



# Summary report of patient experience of cancer care: Culturally and linguistically diverse communities

VICS April 2026

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## 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](http://www.vics.org.au).

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## Acronyms

Acronym	Full Text
CALD	Culturally and Linguistically Diverse
CCV	Cancer Council Victoria
CPES	Cancer Patient Experience Survey
ED	Emergency Department
GP	General Practitioner
NEMICS	North Eastern Melbourne Integrated Cancer Service
NGO	Non-Governmental Organisation
OCP	Optimal Care Pathway
VICS	Victorian Integrated Cancer Services

# Executive summary

**Background:** Culturally and Linguistically Diverse (CALD) 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 CALD people with cancer, and their carers, who have received or are receiving care for their cancer in Victoria.

**Methodology:** The analysis combined 2 data sources. First, the 2023 Victorian Cancer Patient Experience Survey (CPES) captured responses from 247 CALD people diagnosed with cancer who received inpatient cancer 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, ten focus groups were conducted with 12 CALD patients and carers between November 2025 and January 2026. Discussions were structured around the 7 steps of Optimal Care Pathway, spanning prevention and early detection through to survivorship and end-of-life care.

**Findings:** Survey results indicated that most participants felt that information was explained clearly, however, some language groups experienced greater difficulty understanding their diagnosis, treatment options and long-term side effects. Positive experiences were associated with clear explanations, empathy and supportive staff. Areas for improvement included earlier engagement of interpreters, clearer communication methods, shorter waiting times and improved involvement in decision-making. CALD respondents reported receiving less information about financial support and fewer referrals to supportive care services compared with statewide averages. Many noted unmet needs related to psychological, nutritional and practical support.

Focus group findings provided rich insight into these themes. CALD consumers reported that information was often overwhelming or incomplete, interpreter access was inconsistent and carers were not always included in discussions. There was also low awareness of cancer prevention and early symptoms, which contributed to delayed help-seeking. In addition, consumers reported fragmented care pathways and feeling lost when transitioning into survivorship or post-treatment care. Barriers beyond language were also identified, including migration status, visa/ Medicare eligibility, financial insecurity and low social capital. Psychological support, allied health services, and survivorship care were not routinely discussed, with palliative care commonly misunderstood as being only for end-of-life.

**Conclusion:** Together, the survey and focus group findings underscore the need to address communication and language barriers, improve access to consistent and high-quality interpreter services, strengthen cancer awareness among CALD communities, and enhance treatment follow-up and side effect management. The findings also point to the importance of improving access to supportive care services.

Key priorities include improving workforce cultural capability and communication, strengthening the availability and quality of interpreter services, enhancing access to peer support and navigation, increasing transparency in system navigation, empowering workforce and developing technology-enabled communication. 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 CALD patients diagnosed with cancer and their carers/ families in Victoria.

# 1. 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 2025-2026, the program explored unwarranted variations in culturally and linguistically diverse (CALD) communities with cancer.

Australia is home to approximately 8.6 million migrants, representing 31.5% of the population, with people originating from more than 190 countries.[3] In Victoria, individuals born in non-English-speaking countries account for an estimated 25% of all cancer cases.[4] The most common solid cancers diagnosed in Victoria are those of the prostate (16%), breast (13%), colorectal (CRC) (10%), and lung (9%), which together accounted for 48% of all new cancer diagnoses in 2023.[5] For people from CALD backgrounds, patterns of incidence, screening participation, and survival across these cancers often differ from the non-CALD population, reflecting both variations in risk factor profiles and inequities in access to prevention, early detection, and treatment services.[6]

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. There are some tumour streams and populations that do not have an OCP of which includes CALD communities and there is little focus on this population group in existing OCPs. 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. [7,8] and their voices are vital in shaping priorities, informing service delivery, and reducing disparities in outcomes.[9]

To support this, the Victorian Cancer Patient Experience Survey (CPES) was developed by the Department of Health in partnership with 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 CALD Victorians who had a lived experience of cancer. This report draws on both the 2023 CPES and the focus group findings, with the aim of informing the 2026 VICS CALD cancer summit and guiding future quality improvement initiatives across Victoria.

## 2. Aim

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

## 3. 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 public health service campuses. Identified consumers were invited to complete the survey via email, SMS, or letter. The survey sections include Finding out, Deciding on treatment, Surgery, Radiotherapy, Chemotherapy, Emergency Department, Follow-up care, Information received, Overall care, Your health, and About you. Data collection occurred between 13 March and 19 May 2023. The overall response rate for the survey was 32%.

Raw data for the CALD cancer patient cohort were provided by Department of Health (formerly the Victorian Agency for Health Information (VAHI)). Data for CALD respondents were extracted from the state cohort by identifying all survey responses where respondents answered the question 153 'What language do you mainly speak at home?' with any response other than 'English'. These data were then aggregated to calculate the percentage distribution across multiple-choice response options. While helpful for identifying language support needs, this question does not account for respondents who identify as CALD, but who may speak English at home.

#### Positive response coding

Raw data for the CALD cancer patient cohort was provided by VAHI. Data for CALD respondents were extracted from the state cohort by identifying all survey responses where respondents answered the question 153 'What language do you mainly speak at home?' with any response other than 'English'. These data were then aggregated to calculate the percentage distribution across multiple-choice response options.

#### Statistical comparisons

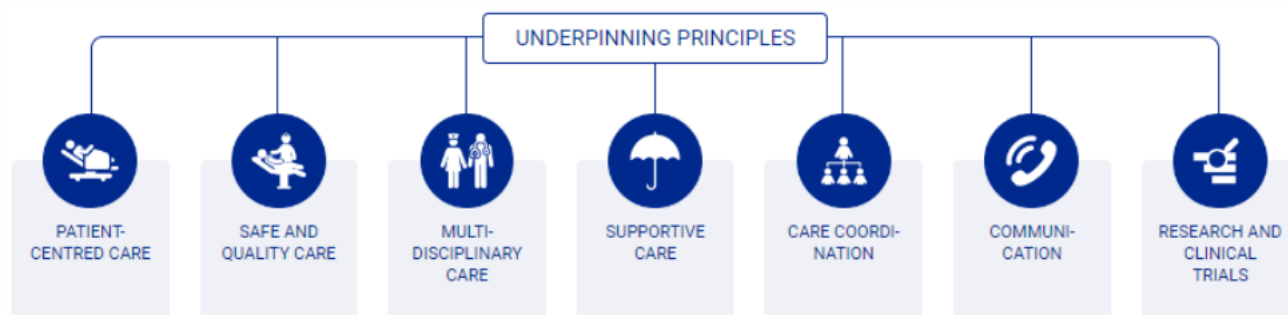
Statistical significance could not be calculated between the CALD cancer patient cohort and the total statewide cohort because raw statewide data were unavailable. Percentage differences are therefore reported descriptively and may not be statistically significant differences. Given the small sample size, results within +/- 10% of the statewide average are considered broadly similar to the statewide average. It should also be noted the CALD cancer cohort is included within the state cohort when comparing the 2 cohorts.

Not all respondents answered every survey question, resulting in variable response rates across the survey. Percentages reported in this analysis were calculated using only the number of respondents who answered a given question. Some language groups (Arabic, North-Western Europe, Middle East, Other) included <10 respondents and were therefore excluded from the individual language group analysis. In line with reporting protocols, any data with <10 responses were excluded from data reporting.

#### 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 responses were open-ended, multiple themes could be assigned to a single response. Thematic codes were reviewed and refined to reduce duplication and overlap. Each refined code was then categorised according to its relevance to the 7 principles of care described in the optimal care pathways that underpin optimal cancer care (Figure 1).

