
		Timeliness	2
6: Communication (n=4, 7%)	Negative	Communication and information sharing	3
	Positive	Communication and information sharing	1
Other (n=1, 2%)	Negative	Food access	1
N/A (n=22, 41%)	Neutral	No further comments	21
		Unsure	1
Total themes identified			54

Table values adjusted to nearest whole number where needed and may not equal 100%

Over a third of all responses to the survey item asking for suggestions for improvements to the surgery experience indicated no further comments (Table 3). Aspects of surgical care that participants indicated could be improved aligned predominantly with Principle 2: Safe and quality care. Aspects of safe and quality care noted by respondents included negative experiences of the hospital environment and comments about the quality of care received. For example:

'Nursing staff were often ordinary in their care and skills, probably due to limited experience. Too many nurses were not informed, or did not read the bedside observations, about my condition'

I was discharged 2 days too early as a country patient. I developed a post op infection the next day after discharge & endured a stressful wait for

treatment due to local treatment waiting times. I waited 6 hours in a cold waiting room 43 minutes [down] from home.

Only negative was one patient in next bed towards end of my stay whose family visits were a major issue - too many at a time & at inappropriate times - basically made me spend long hours out of my room.

Mixed experiences related the compassion and respect provided by different health professionals (principle 1: Patient-centred care) were also noted:

'Surgeon could have been more considered in their response to my fears - I had been told my cancer, in the long term, was terminal. Nurse did step in to counter the attitude of the surgeon.'

'Someone needs to follow up and check on the night staff. There is not generally the same commitment to care, and in one case serious neglect.'

Radiotherapy

Between 64 and 78 respondents with head and neck cancer answered survey items related to radiotherapy (Table 4). Aspects of radiotherapy considered most helpful by respondents focused predominantly on themes related to compassionate care and respect (Principle 1: Patient-centred care). Other themes that appeared in free text responses related to professionalism, care quality, and communication and information sharing (Principles 1: Patient-centred care, 2: Safe and quality care, and 6: Communication, respectively).

Themes related to compassionate care and respect focused on staff helping patients feel comfortable and supported, and the degree of respect shown to respondents.

'All <hospital> staff (clinical and support) were incredibly empathetic, friendly and considerate. This helped me to stay positive throughout what was a challenging few months.'

'They were always sympathetic and treated me with respect.'

Participants also discussed themes related to the quality of care received and communication and information sharing. The ability for staff to provide quality patient-centred care to patients was apparent in several responses:

'Their professionalism and attention to my treatment regime was outstanding.'

'Always respectful and helpful. Explained treatment progress and made the experience as stressless as possible.'

Table 4: Principles discussed in free-text questions related to radiotherapy

Q74. What were the most helpful things staff did during your radiotherapy? (n=78 responses)			
OCP Principle	Experience	Themes	Count
1: Patient-centred care (n=56, 50%)	Positive	Compassionate care and respect	42
		Family/friend involvement	1
		Professionalism	13
2: Safe and quality care (n=22, 20%)	Negative	Outcomes	1
	Positive	Care quality	12
		Clinical skills/knowledge	2
		Outcomes	1

		Pain management	2
		Side effect management	4
3: Multidisciplinary care (n=3, 3%)	Positive	Clinical information sharing	2
		Multidisciplinary care	1
4: Supportive care (n=1, 1%)		Supportive care access/referrals	1
5: Care coordination (n=9, 8%)	Positive	Care coordination	4
		Timeliness	5
6: Communication (n=13, 12%)	Positive	Communication and information sharing	13
Other (n=4, 4%)	Positive	Access to resources	3
		Food access	1
N/A (n=3, 3%)	Positive	Thanks/satisfaction	1
	Neutral	No further comments	1
		Unsure	1
Total themes identified			111

Q75. What could be done to improve your radiotherapy experience? (n=64 responses)

OCP Principle	Experience	Themes	Count
1: Patient-centred care (n=4, 6%)	Negative	Compassionate care and respect	1
		Patient involvement	2
	Positive	Professionalism	1
2: Safe and quality care (n=3, 4%)	Negative	Side effect management	2
	Positive	Care quality	1
4: Supportive care (n=3, 4%)	Negative	Supportive care access/referrals	3
5: Care coordination (n=4, 6%)	Negative	Timeliness	4
6: Communication (n=4, 6%)	Negative	Communication and information sharing	4
Other (n=3, 4%)	Negative	Access to resources	1
		COVID-19	1
	Positive	Access to resources	1
N/A (n=47, 69%)	Positive	Thanks/satisfaction	2
	Neutral	No further comments	44
		Unsure	1
Total themes identified			71

Table values adjusted to nearest whole number where needed and may not equal 100%

Very few comments were provided that identified areas for improvement to the radiotherapy experience, with most responses specifying no further comments. Where provided, recommendations centred on improving access and/or experiences related to supportive care (Principle 4: Supportive care), reducing wait times (Principle 5: Care coordination), and recommendations for improving communication with patients (Principle 6: Communication).

Chemotherapy

Between 46 and 60 respondents with head and neck cancer answered survey items related to chemotherapy. Responses describing what participants found most helpful during chemotherapy aligned primarily with Principle 1: Patient-centred care, Principle 2: Safe and quality care, and Principle 6: Communication (Table 5). Across all aspects of chemotherapy, responses focused almost exclusively on interpersonal experiences with staff. Specifically, comments related primarily to positive experiences with compassionate care and respect, quality care from health professionals, and effective communication and information sharing. For example:

'Making me feel comfortable, informed of the procedure and post procedural support regularly.'

'Reviews before each treatment, asking and checking in on my progress. Kindness & offering many solutions to any issues that arose with eating and swallowing etc.'