**Figure 1. The 7 principles of optimal care.**



## 3.2 Focus groups

### Recruitment

Focus group participants were recruited through several cancer-related organisations and advocacy groups. The VICS Optimal Care Summits team distributed invitations to participate via newsletters. Eligible individuals (CALD adults living in Victoria with experience of cancer treatment and their carers), volunteered to participate, completed a Qualtrics survey, and provided informed consent. None of the participants were known to the VICS Optimal Care Summits team prior to study recruitment. This study received ethically approval (VicTRI-19783).

### Question development

Focus group questions including demographics (Appendix 1), were developed following a review of the literature on consumer experiences and cancer-related surveys. Key questions were identified and systematically mapped against the 7 steps outlined in the OCPs, ensuring coverage from prevention and early detection to end-of-life care. To ensure the rigor and validity, the questions were peer-reviewed and refined through consultations with the 21 expert advisory group members and 3 consumer representatives from the North Eastern Metropolitan Integrated Cancer Service (NEMICS).

### Data collection

Ten focus groups were held between November 2025 and January 2026 using Microsoft video conferencing software, Microsoft Teams. Each focus group session lasted approximately 1–1.5 hours and was facilitated by 2 members of the VICS Optimal Care Summits team. The discussion covered the topic areas listed above.

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 calls, were transcribed by a member of the VICS Optimal Care Summits team with all identifying information removed during transcription. Transcripts from video recordings were cross-checked against the original audio for accuracy. An anonymised draft transcript for each participant was then shared with them for review and comment.

### Analysis

Focus group transcripts were analysed using both latent and semantic coding, followed by thematic analysis to identify patterns of meaning in the data. Qualitative data from the discussions was extracted by a member of the VICS Optimal Summits team and analysed descriptively using Excel.

## 4. Findings

### 4.1 CPES Data

#### General findings

##### Age, gender, and CALD status

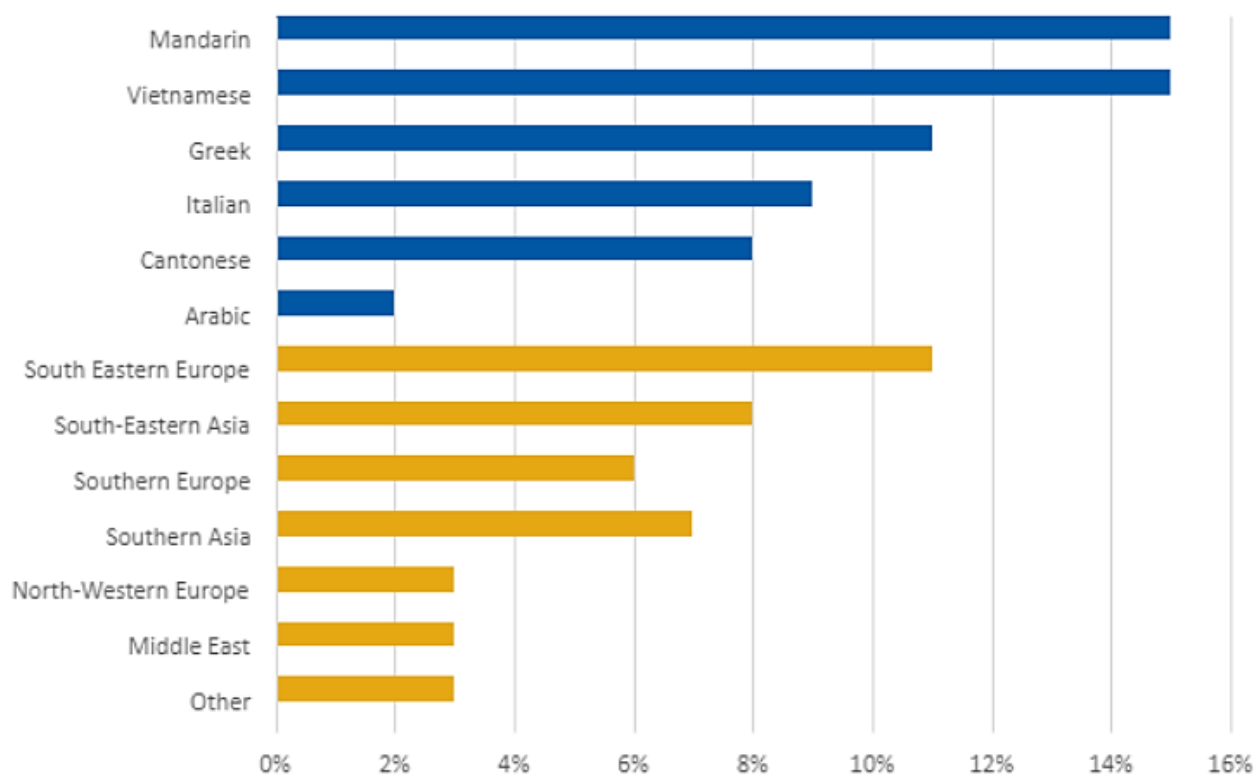
Of the 3,630 people who participated in the CPES, 247 were classified as a CALD cancer patients, representing of 7% of the overall survey cohort. Within this cohort, 51% of respondents identified as men, and 49% identified as women. Forty-six per cent were aged 70 years or older, 45% were aged 50-69 years, and 9% were aged 16–49 years. All respondents identified as neither Aboriginal nor Torres Strait Islander.

##### Language spoken at home and interpreter status

The most common languages spoken at home among the CALD survey cohort were Mandarin (15%) and Vietnamese (15%). The next most frequently reported languages were Greek, Italian, Cantonese, Arabic and other (Figure 2). Responses recorded as 'other' were categorised according to language groupings recommended by the Australian Bureau of Statistics: South-Eastern Europe, Southern Europe, North-Western Europe, South-Eastern Asia, Southern Asia, Middle East and Other (for languages that did not fit into the other language groups). Languages that were included as multiple-choice survey options in the survey were not included within the further categorised regional language groups. The distribution of 'other' languages spoken at home by CALD respondents is shown in orange in Figure 2.

Across the CALD cohort, 62% of respondents reported not needing an interpreter during appointments. Of those who required an interpreter, 56% recalled having one available at most or all appointments. Survey responses were completed in 22 languages other than English. Overall, 65% of CALD respondents completed the survey in English, 10% in Vietnamese, 10% in Mandarin, 6% in Greek, 3% in Cantonese, 3% in Italian, 1% in Arabic, and 1% in Spanish.

**Figure 2: Percentage distribution of languages spoken at home among identified CALD respondents across Victoria**



## Quantitative data

### *Finding out what was wrong*

Among CALD respondents 39% were seen by a specialist or clinic within 2 weeks of a GP referral, compared to 45% across the state. The majority of CALD respondents (75%) reported that their doctor explained their cancer diagnosis in a way they could understand, matching the statewide average. However, differences were observed across language groups: Italian (63%), Southern Europe (60%), Southern Asia (65%) and South-Eastern Asia (58%) language groups were below the state average, while Cantonese-speaking respondents reported understanding their cancer diagnosis that was above the statewide average (94%).

Seventy-seven per cent of CALD respondents were satisfied with the format in which their diagnosis was explained, compared to 73% across the state. The Cantonese cohort reported the highest percentage of respondents who were satisfied with the format in which their diagnosis was explained (89%). Overall, the majority of CALD respondents (95%) felt encouraged to ask questions about their diagnosis during consultations with their doctor.

Ninety-five per cent of the CALD cohort reported that staff repeated treatment options following their diagnosis. Similar to statewide averages, 76–77% of respondents were satisfied with the format in which information about their diagnosis and treatment options was provided. Just over half of CALD respondents (53–54%) reported being informed about how to access additional information and support.

Sixty-seven per cent of the CALD cohort reported that health professionals asked whether family/friends needed information or support during the diagnosis period. All language groups exceeded the statewide average (51%), except for the South-Eastern Asia cohort which reported 38%. Overall, the majority of CALD respondents (93%) felt they were treated with respect and dignity during their diagnosis.