One respondent also described how helpful it was to them for staff to ensure appropriate food access during treatment:

'Provided food (soup) I could consume, otherwise apart from assistance by the [few] experienced staff there was little help other than routine tests.'

Table 5: Principles discussed in free-text questions related to chemotherapy

Q99. What were the most helpful things staff did during your chemotherapy? (n=60 responses)			
OCP Principle	Experience	Themes	Count
1: Patient-centred care (n=36, 42%)	Positive	Compassionate care and respect	28
		Family/friend involvement	1
		Professionalism	7
2: Safe and quality care (n=25, 29%)	Positive	Care quality	13
		Clinical skills/knowledge	1
		Medication management	3
		Outcomes	1
		Pain management	1
		Side effect management	6
3: Multidisciplinary care (n=1, 1%)	Positive	Multidisciplinary care	1
4: Supportive care (n=1, 1%)	Positive	Supportive care access/referrals	1
5: Care coordination (n=2, 2%)	Positive	Care closer to home	1
		Care coordination	1
6: Communication (n=12, 14%)	Positive	Communication and information sharing	12
Other	Positive	Access to resources	1

(n=4, 5%)		Food access	3
N/A	Positive	Thanks/satisfaction	1
(n=4, 5%)	Neutral	No further comments	3
Total themes identified			86
Q100. What could be done to improve your chemotherapy experience? (n=46 responses)			
OCP Principle	Experience	Themes	Count
1: Patient-centred care (n=1, 2%)	Negative	Alternative treatment access	1
2: Safe and quality care (n=5, 11%)	Negative	Clinical skills/knowledge	2
		Hospital environment	1
		Outcomes	1
		Side effect management	1
4: Supportive care (n=2, 4%)	Negative	Supportive care access/referrals	2
5: Care coordination (n=2, 4%)	Negative	Care closer to home	1
		Timelines	1
6: Communication (n=1, 2%)	Negative	Communication and information sharing	1
N/A (n=36, 77%)	Neutral	No further comments	34
		Unsure	2
Total themes identified			48

Table values adjusted to nearest whole number where needed and may not equal 100%

Significantly fewer responses provided suggestions for how chemotherapy care could be improved, with approximately two thirds of all responses to the question about improvements indicating ‘no further comments. Where discussed, opportunities for improvement focused on the clinical skills of nurses, and access to supportive care (Principles 2, and 4, respectively). For example:

‘Most nurses seemed too inexperienced/lacking in understanding of worsening condition of patient as chemo treatment progresses ward doctors hardly seen.’

Better access to psychologists- there seemed to be limited access. Nothing wrong with the service once provided. Better help from social workers when dealing with Centrelink. I was rejected but I later found out there was firm grounds for appeal. I feel the social worker should have had a greater awareness of rules - I was in no state to deal with the process.

ED experiences

Items related to ED experiences were answered by between 24 and 28 respondents with head and neck cancer (Table 6). Aspects of care participants considered most helpful in their ED experiences

focused on care quality (Principle 2: Safe and quality care), and timeliness of care (Principle 5: Care coordination), as represented in the following two responses:

'ED is of course by nature a more chaotic experience. Less calm and assured than the wards or <hospital>, but overall they were great.'

'Ensured I received treatment quickly, checked on me regularly, ensured I was comfortable'

Two respondents described mixed experiences in care quality by ED staff:

'Excellent doctor and senior nurse who knew what to do - others did not'

'Emergency was a nightmare. Going to the ward was a relief.'

Table 6: Principles discussed in free-text questions related to ED experiences

Q107. What were the most helpful things staff did during your Emergency Department visit? (n=28 responses)			
OCP Principle	Experience	Themes	Count
1: Patient-centred care (n=2, 6%)	Positive	Compassionate care and respect	2
2: Safe and quality care (n=17, 55%)	Mixed	Care quality	2
		Care quality	1
	Negative	Clinical skills/knowledge	1
		Vic public hospital system	1
	Positive	Care quality	8
		Hospital environment	1
		Outcomes	1
		Pain management	1
Side effect management		1	
5: Care coordination (n=6, 19%)	Negative	Timeliness	1
	Positive	Care coordination	1
		Telehealth	1
		Timeliness	3
6: Communication (n=2, 6%)	Positive	Communication and information sharing	2
Other (n=2, 6%)	Positive	Access to resources	2
N/A (n=2, 6%)	Neutral	No further comments	2
Total themes identified			31
Q108. What could be done to improve the Emergency Department experience for cancer patients? (n=24 responses)			
OCP Principle	Experience	Themes	Count

1: Patient-centred care (n=2, 7%)	Negative	Compassionate care and respect	2
2: Safe and quality care (n=12, 41%)	Negative	Care quality	3
		Clinical skills/knowledge	3
		Hospital environment	2
		Hospital environment (staffing)	2
		Treatment discrepancy	1
		Vic public hospital system	1
3. Multidisciplinary care (n=1, 3%)	Negative	Clinical information sharing	1
5: Care coordination (n=5, 17%)	Negative	Timeliness	5
6: Communication (n=2, 7%)	Negative	Communication and information sharing	2
N/A (n=7, 24%)	Neutral	No further comments	7
Total themes identified			31

Table values adjusted to nearest whole number where needed and may not equal 100%

Most feedback describing ways that ED experiences could be improved focused on the timeliness of care (Principle 5: Care coordination) and a dissatisfaction with waiting times:

'Waited 9 hours plus to be admitted to ward'

'See patients more quickly.'

Follow-up care

Items related to follow up care were answered by between 50 and 59 respondents with head and neck cancer (Table 7). Aspects of follow-up care considered most helpful primarily related to Principle 6: Communication, and Principle 5: Care coordination. Respondents emphasised the importance of clear communication of information and advice, and the coordination of follow-up care and appointments. For example:

'Thorough checks & reassurance, advice on what to keep an eye on.'