### *Deciding on treatment*

Seventy-seven per cent of CALD respondents reported they were satisfied with their level of involvement in treatment decision-making, similar to the statewide average of 78%. The majority (88%) reported that short-term side effects of treatment were explained before they decided on treatment. Language group comparisons showed higher rates than the statewide average (79%) among Italian (89%), Greek (92%), Cantonese (100%), Southern Europe (93%) and Southern Asian (100%) respondents.

Most respondents (76%) reported that long-term side effects of treatment were explained prior to treatment decisions. Higher-than-average rates were observed among Greek (88%), Cantonese (93%), Vietnamese (77%), and South-Eastern Europe (86%) language cohorts, compared with the statewide average of 67%. However, only 50% of Southern European respondents had the long-term side effects of treatment explained to them. A slightly higher proportion of CALD respondents (81%) reported that staff checked their understanding of treatment side effects, compared to the statewide average (72%).

Eighty per cent of CALD respondents reported that staff encouraged them to ask questions about treatment options, slightly higher than the Victorian average of 74%. Slightly more CALD respondents were referred to services addressing potential treatment-related issues (e.g. reduced fertility, incontinence) before the commencing treatment, compared with the statewide average (79% versus 76%).

In line with the statewide average, 70% of the CALD cohort reported that staff discussed the possibility of participating in clinical trials. However, language group differences were evident: with Cantonese (91%) and Vietnamese (92%) respondents received clinical trial information more

frequently than the state average, whereas Greek (58%) Mandarin (59%), Southern European (55%), Southern Asian (60%) and South-Eastern Asian (54%) respondents received it less frequently.

### *Surgery*

Fifty-nine per cent of CALD respondents reported undergoing surgery to treat their cancer. Of these, 31% waited less than 2 weeks from being informed they were ready for surgery to undergoing the procedure. Among the CALD respondents who reported undergoing surgery, 59% reported that staff asked whether family or friends needed information or support, and 64% felt that staff discussed worries and concerns, both higher than the statewide averages 46% and 50%, respectively though not necessarily indicative of optimal care.

The majority of surgical CALD patients (89–90%) reported they received information about what to expect immediately after surgery and about managing side effects, and 92% reported that surgical staff explained things in a way they could understand. Sixty-seven per cent of CALD respondents reported that side effects and pain following surgery were well managed, lower than the Victorian average of 78%. However, 86% felt that staff did everything they could to manage surgical pain, comparable to the statewide average of 87%. Additionally, 91% of respondents felt they were able to access staff assistance in a timely manner.

For 85% of CALD respondents, follow-up care was reported to be organised prior to discharge. Similarly, 85% reported receiving information on managing at home, and 69% had arrangements made for any required home services, consistent with Victorian averages. Only 35% of CALD respondents reported they were provided with a hospital contact number for concerns or questions, comparable to the statewide average of 43%, indicating an area for potential improvement.

Ninety-two per cent of CALD respondents felt they were treated with respect and dignity during their surgical admission, and 98% rated care from the surgical teams as either 'good' or 'very good'.

### *Radiotherapy*

Forty-three per cent of CALD respondents reported receiving radiotherapy as part of their treatment. Among these, 52% reported they waited less than 2 weeks between radiotherapy planning (mapping) and the start of treatment. Between 79 and 92% of CALD respondents reported receiving information prior to radiotherapy treatment about how to prepare, how to manage stress/anxiety, how to manage side effects, what to expect at the end of treatment, and expected recovery time from radiotherapy. These results were broadly similar to the statewide averages.

In line with Victorian averages, 82% of CALD respondents reported that staff checked their understanding of the information provided about radiotherapy, and 77% felt their personal circumstances were considered when arranging appointments. Similar to the statewide average (94%), 92% of CALD respondents were given a phone number to contact if they had any questions.

Eighty-six per cent of CALD respondents reported that staff checked whether they were experiencing any treatment side effects and assisted them in managing them. Between 76% and 86% indicated that staff checked if they needed help with their emotional well-being, travelling to and from appointments, or managing diet, eating or physical activity. These results were broadly similar to Victorian averages. A slightly higher proportion of CALD respondents (55%) reported that staff asked whether their family or friends needed information or support, compared to the statewide average of 50%.

Ninety-seven per cent of CALD respondents felt they were treated with respect and dignity during radiotherapy, and 98% rated their radiotherapy care as either 'good' or 'very good'.

## *Chemotherapy*

Sixty-four per cent of CALD respondents reported they received chemotherapy treatment. Of these, 51% waited less than 2 weeks between being told they were ready for chemotherapy and commencing treatment compared with the statewide average of 55%. The majority (84%) reported that staff checked their understanding of the information provided about chemotherapy, and 74% felt that their personal circumstances were considered when arranging appointments.

Between 77% and 95% of CALD respondents reported receiving pre-chemotherapy information on key aspects of care: how to prepare (93%), how to manage stress/anxiety (77%), what to expect at the end of treatment (85%), possible side effects (86%), how to manage side effects (85%), the possibility of needing to attend the ED (95%), and how to contact the Symptom and Urgent Review Clinic (84%). These results were broadly similar to statewide averages.

However, lower proportion of Italian-speaking respondents reported receiving this information compared with the broader Victorian cohort. For Italian respondents, 73% were given information about how to prepare for chemotherapy, 60% were given information about how to manage stress/anxiety, 55% were given information about how they might feel after treatment, 64% were given information about side effects, 73% were given information about how to manage side effects at home, 82% were given information about the possibility of attending ED, and 82% were given information about accessing a Symptom and Urgent Review Clinic.

A smaller proportion of CALD respondents reported waiting less than 30 minutes prior to chemotherapy appointments compared to the statewide average (72% versus 83%). During treatment, 94% of CALD respondents reported that staff checked whether they were experiencing any side effects, and 80% felt that these side effects were managed well.

In line with statewide averages, 78–86% of CALD respondents reported that staff checked if they needed assistance with emotional support or travelling to and from chemotherapy appointments, and 91% reported that staff checked whether they needed help with their diet, eating and/or physical activity.

Almost all of CALD respondents (96%) reported they were provided with a phone number to contact if they had any questions. The majority (92%) reported they received a card explaining their chemotherapy treatment, which could be shown to ED staff if needed. Despite this, only 59% of CALD respondents reported that health professionals asked if family or friends needed information or support during chemotherapy, this was however higher than the statewide average of 49%.

Ninety-eight per cent of CALD respondents felt they were treated with respect and dignity during chemotherapy, and 99% rated their chemotherapy care as either 'good' or 'very good'.

## *Emergency Department experience*

Sixty-eight per cent of CALD respondents who attended ED during cancer treatment reported they waited more than 30 minutes to be seen, higher than the statewide average of 54%. Slightly fewer CALD respondents felt their condition was well managed in the ED (72% versus 75% statewide). Language group differences were observed: 88% of Vietnamese respondents felt their condition was well managed in the ED, above the Victorian average (75%), whereas 65% of Southern Asian respondents reported the same issue, slightly below the statewide average of 60%.

Overall, 77% of CALD respondents felt that ED staff had the knowledge and skills to care for them, compared with 73% statewide. This perception was highest among Vietnamese (89%) and Mandarin (86%) language groups.

## *Follow-up care*

Sixty-seven per cent of CALD respondents reported receiving a written plan for 12-month follow up care compared with the statewide average of 56%. Slightly higher proportions of CALD respondents felt staff considered their personal circumstances when arranging follow-up appointments and that

appointments and tests were coordinated to reduce travel time (66–67% versus 62% and 60%, respectively).

The majority (80%) of CALD respondents reported that test results and other information were always available to their GP and specialists, compared to the Victorian average (77%). However, fewer CALD respondents expressed confidence in their GPs' ability to manage ongoing care than the statewide average (49% versus 55%). Confidence was lowest among Mandarin (33%) and South-Eastern Asian (22%) language groups in their GPs' abilities to manage their ongoing care.

Between 80% and 88% of CALD respondents reported receiving information about required follow-up tests, strategies to stay healthy, and the frequency of tests and check-ups, consistent with statewide averages.

Sixty-four per cent of CALD respondents reported receiving information about which new symptoms require investigation, and 67% were provided guidance on how to access additional support for themselves or their family, similar to the statewide averages of 59% and 62%, respectively. A greater proportion of CALD respondents (69%) reported receiving information about how people generally feel after completing cancer treatment, compared with 58% of the broader Victorian cohort. Additionally, 73% of CALD respondents received information on managing ongoing symptoms, consistent with the statewide average of 69%. Forty-six per cent of Mandarin respondents and 43% of South-Eastern Asian respondents received information about how to get extra support, which was lower than the statewide average (62%). Just over half (56%) of South-Eastern Asian respondents were given information about required follow-up tests which was lower than the statewide average (82%). Only 25% of South-Eastern Asian respondents were given information about the investigation of new symptoms, which was lower than the statewide average (59%). Less than a quarter (22%) of South-Eastern Asian respondents were given information about how people generally feel after treatment, which was lower than the statewide average (58%). Only 40% of South-Eastern Asian respondents were given information about the frequency of check-ups and tests, which was lower than the statewide average (80%).

### *Information received*

CALD respondents reported receiving sufficient information about possible impacts on usual activities (84%), possible changes in energy levels (82%), and fertility preservation (75%), all broadly similar to the statewide averages of 77%, 76% and 68%, respectively. Most respondents (76%) felt that they could ask health professionals questions, comparable to the statewide average of 83%.

Fewer CALD respondents felt able to discuss complementary or alternative therapies for symptom management, compared with the statewide average (36% versus 42%).

CALD respondents reported being informed by health professionals about financial support programs less frequently than the overall state cohort (36% versus 47%). Frequencies for discussions regarding specific supportive care services provided to the CALD cohort during their cancer care are presented in Table 1.

Rates varied across questions related to whether health professionals asked CALD respondents if they needed help with a range of other activities. Sixty-five per cent of CALD respondents were asked about domestic chores (Victorian average 77%), 68% were asked about family problems (Victorian average 73%), 69% were asked about childcare (Victorian average 67%), 41% were asked about finances (statewide average 45%), and 59% were asked about support groups (Victorian average 69%).

**Table 1: Additional supportive services mentioned by staff to respondents**

	State	CALD overall	Italian	Greek	Vietnamese	Mandarin	Southern European	South-Eastern European	Southern Asian	South-Eastern Asian
<b>Social Worker</b>	85%	79%	75%	92%	90%	63%	-	-	-	60%
<b>Psychologist</b>	73%	76%	83%	85%	-	67%	-	-	-	-
<b>Dietitian</b>	82%	76%	80%	82%	83%	68%	91%	90%	-	-
<b>Speech Therapist</b>	77%	58%	-	-	-	-	-	-	-	-
<b>Occupational Therapist</b>	74%	60%	-	-	-	55%	-	-	-	-
<b>Pain management specialist</b>	64%	57%	-	-	-	43%	-	-	-	-
<b>Cancer Helpline</b>	84%	75%	80%	85%	86%	62%	70%	82%	91%	50%
<b>Financial planner/ services</b>	42%	43%	-	-	-	-	-	-	-	-
<b>Physio</b>	75%	66%	-	-	-	59%	-	-	-	-
<b>Palliative Care</b>	77%	56%	-	-	-	36%	-	-	-	-

Green shading indicates performance scores  $\geq 10\%$  higher than the statewide average.

Red shading indicates performance scores  $\leq 10\%$  lower than the statewide average.

- indicates that the response rate was below 10 responses.

## Overall care

When asked about their overall cancer care, 98% of CALD respondents rated their overall care as either 'very good' or 'good'. Ninety-two per cent rated how well staff worked together as either 'excellent' or 'very good'.

Fewer CALD respondents than the broader Victorian cohort reported that there was never a time they were so unhappy that they would want to complain (48% versus 56%).

Ten per cent of CALD respondents reported receiving conflicting information from different health professionals during their cancer care, and 12% felt that a health professional was not fully informed about their treatment and progress, compared with the statewide averages 18% and 17% respectively.

Only 3% of CALD respondents felt that tests were repeated unnecessarily, and 11% attended at least one appointment where their results were unavailable, compared with the statewide averages of 6% and 14% respectively.

Only 10% of CALD respondents felt that health professionals did not share information with other providers, compared with the statewide average of 15%. Additionally, just 2% of CALD respondents reported experiencing discrimination based on racial, ethnic or cultural background.

Fewer CALD respondents reported having a health professional they could contact to address questions or concerns throughout their care compared with the Victorian average (71% versus 83%). A similar proportion felt that treatment centres were well informed about care received at other sites (CALD cohort 84% and Victorian cohort 82%). Over half (64%) of CALD respondents believed their GP was kept informed throughout their care, in line with the broader Victorian cohort.

Sixty-seven per cent of CALD respondents reported they were provided with the name of the Clinical Nurse Specialist responsible for their care, and 70% reported that it was easy to contact their Clinical Nurse Specialist compared with the statewide averages of 67% and 74%, respectively. The majority (92%) of CALD respondents felt that their Clinical Nurse Specialist listened carefully, similar to the Victorian average of 91%. However, fewer CALD respondents reported that they often received answers from their Clinical Nurse Specialist that they understood, compared with the broader Victorian cohort (87% versus 92%).

## Your health today

At the time of the survey, 29% of CALD respondents rated their health at 81/100 or higher compared with 40% across Victoria. Across 5 areas of daily functioning, 41–83% of CALD respondents reported no issues: self-care (83%), mobility (61%), anxiety/depression (54%), ability to perform usual activities (58%), and pain/discomfort (41%). These results were broadly similar to statewide averages: 89%, 68%, 57%, 57%, and 45%, respectively.

## Qualitative data

Open-ended survey questions received responses from 17–145 CALD respondents, depending on the item. Each free-text response addressed between 4 and 7 principles from the OCP. Brief descriptions of each OCP principle are provided below before results are presented by aspect of care. For detailed descriptions of each principle, please refer to:

<https://optimalcarepathways.com.au/principles>. Responses coded as N/A were excluded from the analysis.

## 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. It addresses the range of 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 and throughout the cancer care continuum.

### *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

The CPES was designed to align with the steps of the OCP steps, addressing various aspects of optimal cancer care. Free-text responses were collected within some of these categories, focusing on what respondents considered helpful and areas they felt could be improved. Additional open-ended questions invited respondents to describe specific instances in which they experienced particularly good or bad cancer care.

### *Diagnosis*

Aspects of diagnosis that CALD respondents found most helpful, reflected 5 principles: Patient-centred care; safe and quality care; supportive care; care coordination; and communication (Table 2). CALD respondents most frequently referred to communication, followed by patient-centred care. Responses indicated that respondents found direct communication, information sharing, and staff who were helpful, patient and had a positive and professional attitude to be most beneficial during diagnosis. Responses related to patient-centred care focused on the ways in which clinical staff

displayed empathy and support throughout the diagnosis process. Some CALD respondents also found the involvement of family members during the diagnostic stage of care helpful, and 7 CALD respondents specifically acknowledged the value of access to effective interpreting services or bilingual staff as being helpful.

CALD respondents discussed Principles 2: Safe and quality care and 5: Care coordination less frequently. When discussing helpful aspects of safe and quality care, most responses focused on respectful and friendly interactions with staff and the breadth of clinical experience among healthcare professionals. One respondent, however, reported poor experiences with their GP and haematologist, while noting effective communication from the oncology team. Responses related to care coordination emphasised the timeliness of care and respondents' ability to follow up with or contact staff, as well as access telehealth readily. The 3 responses categorised as 'other' referred to the impacts of COVID lockdowns on cancer care and satisfaction with having no out-of-pocket costs associated with their cancer care. One positive response related to supportive care noted the value of coordinated appointments: *'Have all the appointments ready, including psychologist'*.