'Listened, coordinated appointments.'

Respondents also found that experiences of compassion and respect from staff (Principle 1: Patient-centred care) were helpful. Less frequent responses related to Principle 2: Safe and quality care, Principle 4: Supportive care, and Principle 3: Multidisciplinary care. Themes related to these principles included attentiveness of staff, care being managed across a clinical team, and appropriate advice and referrals to supportive care services:

'I felt like nothing was too much for them to help me.'

'Providing advice to manage my diet (help put weight back on).'

'It was a team effort. All streams of staff had access to the one data base and made sharing of information very easy'

Table 7: Principles discussed in free-text questions related to follow-up care

Q120. What were the most helpful things staff did during your follow-up care? (n=59 responses)			
OCP Principle	Experience	Themes	Count
1: Patient-centred care (n=11, 17%)	Positive	Compassionate care and respect	9
		Professionalism	2
2: Safe and quality care (n=9, 14%)	Negative	Care quality	1
	Positive	Care quality	7
		Side effect management	1
3: Multidisciplinary care (n=2, 3%)	Negative	GP experiences	1
	Positive	Multidisciplinary care	1
4: Supportive care (n=4, 6%)	Positive	Supportive care access/referrals	4
5: Care coordination (n=19, 29%)	Negative	Follow-up care	2
		Timeliness	1
	Positive	Care coordination	11
		Follow-up care	5
6: Communication (n=18, 28%)	Positive	Communication and information sharing	18
Other (n=1, 2%)	Positive	Access to resources	1
N/A (n=1, 2%)	Neutral	Unsure	1
Total themes identified			70
Q121. What could be done to improve the follow-up experience for cancer patients? (n=50 responses)			
OCP Principle	Experience	Themes	Count
1: Patient-centred care (n=1, 2%)	Negative	Compassionate care and respect	1
3: Multidisciplinary care (n=1, 2%)	Negative	Multidisciplinary care	1
4: Supportive care (n=4, 7%)	Negative	Supportive care access/referrals	3
	Positive	Supportive care access/referrals	1
5: Care coordination (n=15, 28%)	Negative	Care coordination	6
		Follow-up care	5
		Timeliness	4

6: Communication (n=8, 15%)	Negative	Communication and information sharing	8
N/A (n=25, 46%)	Neutral	No further comments	21
		Unsure	4
Total themes identified			60

Table values adjusted to nearest whole number where needed and may not equal 100%

Just under half of respondents that discussed follow up care in free text responses did not have additional comments related to what could be done to improve the follow-up experience for cancer patients (Table 7). Where suggestions were provided, responses primarily related to Principle 5: Care coordination and Principle 6: Communication. Limited responses were provided that related to Principles 1-4. Suggestions for improvements included improving information about what to expect after treatment, reducing waiting times for appointments/tests, and increasing access and coordination of supportive care services. One respondent felt that staff involved in their follow-up care could have been more compassionate:

'A less clinical approach would be helpful. For example, no one seems interested in how you are emotionally coping emotionally.'

Additional comments made in survey

All principles were discussed by respondents across the four survey items for additional comments (Table 8), with response numbers ranging from 17-52 depending on the item. Comments from head and neck cancer patients about their experiences regarding the information they received or would like to have received primarily described positive experience of compassionate care and respect, care quality, and communication and information sharing (Principles 1: Patient-centred care, 2: Safe and quality care, and 6: Communication, respectively). Where specific suggestions were made for opportunities for improved information sharing, these highlighted a need for better information about symptom/side effect management after treatment, more information about alternative therapies, and transparency from clinicians regarding treatment complications:

'Far more information about dealing with side effects 4 months after treatment this is still an issue.'

The only negative in my cancer journey so far was my surgeon was not transparent about nicking my chyle thoracic duct during surgery, which required me to be hospitalized for 9 weeks, hence delaying my radiotherapy and chemo treatment

'I wish that the health professionals could provide me with information about and recommend me complement or alternative therapies such as massage, acupuncture...'

Twenty-seven respondents described experiences during their cancer care where they received conflicting information or advice from different health professionals, were not fully informed about their treatment and/or progress, were required to undergo unnecessary tests, had appointments where test results were not available, or where they experienced discrimination. Most often, respondents described instances where clinical information was not appropriately shared among the multidisciplinary team (Principle 3: Multidisciplinary care):

'I was experiencing some hearing loss due to chemo and the doctor was not informed.'

'Scans result not available during one appointment, so I had to come another day.'

Only 17 respondents indicated there was a time they were so unhappy with their treatment that they wanted to or did complain about it. Broadly, dissatisfaction and cause for complaint were reflections of poor experiences of care, a lack of compassion and respect from staff, and poor timeliness of care (Principles 2, 1 and 5, respectively). For example:

'Only once was I taken to the toilet with oxygen mask removed & left for some time. This was most distressing as I had trouble breathing. This was an isolated treatment.'

'They seldom treated me as a person, rather than an object or puzzle to be solved.'

'Had to wait hours for treatment. Pharmacy did not take my medicine in a timely manner.'

Over two thirds of the general comments about head and neck cancer patient care experiences focused on reiterating positive experiences across their cancer treatment journey:

'I cannot congratulate them enough for the support I received which helped me right this cancer mentally and physically.'

'Extremely happy with all the staff I dealt with, from receptionists through to specialists.'

Where negative experiences were discussed, these generally related to management of pain and side-effects (Principle 2), the coordination of care including timeliness and having care closer to home (Principle 5), and issues with communication and information sharing (Principle 6). For example:

'My pain management was not monitored closely.'

'My initial surgery was delayed by covid protocols cancer was only confirmed after surgery. Earlier biopsies were negative. The delay was several months.'

'Radiation nurses advice was different to advice from staff giving radiation treatment which caused me to develop severe rash to neck and chest.'

Table 8: Additional free-text questions

Q128. If you would like to make any other comments about your experiences regarding information you received or would like to have received, please use the space below. We would like to know about them. (n=35 responses)			
OCP Principle	Experience	Themes	Count
1: Patient-centred care (n=6, 14%)	Negative	Alternative treatment access	1
	Positive	Compassionate care and respect	5
2: Safe and quality care (n=16, 38%)	Mixed	Care quality	1
		Care quality	1
	Negative	Hospital environment	1
		Hospital environment (staffing)	1
		Management of complaints	1
		Side effect management	2
	Positive	Care quality	8
		Vic public hospital system	1
3: Multidisciplinary care	Negative	Multidisciplinary care	1

(n=1, 2%)			
4: Supportive care (n=2, 5%)	Negative	Supportive care access/referrals	1
	Positive	Supportive care access/referrals	1
5: Care coordination (n=2, 5%)	Negative	Follow-up care	1
	Positive	Timeliness	1
6: Communication (n=7, 17%)	Negative	Communication and information sharing	1
	Positive	Communication and information sharing	6
N/A (n=8, 19%)	Neutral	No further comments	7
		Unsure	1
Total themes identified			44

Q131. If you experienced any of the things listed in the previous question, could you please provide us with information about what happened and when it happened (n=27 responses)

OCP Principle	Experience	Themes	Count
2: Safe and quality care (n=10, 29%)	Mixed	Care quality	1
		Care quality	2
	Negative	Clinical skills/knowledge	3
		Hospital environment	1
		Hospital environment (staffing)	2
		Treatment discrepancy	1
3: Multidisciplinary care (n=10, 29%)	Negative	Clinical information sharing	7
		Multidisciplinary care	3
5: Care coordination (n=2, 6%)	Negative	Care coordination	1
		Timeliness	1
6: Communication (n=3, 9%)	Negative	Communication and information sharing	3
N/A (n=9, 26%)	Neutral	No further comments	8
		Unsure	1
Total themes identified			39

Q142. If yes, what was the issue you wanted to complain about? (n=17 responses)

OCP Principle	Experience	Themes	Count
1: Patient-centred care (n=6, 25%)	Negative	Compassionate care and respect	4
		Professionalism	1
	Positive	Compassionate care and respect	1
2: Safe and quality care (n=11, 46%)	Negative	Care quality	7
		Clinical skills/knowledge	1
		Hospital environment	1
		Management of complaints	1

		Vic public hospital system	1
5: Care coordination (n=6, 25%)	Negative	Care closer to home	1
		Care coordination	2
		Timeliness	3
6: Communication (n=1, 4%)	Negative	Communication and information sharing	1
Total themes identified			25
Q157. If you would like to make any other comments about your care experiences during your treatment, please use the space below. We would like to know about them. (n=52 responses)			
OCP Principle	Experience	Themes	Count
1: Patient-centred care (n=4, 7%)	Negative	Compassionate care and respect	1
	Positive	Patient involvement	1
		Professionalism	2
2: Safe and quality care (n=29, 49%)	Mixed	Care quality	1
		Hospital environment	1
	Negative	Pain management	1
		Side effect management	1
		Care quality	22
	Positive	Hospital environment	1
		Vic public hospital system	2
4: Supportive care (n=2, 3%)	Negative	Supportive care access/referrals	1
	Positive	Supportive care access/referrals	1
5: Care coordination (n=5, 8%)	Negative	Care closer to home	1
		Care coordination	2
		Timeliness	1
	Positive	Timeliness	1
6: Communication (n=5, 8%)	Negative	Communication and information sharing	3
	Neutral	Communication and information sharing	1
	Positive	Communication and information sharing	1
7. Research and clinical trials (n=1, 2%)	Positive	Clinical trials	1
Other (n=1, 2%)	Negative	Food access	1
N/A (n=12, 20%)	Positive	Thanks/satisfaction	6
	Neutral	No further comments	6
Total themes identified			63

Table values adjusted to nearest whole number where needed and may not equal 100%

4.2 Focus Groups

Seventeen people with head and neck cancer or carers participated in the focus group discussions.

Demographics

Table 9 below shows the demographic data provided by focus group participants. Almost three quarters of the participants were male (71%, n=12). Age varied widely with 18% (n=3) being younger than 50 years old, 18% (n=3) between 50 and 60 years old, 35% (n=6) between 61 and 70 years old and 29% (n=5) being older than 70 years old. Three quarters (76%, n=13) of participants were from the metropolitan region. About one third (35%, n=6) were unsure of their diagnosis stage, 24% (n=4) reported being diagnosed with stage IV head and neck cancer, 18% (n=3) reported being diagnosed with stage I head and neck cancer, 18% (n=3) reported being diagnosed with stage III head and neck cancer and only 6% (n=1) reported being diagnosed with stage II head and neck cancer.

Table 9. Head and neck cancer focus group demographic information

Gender	n = 17	Percentage
Women	5	29%
Men	12	71%
Total	17	100%
Age	n = 17	Percentage
Younger than 50	3	18%
50 - 60	3	18%
61 - 70	6	35%
Older than 70	5	29%
Total	17	100%
Stage/Grade	n = 17	Percentage
I	3	18%
II	1	6%
III	3	18%
IV	4	24%
Unsure	6	35%
Total	17	100%
Region	n = 17	Percentage
Metropolitan	13	76%
Regional	4	24%
Total	17	100%
Aboriginal Background	n = 17	Percentage
Yes	0	0%
No	17	100%
Total	17	100%

OCP Step One: Prevention and early detection

Focus group participants were asked if they were aware of head and neck cancer prior to their diagnosis.