**Table 2. Principles discussed in free-text questions related to diagnosis**

Survey item	Responses <sup>1</sup>	OCP Principle <sup>2</sup>	Frequency	% Freq
Q11: What were the most helpful things staff did during your diagnosis?	145	1: Patient-centred care	85	36%
		2: Safe and quality care	26	11%
		4: Supportive care	1	<1%
		5: Care coordination	17	7%
		6: Communication	107	45%
		Other	3	1%
Q12: What could be done to improve the diagnosis experience?	115	1: Patient-centred care	24	26%
		2: Safe and quality care	5	5%
		3: Multidisciplinary care	2	2%
		4: Supportive care	6	7%
		5: Care coordination	24	26%
		6: Communication	27	30%
		7: Research and clinical trials	1	1%
		Other	2	2%

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

Most areas that CALD respondents felt could be improved during diagnosis related to patient-centred care, care coordination, and communication. CALD respondents most frequently described a need for clearer explanations of information, improved communication with patients, and the use of multiple communication methods during diagnosis. One CALD respondent described an instance in which staff were not being helpful or supportive (Principle 6: Communication). Responses related to Principle 1: Patient-centred care mainly focused on a perceived lack of empathy and support from staff, the need for greater family involvement, and patients feeling excluded from decision-making. Three CALD respondents reported that they did not have access to an interpreter. Responses related to Principle 5: Care coordination focused on long waiting times for diagnostic investigations, appointments with doctors, and cancer screening. One CALD respondent also described feeling that their discharge from hospital was very rushed:

*'Patient shouldn't be asked to leave hospital while in shocked. I had to begged to stay one more night, and I made offer to pay for it. I was so desperate'*.

Other responses relating to Principle 5 described problems with appointment scheduling, support at home, access to in-person appointments, regular testing, and coordination between treatment sites.

### Treatment decision-making

Aspects of treatment decision-making that CALD respondents found most helpful reflected six principles: 1: Patient-centred care, 2: Safe and quality care, 3: Multidisciplinary care, 5: Care coordination, 6: Communication, and 7: Research and clinical trials (Table 3). Respondents most frequently referred to Principle 6: Communication, highlighting the importance of direct communication, clear explanations, information sharing, and staff who were helpful, positive, patient and professional in supporting treatment decision-making.

Responses related to Principle 1 focused primarily on staff who demonstrated empathy and support, as well as involving patients and family members in decision-making. Two CALD respondents mentioned having access to effective interpreter services was helpful. Responses related to Principle 2 focused on general satisfaction with care, the knowledge and experience of clinical staff, and the friendliness of staff. Responses related to Principle 5 centred on the timeliness of care and the ability to follow up with or contact doctors regarding questions. One respondent reported that receiving a referral to a fertility specialist was helpful during treatment decision-making (Principle 3), and one noted that being offered participation in a medical trial was beneficial (Principle 7: Research and clinical trials).

**Table 3. Principles discussed in free-text questions related to treatment decision-making**

Survey item	Responses	Principle	Frequency	% Freq
Q23: What were the most helpful things staff did in relation to treatment decisions?	117	1: Patient-centred care	41	22%
		2: Safe and quality care	29	16%
		3: Multidisciplinary care	1	<1%
		5: Care coordination	13	7%
		6: Communication	98	54%
		7: Research and clinical trials	1	<1%
Q24: What could be done to improve your experience in relation to treatment decisions?	78	1: Patient-centred care	6	15%
		2: Safe and quality care	1	2%
		4: Supportive care	5	12%
		5: Care coordination	7	17%
		6: Communication	20	49%
		7: Research and clinical trials	1	2%
		Other	1	2%

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

When CALD respondents were asked what could be improved during treatment decision-making, they most commonly described a need for better communication and information sharing from staff, use of different methods for information provision and the offering of multiple treatment options (Principle 6: Communication). Other issues highlighted included lack of access to interpreter services (Principle 1: Patient-centred care), poor medication management (Principle 2: Safe and quality care), a desire for more spiritual and emotional support including access to support groups (Principle 4: Supportive care), long waiting times (Principle 5: Care coordination), limited access to cancer research centres (Principle 7: Research and clinical trials), and the impact of COVID-19 lockdowns on cancer care (other).

## *Surgery*

Themes related to six of the OCP Principles were highlighted as being helpful during a hospital stay for surgery (Principles 1, 2, 3, 4, 5, and 6, see Table 4). Responses related to Principle 2 focused on general satisfaction with care, knowledge and experience of clinical staff, effective management of side effects and symptoms, and friendly, respectful staff. Responses related to Principle 6 emphasised clear communication with patients and staff who were helpful, professional, and positive. Responses related to Principle 1 highlighted empathy and support from staff, with one CALD respondent expressing gratitude for a bilingual nurse. Responses related to Principle 5 centred on timeliness of care and effective follow-up care following surgery. One response related to Principle 3 noted good coordination between departments and specialities, while one response related to Principle 4 highlighted helpful referrals to social work and psychiatry. Additionally, one response related to accommodations for visitors during COVID lockdowns (other).

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

Survey item	Responses	Principle	Frequency	% Freq
Q50: What were the most helpful things staff did while you were in hospital for surgery?	64	1: Patient-centred care	24	26%
		2: Safe and quality care	23	25%
		3: Multidisciplinary care	1	1%
		4: Supportive care	1	1%
		5: Care coordination	14	15%
		6: Communication	27	30%
		Other	1	1%
Q51: What could be done to improve your surgery experience?	42	1: Patient-centred care	7	18%
		2: Safe and quality care	14	36%
		5: Care coordination	7	18%
		6: Communication	10	26%
		Other	1	3%

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

Aspects of surgical care that CALD respondents felt could be improved centred around Principle 1: Patient-centred care, Principle 2: Safe and quality care, Principle 5: Care coordination and Principle 6: Communication. Responses related to Principle 2 focused primarily on a perceived lack of knowledge and experience among clinical staff, and negative post-surgery experiences. One respondent also highlighted the need for increased staffing to support care:

*'On my first surgery the night nurse was probably overworked but she definitely [sic] was not very helpful - more night staff would be good'.*

Responses related to Principle 6 highlighted a lack of communication and information sharing with patients. Responses related to Principle 1 focused on limited access to interpreting services or bilingual staff, as well as dissatisfaction with the food provided during the surgical admission. Responses related to Principle 5 focused on long waiting times for surgery and post-surgery care, as well as insufficient follow-up information. One response noted the impact of COVID lockdowns on surgical admissions (other).

CALD respondents most frequently highlighted the need for clearer communication with patients including providing more information, involving family and/or friends in discussions, and ensuring information is communicated in a way patients can understand. CALD respondents also described issues with not receiving call-backs from hospital staff after their surgery, experiences of inadequate pain management, and discomfort caused by noisy equipment in patient rooms overnight (Principles 1 and 2; see Table 4).

### *Radiotherapy*

Aspects of radiotherapy considered most helpful by CALD respondents related to Principle 1: Patient-centred care, Principle 2: Safe and quality care and Principle 6: Communication (Table 5). Responses related to Principle 1 focused primarily on the empathy and support provided by staff, access to transport services, availability of departmental contact details, and assistance with managing treatment side effects. Responses related to Principle 2 focused most often on positive experiences with friendly and respectful staff. Responses related to Principle 6 emphasised clear communication with patients, and staff who were helpful, professional, and positive. Responses related to Principle 5 focused on receiving timely care and adequate follow-up care after radiotherapy.