More than half of participants, (59%, n=10) reported being unaware of head and neck cancer prior to their diagnosis. Many noted that while they were aware of general health messages (e.g., smoking, alcohol, 'Slip, Slop, Slap' for skin cancer), these did not translate into awareness about oral, throat, or neck cancers.

'No, I had no information and knew nothing about it. I worked in a hospital for 15 years and still didn't know about it.'

'More what you see on the TV... ads about smoking, but mostly about your lungs or liver, not your throat.'

Some participants (18%, n=3) reported some awareness from personal or family experience via other cancers.

OCP Step Two: Presentation, initial investigations and referral

Focus group participants were asked how long it took them to see a health professional after noticing an initial symptom. Many participants reported their symptoms as minor and unthreatening, which led to delays in seeking care. Symptoms included a lump or growth in the head and neck area (35%, n=6), persistent ulcer or sores (29%, n=5), sore throat (18%, n=3) and other (18%, n=3).

'I had a sore throat, nothing out of the ordinary, it just wouldn't go away.'

The time taken to consult a health professional varied widely across the group. Around one-third (35%, n=6) presented promptly within weeks of first noticing symptoms, while another third (29%, n=5) sought care after one to three months. The remaining participants (35%, n=6) reported delays of more than three months, most often because they underestimated the seriousness of their symptoms or attributed them to other causes.

'If I had known an ulcer could be cancer, I would have gone to the doctor sooner and insisted something be done.'

OCP Step Three – Diagnosis, staging and treatment planning

Focus groups explored how long from investigation of their symptoms it took for their symptoms to be appropriately investigated. For most (59%, n=10), initial investigations were handled promptly and appropriately. However, nearly one-third (29%, n=5) encountered dismissals or delays. A few (12%, n=2) had mixed experiences where GPs may have been prompt but referral processes were slow. These delays may have worsened patient anxiety and sometimes progression of disease.

'If I hadn't asked for a referral, I don't know if I'd have been diagnosed when I was.'

Focus group participants were then asked about their experience of receiving their cancer diagnosis and beginning their treatment journey.

Over half of participants (59%, n=10) described their experience as supportive and well-managed and emphasised the role of clear explanations and compassionate communication from their clinical teams.

'My experience with the cancer centre was exceptional on all fronts. I am indebted to them all.'

Around one-third (29%, n=5) said they were shocked or caught off guard, particularly those who did not consider themselves at risk due to lifestyle factors such as not smoking or drinking.

'I wasn't expecting it in my throat or tongue. I've never smoked and rarely drink, so I didn't think I was in the high-risk category.'

A few participants (12%, n=2) reported negative or mixed experiences, describing either blunt communication or a lack of psychological support at the time of diagnosis.

OCP Step Four – Treatment

Focus group participants were asked how long it took for them to begin active treatment after their diagnosis. More than half (53%, n=9) began their treatment within two weeks, while almost one-third (29%, n=5) started between two and six weeks. A small number of participants (18%, n=3) reported longer delays, often due to the need for complex surgery or referral between services.

Participants were also asked about their treatment and experiences of the treatments they received. The majority underwent surgery (71%, n=12) and/or radiation therapy (65%, n=11), with almost one-third also receiving chemotherapy (29%, n=5). One participant also reported receiving immunotherapy, highlighting that although rare in this group (6%, n=1), newer systemic therapies are relevant to cancer care.

The vast majority (76%, n=13) reported physical side effects which include significant ongoing difficulties, including swallowing challenges, dry mouth, loss of taste, speech difficulties, and substantial weight loss. Others noted lasting dependence on modified diets or tube feeding, and difficulty returning to normal eating.

'The radiation burnt my throat, I lost a huge amount of weight, and swallowing was a nightmare.'

Functional impacts were also widespread, with more than two-thirds (69%, n=7) experiencing speech or swallowing challenges that affected daily life. Emotional wellbeing was also heavily impacted, with 53% (n=9) reporting heightened distress, anxiety, or fear during treatment.

'I never thought it would hit me so hard emotionally. I felt very isolated.'

Accessing treatment often required substantial travel. Almost half (47%, n=8) travelled long distances (>100km), sometimes daily for weeks at a time. Others travelled moderate distances (29%, n=5), while only a minority (24%, n=4) were treated locally.'

'I had to travel 250km for surgery and 79km every day for radiation. The driving was exhausting.'

Focus group participants were asked about their supportive care needs and referrals they may have received. Supportive care discussions and referrals were inconsistently provided: just over half (53%, n=9) reported being offered supportive care services such as speech pathology, dietetics, or counselling, while almost half (47%, n=8) said these were not mentioned.

Everyone should have the same access to a holistic, supportive approach to their care. And again, I sat there, and I would look around and [think]...I know how to advocate for myself but these other people don't. It's not fair.

OCP Step Five – Care after initial treatment and recovery

Focus group participants were asked about the health professionals that were involved in their care after finishing active treatment.

Participants reported mixed experiences of follow-up care once initial treatment ended. Two-thirds (65%, n=11) described adequate clinical follow-up, with regular specialist appointments providing reassurance. However, over one-third (35%, n=6) said follow-up was minimal or absent, limited to tumour surveillance without broader support.

Survivorship and rehabilitation support were underdeveloped. Less than half (44%, n=7) received structured survivorship care, such as dietetics, speech therapy, or nurse-led programs, while most (56%, n=10) said they managed largely on their own.

Focus group participants were asked about their experience of having their GP informed of their cancer care the communication between their treating team and GP. General practitioner (GP) involvement was inconsistent. Almost half (47%, n=8) reported an active GP role in their care, while 53% (n=9) said their GP was largely uninvolved. Some praised smooth communication between hospital teams and their GP, while others described little contact or fragmented care.

Participants were asked about their experience with transitioning back into day-to-day life after finishing active treatment. A majority (59%, n=10) reported significant physical impacts that persisted well beyond treatment, including ongoing swallowing problems and fatigue. Nearly half (47%, n=8) described difficulties with work, social functioning, or finances, and 41% (n=7) reported ongoing emotional needs such as fear of recurrence and anxiety.

'Every little sore or ulcer makes me worry the cancer is back.'

Overall, the post-treatment phase was marked by uneven access to follow-up, inconsistent GP involvement, and significant unmet survivorship needs. For many, returning to daily life was more difficult than undergoing treatment, with ongoing physical, functional, and emotional challenges.

OCP Step Six – Managing recurrent, residual or metastatic disease

Focus group participants were asked if they had the opportunity to discuss their prognosis with their healthcare providers.

Over one-third of participants (35%, n=6) reported experiencing recurrence, while almost two-thirds (65%, n=11) did not. Recurrence was often described as devastating, with participants reflecting on the psychological burden as much as the clinical management.

'When it came back, I felt like my world collapsed again.'

Support during recurrence was inconsistent. Some (29%, n=5) described specialist-led care that addressed their needs, while others (18%, n=3) reported limited additional support, with little emphasis on psychosocial care.

The emotional toll of recurrence was considerable. Almost one-third (29%, n=5) reported high levels of distress and anxiety, while only a small number (6%, n=1) described acceptance. For most, recurrence reinforced feelings of fear, uncertainty, and isolation.

OCP Step Seven – End-of-life care

Access to palliative care varied considerably. More than half of participants (53%, n=9) reported no access to palliative care services, while 29% (n=5) said they eventually received support, though often late in the illness trajectory. A further 18% (n=3) described poorly coordinated or limited care.

'Palliative care came in very late, when things were already very advanced.'

'It was mostly about managing medications, not much emotional support.'

These accounts suggest that palliative care is often introduced too late, focused narrowly on symptom control rather than holistic support. Emotional and family needs were frequently overlooked, leaving gaps in care during one of the most vulnerable stages of the journey.

Other experiences in their cancer journey

When reflecting more broadly, participants shared their experiences of information, communication, recognition of needs, and suggestions for improvement. Information provision was highly variable: only 29% (n=5) felt information was given in a way that suited them, while nearly half (47%, n=8) described it as too general, and one-quarter (24%, n=4) relied on their own research.

'I was told to look things up myself online.'

'I was given clear explanations in a way that helped me understand.'

Most participants (71%, n=12) felt involved in decisions about their care, while 12% (n=2) felt excluded or disempowered. Just 6% (n=1) did not want to be involved in discussions and 12% (n=2) did not answer. Less than half (47%, n=8) felt their unique needs were fully recognised, with 24% (n=4) reporting partial recognition and 29% (n=5) feeling they were not acknowledged at all.

Participants offered many constructive suggestions for improvement. More than half (53%, n=9) called for targeted information specific to head and neck cancers, rather than generic cancer advice. Almost half (47%, n=8) recommended earlier and consistent access to allied health and rehabilitation, and over one-third (35%, n=6) highlighted the need for greater psychosocial and emotional support. A further 29% (n=5) suggested improved GP and community awareness, and 18% (n=3) recommended timelier access to palliative care.

'We need information that is specific to head and neck cancer, not just general cancer advice.'

'Follow-up should include counselling and support, not just scans.'

Overall, participants' reflections in this step reinforce the systemic gaps across the cancer journey: information and communication inconsistencies, insufficient attention to unique needs, and a strong demand for holistic, person-centred care.

Key findings

The results of the Victorian CPES and focus groups indicate there are opportunities to improve aspects of head and neck cancer care in Victoria. It is important to note that these may not be reflective of all the gaps to optimal head and neck cancer care experienced by consumers. The methods used in this report involved limited representation of consumers living in rural and regional areas and those from a culturally and linguistically diverse background.

Key findings include:

Awareness and diagnosis – Awareness of head and neck cancer remains very limited. Few participants recalled prevention or early detection messages, and many delayed seeking care due to dismissing symptoms. Some described repeated dismissals before being referred for specialist assessment. Confidence in GPs was low, with only 55% of survey respondents expressing trust in their GP's ability to manage ongoing cancer care. These findings emphasise the need for stronger GP education and clearer diagnostic pathways to ensure timely recognition and referral.

Treatment experiences – Most participants reported being treated with dignity and respect across treatment phases, and survey results showed high satisfaction with management of pain, side effects, and follow-up arrangements. However, treatment was described as intensive and life-altering, with lasting impacts on swallowing, speech, nutrition, and fatigue. Information provision was inconsistent: while most patients received adequate preparation for treatment, fewer felt they were given tailored or detailed advice. Across surgery, radiotherapy, and chemotherapy, discussion of out-of-pocket costs was notably low (38–43%), well below statewide averages in some areas, highlighting a need for financial transparency and support.

Supportive care and psychosocial needs – Emotional distress was common, compounded by isolation and, for many, the burden of long-distance travel. Access to allied health and psychosocial services was inconsistent, with gaps in rehabilitation and survivorship support. While survey results showed that staff frequently checked on emotional wellbeing and diet, less than half of patients felt able to discuss complementary therapies, and carer engagement was limited, with fewer than half reporting that family or friends were asked about their needs. Embedding supportive care, allied health, and consistent carer engagement across the pathway is critical.

Follow-up and Survivorship – Post-treatment care was largely limited to tumour surveillance. Only 63% of participants received a written follow-up plan, and fewer were given clear guidance on which new symptoms required attention. Both surveys and focus groups highlighted the need for more structured survivorship care, including better GP involvement, integration of rehabilitation, and access to tailored survivorship resources. Fear of recurrence remained a significant concern.