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

Survey item	Responses	Principle	Frequency	% Freq
Q74: What were the most helpful things staff did during your radiotherapy?	52	1: Patient-centred care	26	36%
		2: Safe and quality care	20	27%
		5: Care coordination	8	11%
		6: Communication	19	26%
Q75: What could be done to improve your radiotherapy experience?	33	1: Patient-centred care	2	15%
		2: Safe and quality care	3	23%
		5: Care coordination	4	31%
		6: Communication	3	23%
		Other	1	8%

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

Aspects of radiotherapy that CALD respondents felt could be improved centred around Principle 1: Patient-centred care, Principle 2: Safe and quality care, Principle 5: Care coordination, and Principle 6: Communication. Responses related Principle 5 focused on appointments running late during radiotherapy. Responses related to Principle 2 highlighted the need for more staff and improvements to available radiotherapy equipment. Responses related to Principle 6 emphasised poor communication with CALD respondents regarding radiotherapy and a perception that staff were not sufficiently positive or friendly. Responses related to Principle 1 centred on a lack of bilingual staff and a perceived absence of empathy and support from staff. One response suggested that a self-check-in system should be adopted (other):

*'Reception can be replaced by self-check-in'.*

### **Chemotherapy**

Responses regarding what CALD respondents found most helpful during chemotherapy aligned primarily with Principle 1: Patient-centred care, Principle 2: Safe and quality care, and Principle 6: Communication (Table 6). Responses related to Principle 1 focused on aspects of care such as the empathy and support of staff, access to transport and meals during chemotherapy, involvement of family members, and access to bilingual staff and/or interpreters as particularly helpful.

Responses related to Principle 6 focused primarily on the benefits of clear communication with patients, and staff who were helpful, positive, professional and patient. Responses related to Principle 2 focused on being treated with respect by staff and having attentive and friendly staff, although 2 CALD respondents described poor experiences with staff during chemotherapy. Responses related to Principle 5 focused primarily on access to treatment and support at home and effective follow-up during and after chemotherapy treatment. Responses related to Principle 4 centred on emotional and spiritual support. One response noted staff being accommodating during the COVID lockdowns (other):

*'...made special consideration for my family to visit during covid-19 [sic]...'*

**Table 6: Principles discussed in free-text questions related to chemotherapy**

Survey item	Responses	Principle	Frequency	% Freq
Q99: What were the most helpful things staff did during your chemotherapy?	79	1: Patient-centred care	42	34%
		2: Safe and quality care	28	22%
		4: Supportive care	3	2%
		5: Care coordination	14	11%
		6: Communication	37	30%
		Other	1	1%
Q100: What could be done to improve your chemotherapy experience?	47	1: Patient-centred care	6	21%
		2: Safe and quality care	6	21%
		4: Supportive care	3	11%
		5: Care coordination	7	25%
		6: Communication	4	14%
		7: Research and clinical trials	1	4%
		Other	1	4%

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

Aspects of chemotherapy that CALD respondents indicated could be improved centred around Principle 1: Patient-centred care, Principle 2: Safe and quality care, and Principle 5: Care coordination. Responses related to Principle 5 mainly focused on long waiting times during appointments. Responses related to Principle 1 highlighted lack of access to transport and parking during appointments, restrictions on family visiting during treatment, and suggestions for having music playing. Responses related to Principle 2 focused on the perceived deficiencies in the clinical skills and experience of chemotherapy staff, as well as limited availability of doctors. One CALD respondent also described a negative experience with a nurse:

*‘One of the nurses cut off the iv saline halfway [sic]. Never finish the pack. When questioned. She said there is no need & quite rude’.*

Responses related to Principle 6 highlighted a lack of information and poor communication with CALD respondents regarding the chemotherapy experience and potential side effects. Responses related to Principle 4 focused on a lack of access to assistance with mental health, nutrition, and exercise. One respondent noted a perceived lack of research on hair loss as a side effect of chemotherapy (Principle 7) and one response related to chemotherapy medication being lost in the mail during COVID lockdowns (other).

### ***Emergency department (ED) experiences***

Responses regarding what CALD respondents found most helpful during ED experiences aligned primarily with Principle 2: Safe and quality care (Table 7). Responses related to Principle 2 described the good clinical skills of staff, adequate management of side effects, symptoms and medication, and general satisfaction with care as most helpful during ED experiences. However, one CALD respondent described a negative experience in which they were not triaged from the waiting room:

*‘Nothing – was sent home. Did not even make it out of waiting room’.*

Responses related to Principle 6 focused primarily on clear communication with CALD respondents and engagement with professional, helpful staff in the ED. Responses related Principle 5 emphasised timeliness of care and satisfaction with the investigations conducted during the ED admission. Responses related to Principle 1 solely highlighted the helpfulness of empathy and support provided by ED staff. One response related to reassurance regarding communication between ED and haematology (Principle 3), and one response described satisfaction except for a ‘very expensive fee’ (other).

**Table 7: Principles discussed in free-text questions related to ED experiences**

Survey item	Responses	Principle	Frequency	% Freq
Q107: What were the most helpful things staff did during your Emergency Department visit?	38	1: Patient-centred care	5	10%
		2: Safe and quality care	22	44%
		3: Multidisciplinary care	1	2%
		5: Care coordination	8	16%
		6: Communication	13	26%
		Other	1	2%
Q108: What could be done to improve the Emergency Department experience for cancer patients?	34	1: Patient-centred care	7	19%
		2: Safe and quality care	7	19%
		3: Multidisciplinary care	1	3%
		5: Care coordination	18	49%
		6: Communication	2	5%
		Other	2	5%

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

Aspects of ED that CALD respondents indicated could be improved primarily centred on Principle 5: Care coordination, with a particular focus on the long waiting times during ED admission. CALD respondents also described areas of improvement related to Principle 1: Patient-centred care and Principle 2: Safe and quality care. Patient-centred responses to Principle 1 emphasised a lack of empathy and support from ED staff. One respondent described the challenge of not having family available to translate during COVID lockdowns:

*'It was during COVID, so my issue was I had no family to help me translate. So that was a big issue'.*

Responses related to Principle 2 described concerns about perceived lack of knowledge and experience among clinical ED staff, as well as limited resources and staffing in the ED. CALD respondents also described a desire for more reassurance from staff (Principle 6). Two responses noted the high cost of ED services and the impact of COVID lockdowns on care (as quoted above; Other). One response also described the need for quicker referrals to specialists (Principle 3: Multidisciplinary care).

### *Follow-up care*

Aspects of follow-up care that CALD respondents found most helpful primarily related to Principle 6: Communication, and Principle 5: Care coordination (Table 8). Responses related to Principle 6 mainly focused on clear communication and information provision to patients, helpful staff, and reassurance from staff. Responses related to Principle 5 highlighted access to comprehensive follow-up care, regular testing and investigations, and staff assistance with organising appointments. Responses related to Principles 1 and 2 emphasised the friendliness, empathy, and support shown to CALD patients demonstrated by staff. One CALD respondent also noted that access to an interpreter was helpful.

**Table 8: Principles discussed in free-text questions related to follow-up care**

Survey item	Responses	Principle	Frequency	% Freq
Q120: What were the most helpful things staff did during your follow-up care?	63	1: Patient-centred care	9	12%
		2: Safe and quality care	7	9%
		5: Care coordination	25	33%
		6: Communication	35	46%
Q121: What could be done to improve the follow-up experience for cancer patients?	47	1: Patient-centred care	1	3%
		2: Safe and quality care	4	14%
		3: Multidisciplinary care	2	7%
		4: Supportive care	2	7%
		5: Care coordination	17	59%
		6: Communication	2	7%
		Other	1	3%

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

In contrast, responses describing possible improvements to follow-up care were primarily related to Principle 5: Care coordination. These included experiences of long waiting times to see and/or contact doctors and a desire for more and better access to telehealth appointments. Less frequently, responses described perceived deficiencies in clinical staff experience, miscommunication between staff, limited information sharing among health professionals, inadequate mental health and dietetics support, and insufficient communication with patients. One CALD respondent also expressed dissatisfaction with their GP's approach to follow-up care:

*'GPs [sic] generally don't care; hence you are on your own and reliant on the hospital contacts'.*

One response also described a negative impact on follow-up care related to the busyness of the hospital due to COVID-19 (other).