Recurrence and end-of-life care – Recurrence was described as devastating, with many patients and families reporting inadequate support. Access to palliative care was often delayed and narrow in scope. While survey results showed high rates of discussion about palliative care when it was needed (100%), focus groups revealed this support often came too late and lacked a holistic approach. Early integration of palliative care, with attention to psychosocial, cultural, and family needs, is essential.

Information, communication and equity – Communication and information sharing were consistently identified as areas for improvement. Patients frequently described information as too generic or poorly tailored to head and neck cancer, and particularly limited in the surgical setting. Survey data echoed this, with lower than statewide averages reported for discharge information and communication about costs. Rural and regional patients faced particular challenges with travel and access to local supports, while culturally and linguistically diverse communities were under-represented in both data sources, highlighting ongoing equity gaps.

Implications

The findings of this report highlight several opportunities to improve head and neck cancer care in Victoria. While many participants expressed gratitude for the expertise and compassion of their treating teams, the identified gaps in awareness, timeliness to diagnosis and treatment, communication, supportive care, and survivorship care indicate the need for targeted improvements to deliver more equitable and patient-centred care. These include:

- Strengthening public awareness campaigns and GP education to promote earlier detection and referral.
- Strengthening timely access to diagnosis and multidisciplinary treatment planning.
- Ensuring head and neck cancer specific and clear information and communication about treatment, what to expect such as out-of-pocket costs and travel, and available support programs.
- Embedding consistent carer engagement and support across the care pathway.
- Standardising early access to credentialled allied health, psychosocial, and rehabilitation workforce and services as integral to treatment and survivorship care.
- Improving coordination between hospital teams and GPs through structured survivorship and shared care models.
- Integrating palliative care earlier, with a stronger focus on holistic, family-centred support.
- Providing clear, tailored, and culturally appropriate information at all stages of care.
- Expanding equity-focused strategies, including telehealth, outreach to rural communities, and culturally responsive models of care.

By addressing these gaps, cancer services can enhance the quality and consistency of care, improve patient and family experiences, and ultimately contribute to better health outcomes for people diagnosed with head and neck cancer.

Appendices

Appendix 1: Discussion points for the focus group

Demographic Information Form

Participant ID: __	
Date: __ / __ / _____	
What is your age?	
What is your sex? (<i>please tick</i>)	<input type="checkbox"/> Female <input type="checkbox"/> Male <input type="checkbox"/> Other
Have you or your loved one been diagnosed with head and neck cancer? <input type="checkbox"/> Yes <input type="checkbox"/> No	
PATIENT: How long ago were you or your loved one diagnosed with head and neck cancer?	
Which country were you born in? (<i>please tick</i>)	<input type="checkbox"/> Australia <input type="checkbox"/> Other (<i>please specify below</i>) _____
If you were born in a country other than Australia, how many years have you resided in Australia?	
What is your postcode of residence?	_____
Are you of Aboriginal or Torres Strait Islander descent? (<i>please tick</i>)	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Prefer not to answer
What is your highest level of education? (<i>please tick</i>)	<input type="checkbox"/> Below year 12 <input type="checkbox"/> Year 12 <input type="checkbox"/> Certificate or diploma <input type="checkbox"/> Undergraduate degree <input type="checkbox"/> Postgraduate degree
Do you currently work: (<i>please tick</i>)	<input type="checkbox"/> Full time <input type="checkbox"/> Part time <input type="checkbox"/> Casual <input type="checkbox"/> No paid work

Prevention and early detection:

1. Were you given any information before your diagnosis about cancer prevention and/or early detection (weight, smoking, exercise, screening programs)?

Presentation:

2. From your initial symptoms, how long did it take for you to see a health professional about these?

3. Did you feel your symptoms were investigated timely and appropriately?

Diagnosis:

4. How long from initial presentation of symptoms or a positive screening result did it take you to receive a cancer diagnosis?

5. What was your experience with receiving your cancer diagnosis and considerations with beginning the treatment journey?

Treatment:

6. How long from diagnosis did it take for you to begin active treatment?

7. What types of treatment did you receive? What was your experience with each of these treatments? (Prompt: surgery, chemotherapy, radiotherapy)

8. Did you have to travel to receive care? What was your experience with this if you did?

9. What has been your experience with receiving information about clinical trials?

10. Were fertility implications of your treatment discussed with you?

11. Supportive care refers to cancer services available to those affected by cancer. Supportive care needs include physical needs, social and practical needs, spiritual and religious needs, information needs, emotional and psychological needs. Did health professionals talk to you about supportive care and offer you referrals to services?

Care after treatment:

12. Did you have any contact with health professionals after finishing treatment? (Prompt: doctors, cancer nurses, dietitians, physios, etc)

13. Was your GP informed about your cancer care? What was your experience of care between your GP and specialist care?

14. Once you finished active treatment, what was your experience with transitioning back into day-to-day life? (e.g. did you feel support to manage work, finances, emotional and physical support, addressing fears of recurrence and health needs).

Managing recurrence:

15. Did you have an opportunity to ask about your prognosis?

16. Did anyone discuss advance care planning or making future medical decisions with you?

17. Did you receive or were you offered a referral for palliative care?

End-of-life care (if applicable):

18. Were you happy with the care your loved one received? (e.g. addressing cultural and spiritual needs, pain management, trust in medical team, appropriate level of communication with you, your loved one and the medical team)

General Questions:

19. Were you given information about your cancer diagnosis, treatment, care and recovery in a way that suited you (e.g. verbal, written, video)?