### *Additional comments made in survey*

All principles were reflected in the additional comments section of the survey (Table 9).

Additional comments related to the provision of information during cancer care primarily aligned with Principle 6: Communication. Three responses described adequate information provision and effective communication with patients. However, 8 responses described instances of limited information provision and/or a lack of treatment options being offered to CALD respondents (Principle 6). One respondent reported:

*'I did not feel I could talk to my surgeons about alternative treatment at the time I've been told they do not have a suitable treatment for me when we find out my cancer'.*

Responses describing negative instances of care primarily related to Principle 2, Principle 5: Care coordination, Principle 6: Communication, Principle 2: Safe and quality care, and Principle 3: Multidisciplinary care mainly focused on perceived deficiencies in clinical skills and experience of staff, poor treatment outcomes, and inadequate management of side effects, symptoms, and medication. One respondent also described a desire for earlier access to supportive care during their cancer journey:

*'...I would have liked psychological help at the beginning and not wait for the results for months'.*

Other comments regarding negative experiences of care described issues such as unavailability of results during appointments, long waiting times, poor appointment scheduling, treatment delays, inadequate communication and provision of information to patients, perceived deficiencies in clinical skills and experience of clinical staff, poor management of side effects and medication, and negative

interactions with clinical staff. One respondent also reported feeling discriminated against by a chemotherapy nurse:

*'When I had chemotherapy, the nurse discriminate me; they often said that I was a bad one'.*

Responses related to Principle 3 focused primarily on poor communication and provision of information between health professionals and departments, for example:

*'There was a time, just once, when information was not forwarded to my GP [sic]'.*

Responses describing instances in which respondents wanted to, or did, make a complaint mainly related to Principle 2: Safe and quality care. These comments primarily focused on poor treatment outcomes, negative experiences with clinical staff, perceived deficiencies in clinical skills and experience, and inadequate management of side effects and medication. One response highlighted issue with the poor coordination of care between departments (Principle 3):

*'After my 1st surgery, the team seemed not well planned on whether or not to discharge me (Different opinions from different departments).'*

Additional comments provided at the end of the survey addressed at least one aspect of all Optimal Care Principles, with the exception of Principle 3: Multidisciplinary care. Overall, responses conveyed general satisfaction with the care received, with several respondents expressing gratitude toward their care team. However, one response highlighted the need for improvements in communication and staff tact relating specifically to (Principles 1 and 6.

*'The nursing team are wonderful, but level of communication can be improved. Doctors sometimes lack diplomacy on how they speak with patients'.*

One response also described difficulty with getting access to an adequate interpreter:

*'[I] would like to be more independent for hospital visits ...[but] interpreting services being so unreliable, my daughter had to come with me. Plus, no interpreter service would help me check in etc, they all just come for appointment times'.*

**Table 9: Additional free-text questions**

Survey item	Responses	Principle	Frequency	% Freq
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.	46	1: Patient-centred care	5	10%
		2: Safe and quality care	8	16%
		3: Multidisciplinary care	1	2%
		4: Supportive care	4	8%
		5: Care coordination	8	16%
		6: Communication	22	44%
		Other	2	4%
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. <sup>3</sup>	40	1: Patient-centred care	1	2%
		2: Safe and quality care	9	18%
		3: Multidisciplinary care	8	16%
		5: Care coordination	19	38%
		6: Communication	13	26%
Q142: If yes, what was the issue you wanted to complain about? <sup>4</sup>	17	1: Patient-centred care	4	18%
		2: Safe and quality care	9	41%
		3: Multidisciplinary care	2	9%
		5: Care coordination	3	14%
		6: Communication	4	18%
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.	71	1: Patient-centred care	17	25%
		2: Safe and quality care	19	25%
		4: Supportive care	2	3%
		5: Care coordination	11	16%
		6: Communication	18	26%
		7: Research and clinical trials	1	1%
		Other	1	1%

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

## 4.2 Focus groups

Twelve people from CALD backgrounds diagnosed with cancer or were carers participated in the focus group discussions.

### Demographics

Table 10 summarises the demographic characteristics of focus group participants. Three-quarters of participants were female (75%, n=9). Participants varied in age, with 42% (n=5) younger than 50 years, 8% (n=1) aged 50–60 years, 33% (n=4) aged 61–70 years, and 17% (n=2) older than 70 years. All participants resided in metropolitan areas. Three-quarters of participants (75%, n=9) identified as being from Asian backgrounds, while 8% (n=1) were from the Middle East, 8% (n=1) from East Africa, and 8% (n=1) from South America. Most participants (67%, n=8) had lived in Australia for more than 20 years. Two participants had lived in Australia for less than 10 years, and two (17%, n=2) did not provide a response.

**Table 10. CALD cancer focus group demographic information**

<b>Gender</b>	<b>n = 12</b>	<b>Percentage</b>
Women	9	75%
Men	3	25%
Total	12	100%
<b>Patient/carer</b>	<b>n = 12</b>	<b>Percentage</b>
Patient	7	58%
Carer	5	42%
Total	12	100%
<b>Age</b>	<b>n = 12</b>	<b>Percentage</b>
Younger than 50	5	42%
50–60	1	8%
61–70	4	33%
Older than 70	2	17%
Total	12	100%
<b>Stage/grade</b>	<b>n = 12</b>	<b>Percentage</b>
Asia	9	75%
Middle East	1	8%
South America	1	8%
East Africa	1	8%
Total	12	100%
<b>Region</b>	<b>n = 12</b>	<b>Percentage</b>
Metropolitan	12	100%
Regional	0	0%
Total	12	100%
<b>Years resided in Australia</b>	<b>n = 12</b>	<b>Percentage</b>
<5 years	0	0%
5–10 years	2	17%
11–20 years	0	0%
20+ years	8	67%
Unanswered	2	17%
Total	12	100%

### OCP Step 1: Prevention and early detection

**Focus group participants were asked if they were aware of cancer prior to their diagnosis.**

Most participants (67%, n=8) reported having limited or no awareness of cancer risks prior to their diagnosis. A smaller proportion (33%, n=4) described some general awareness through public campaigns or media messaging, particularly relating to skin cancer and breast screening campaigns. However, these participants noted that the information felt generic and not personally targeted.

*'With GPs, there hasn't been much of a focus on preventative measures. It's been more reactive treatment... Nothing has ever been mentioned about cancer screening or family history.'*

Screening awareness was reported by 25% of participant (n=3), who described learning about screening primarily through family members' experience rather than through advice from health professionals.

*'I was aware of screening because of my mum - but not for myself, not for my age group.'*

Language and translation gaps in prevention materials were identified by 25% (n=3), who reported that multilingual resources were either incomplete or not culturally appropriate. Overall, knowledge of cancer prevention was typically acquired incidentally rather than being systematically delivered through primary care channels.

*'A lot of information is lost in translation... there is not enough language support for a multicultural society.'*

## **OCP Step 2: 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.**

Help-seeking timelines varied widely among participants. Delayed help-seeking beyond one month was reported by 42% (n=5), often linked to misinterpretation of symptoms or initial reassurance that symptoms were not serious. A third of participants (33%, n=4) reported seeking medical help within weeks; however, this was typically when symptoms were severe or rapidly progressing. A further third (33%, n=4) described experiences of initial misdiagnosis, where symptoms were attributed to benign causes such as infection, stress, or other minor symptoms.