20. Were you involved in discussions and how did you find the level of communication?
--

21. People with cancer come from a range of diverse backgrounds, did you feel like the cancer care system recognised your unique needs?
--

22. Are there any improvements you would like to see in the care provided to people with head and neck cancer and their families?
--

Appendix 2: Definitions of all identified themes from free text responses and the OCP principles they align to

Theme	OCP Principle	Definition
Access to resources	Other	Refers to the experience patients had in accessing equipment and/or resources related to their health management (e.g. stoma bags, etc.)
Alternative treatment access	1: Patient-centred care	Refers to patient access to alternative treatments
Care closer to home	5: Care coordination	Refers to receiving or desiring cancer care at home, or at facilities that are closer to the respondent's home residence.
Care coordination	5: Care coordination	Refers to aspects of care coordination including appointment setting, etc.
Care quality	2: Safe and quality care	Refers to the perceived quality of the care received
Clinical information sharing	3: Multidisciplinary care	Refers to the way that clinical information was shared between clinical care providers (e.g., GP, different departments, different hospitals, etc.)
Clinical skills/knowledge	2: Safe and quality care	Refers to the skills and/or knowledge displayed by clinical staff
Clinical trials	7: Research and clinical trials	Refers to patient access to clinical trials
Communication	6: Communication	Refers to the way staff communicated with participants, including discussions with staff about clinical details of diagnosis, treatment, procedures or side effects and professional advice
Compassionate care and respect	1: Patient-centred care	Refers to the degree to which patients perceived staff to display empathy, respect and understanding for them when providing care or interacting with them
COVID-19	Other	Describes COVID-19 impact on cancer care
Delayed discharge	2: Safe and quality care	Refers to when a patient has had a longer hospital stay than they anticipated
Early discharge	2: Safe and quality care	Refers to when a patient was discharged from hospital earlier than they expected and/or wanted to be
Family/friend involvement	1: Patient-centred care	Refers to the involvement of family/friends/loved ones in the care journey
Follow-up care	5: Care coordination	Refers to patient experience of follow-up care received from health professionals, including check-in phone calls, and recommendations for follow-up care from external providers such as GPs
Food access	Other	Refers to access a patient has to appropriate food and/or drink while receiving onsite care

GP experiences	3: Multidisciplinary care	Refers to patient experiences with GP regarding their cancer and cancer care
Hospital environment	2: Safe and quality care	Refers to the perceived quality of the hospital environment, including staffing levels
Management of complaints	2: Safe and quality care	Refers to how patient complaints were managed
Medication management	2: Safe and quality care	Refers to how patient medications were managed
Multidisciplinary care	3: Multidisciplinary care	Refers to aspects of care that involved a multidisciplinary team
N/A	N/A	Response not relevant to question and/or not able to be coded
No further comments	N/A	No further comments provided
Outcomes	2: Safe and quality care	Refers to patient outcomes
Pain management	2: Safe and quality care	Refers to how patient pain was managed
Patient involvement	1: Patient-centred care	Refers to how involved patients felt in their own care
Professionalism	1: Patient-centred care	Refers to the degree to which patients perceived staff to be acting in a professional manner with them
Public health recommendations	Other	Comment that relates to preventative and/or information needs at a public health level
Side effect management	2: Safe and quality care	Refers to how patient side effects were managed
Supportive care access/referrals	4: Supportive care	Describes patient access to supportive care services, including referrals
Telehealth	5: Care coordination	Refers to telehealth cancer care
Thanks/satisfaction	N/A	Expression of thanks and/or gratitude from patient without other feedback, including overall comments about satisfaction
Timeliness	5: Care coordination	Refers to the perceived timeliness of the care received
Treatment discrepancy	2: Safe and quality care	Refers to perceived over/under treatment, misdiagnoses and other unwarranted clinical disparities
Unclear	N/A	Used to identify statements where the response does not provide enough context to be adequately coded
Unsure	N/A	Used to identify statements where the respondent is unsure of how to answer the question
Vic public hospital system	2: Safe and quality care	Refers to perceptions of the Victorian public hospital system (including Victorian cancer care)

References

1. Cancer Council Victoria. Optimal Care Pathways. Victoria (AU): Cancer Council Victoria. [Online] Available from: <https://www.cancer.org.au/health-professionals/optimal-cancer-care-pathways> [Accessed 24 February 2025].
2. Department of Health and Human Services 2024. Victorian Cancer Plan 2024-2028 – Optimal and equitable cancer outcomes for all Victorians. [Online] Available at: <https://www.health.vic.gov.au/victorian-cancer-plan> [Accessed 24 February 2025].
3. Cancer Council Victoria. *VCR data explorer*. [cited 2025 24 February]; Available from: <https://www.cancervic.org.au/cancer-information/statistics/data-explorer>.
4. Victorian Cancer Registry, *Cancer in Victoria 2023*. 2024, Cancer Council, Victoria, Melbourne, Australia. p. 66.
5. Bryant J, Boyes A, Jones K, Sanson-Fisher R, Carey M, Fry R. 2014. Examining and addressing evidence-practice gaps in cancer care: a systematic review. *Implementation Science* 9(1):1–7.
6. Harrison R, Walton M, Manias E, Wilson C, Girgis A, Chin M, Leone D, Seale H, Smith AB, Chauhan A. 2021. CanEngage Project group. Codesigning consumer engagement strategies with ethnic minority consumers in Australian cancer services: the CanEngage Project protocol. *BMJ Open* 2; 11(8):1-8.
7. Wright David, Corner Jessica, Hopkinson Jan, Foster Claire. 2006. Listening to the views of people affected by cancer about cancer research: an example of participatory research in setting the cancer research agenda. *Health Expectations* 9(2006): 3–12.
8. Cancer Australia and Cancer Voices Australia. 2011. National Framework for Consumer Involvement in Cancer Control. Cancer Australia, Canberra, ACT.