One third of participants (33%, n=3) reported attending multiple consultations before their health professional escalated the issue for further investigation. Participants more often attributed these delays to diagnostic gatekeeping and early clinical framing rather than to cultural reluctance to seek care.

*'It went on for a year. I was told it was infection... It didn't occur to me that it could be cancer.'*

## **OCP Step 3: Diagnosis, staging and treatment planning**

**Focus groups explored how long from investigation of their symptoms it took for their symptoms to be appropriately investigated.**

Diagnostic timelines varied considerably among participants. One third (33%, n=4) reported being quickly referred to a specialist, while 2 participants (17%, n=2) reported referred within one month. A quarter of participants (25%, n=3) reported delays of more than 4 weeks, and another quarter (25%, n=3) reported delays exceeding 3 months, often involving multiple GP visits and missed escalation opportunities for escalation.

Participants attributed delays primarily to system fragmentation and early misclassification of symptoms, rather than to cultural hesitation in seeking care. Several delayed cases involved repeated reassurance or symptoms being framed as non-specific.

*'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.**

Understanding of the cancer diagnosis was influenced by communication supports and the medical literacy of family members. Just under half of participants (42%, n=5) reported a clear understanding of diagnosis, typically where clinicians used plain language or repeated explanations. In several cases, understanding was further supported by family members with higher levels of medical literacy.

*'She (a medically trained family member) explained in layman terms - that helped me understand what was happening.'*

Approximately one third of participants (33% (n=4) reported having a partial understanding of their diagnosis. A quarter of participants (25%, n=3) indicated that they required repeated explanations from clinicians, while another quarter reported relying on independent research to better understand their condition. Language alone was not identified as the primary barrier; rather, medical literacy and emotional state were described as stronger determinants of understanding.

*'I didn't understand everything at the time - later I had to look it up myself.'*

### **OCP Step 4: Treatment**

#### **Focus group participants were asked how long it took for them to begin active treatment after their diagnosis.**

Treatment initiation occurred relatively quickly for most participants. Half of participants (50% (n=6) reported commencing treatment within 2 weeks. A further 25% (n=3) state they began treatment within 6 weeks. Delays beyond 6 weeks were reported by 17% (n=2), while one participant (8% (n=1) experienced a delay of more than 3 months before treatment commenced. Delays were attributed to imaging complexity, surgical scheduling, or decision-making needs rather than cultural refusal. Several participants emphasised that clinicians communicated timing targets clearly when delays occurred

Participants attributed delays primarily to imaging complexity, surgical scheduling, or the need for additional decision-making, rather than to cultural reluctance to proceed with treatment. Several participants also emphasised that clinicians clearly communicated expected timing and reasons for delays when they occurred.

#### **Participants were also asked about their treatment and experiences of the treatments they received.**

Understanding of treatment processes and potential side effects varied among participants. Over half of participants (58%, n=7) reported partial or delayed understanding, often describing information overload during diagnosis and early treatment phases, where large volumes of technical explanations were provided at times of high emotional distress.

*'Some things I never understood... it was too overwhelming.'*

Family members or medically literate relatives served as interpreters or explainers in 42% of responses (n=5), particularly among CALD participants who relied on bilingual children or siblings with health-training. Clear and repeated explanations from clinicians, especially nurse coordinators and specialist teams, were associated with strong understanding in 33% of participants (n=4).

Insufficient preparation for long-term or late side effects was reported by 33% participants (n=4), particularly regarding survivorship complications and permanent treatment consequences. An equal proportion (33% (n=4) reported relying on independent self-education to address these knowledge gaps.

*'I just don't think I was prepared for what life looks like after treatment... permanent side effects.'*

Experiences of pain and symptom management were mixed. Adequate symptom control was reported by 42% of participants (n=5) and was associated with responsive inpatient teams and proactive nurse engagement. Conversely, an equal proportion (42%, n=5) reported insufficient discussion or inconsistent symptom follow-up particularly for chronic symptoms, survivorship-related pain, and non-visible side effects.

Family advocacy to escalate symptom concerns was reported in 25% of responses (n=3). Cultural stoicism or reluctance to complain was implied and explicitly mentioned by a few participants (17%, n=2). More commonly, participants identified system factors such as short consultation times, limited proactive symptom inquiry and overall system pacing, as the primary contributors to under-managed pain.

Clinical trials were not discussed or not offered for the majority of participants (83%, n=10). Among CALD participants, clinical trials were often perceived as unnecessary or as being reserved for other patients with more advanced-stage diagnoses.

Fertility preservation was discussed with a minority of participants (25%, n=3), primarily younger patients whom clinicians raised the topic proactively.

*'There were many decisions to make in a very short period of time... different types of surgery... prevention.'*

**Focus group participants were asked about their supportive care needs and referrals they may have received.**

Supportive care was accessed by just over half of participants (58%, n=7), with commonly used services including social work, psychology, physiotherapy, breast care nursing, and pastoral care. Strong supportive care experiences linked to proactive referral and coordination and were reported by 42% of participants (n=5).

Unmet supportive care needs, particularly in social work, financial navigation, and rehabilitation, were reported by 33% of participants (n=4). Excellent social work support was explicitly described by 25% (n=3), including assistance with visa letters, financial support, and university documentation. Access to psychology or psychiatric care was reported by 33% of participants (n=4), while 25% (n=3) utilised peer support groups.

*'That first week I met with a social worker... they helped with insurance, university letters, my mum's visa... they were very, very helpful.'*

## **OCP Step 5: 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.**

Ongoing post-treatment follow-up was reported by most participants (67%, n=8), typically through specialist review schedules and GP monitoring. However, confusion about the transition between specialist and GP care was reported by 42% of participants (n=5). Feelings of being 'lost' after treatment completion were described by 33% (n=4), despite continued appointments.

Strong continuity experiences, including direct nurse access and rapid call-back systems and were reported by 33% of participants (n=4). Interpreter or communication support issues persisted post-treatment for 25% (n=3). When present, clear discharge and surveillance planning helped reduce anxiety.

**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.**

Experiences of GP-specialist interaction were mixed, ranging from strong coordination to significant fragmentation. Effective information flow and well-informed GPs were reported by 33% of participants (n=4), with participants noting rapid transmission of specialist letters and shared awareness of treatment status. Conversely, an equal proportion (33%, n=4) reported fragmented communication, where patients or carers were required to personally relay clinical information between providers.

A lack of GP awareness of the treatment journey was explicitly described by 25% of participants (n=3). The impact of privacy rules on carer communication was also reported by 25% of participants (n=3), with carers formally recorded as support persons sometimes denied information outside appointments. Additionally, a small number of participants (17%, n=2) reported changing GPs following poor early experiences.

*'If I attended appointments, information was shared. If I approached alone, it was withheld... even though I was recorded as a carer.'*

**Participants were asked about their experience with transitioning back into day-to-day life after finishing active treatment.**

Transitioning back to daily life after treatment was described as challenging by most participants (75%, n=9), with physical fatigue and psychological adjustment commonly reported. Work or study disruption was reported by 58% of participants (n=7), including role changes, reduced hours, resignation, or delayed return. Supportive workplaces or flexible study arrangements delayed recovery for 42% of participants (n=5).

Ongoing physical limitations affecting mobility or function were reported in 33% of participants (n=4). Family caregiving load, either receiving or providing care during recovery, was described by 42% of participants (n=5). CALD-specific pressures, including visa insecurity, migrant family responsibilities, and financial strain, were explicitly noted in 25% of participants (n=3). Several participants (33%, n=4) described survivorship as more challenging than active treatment due to reduced contact with healthcare services.

Overall, the post-treatment phase was characterised by uneven access to follow-up, inconsistent GP involvement, and substantial unmet survivorship needs. For many participants, returning to daily life was more challenging than undergoing treatment, with ongoing physical, functional, and emotional difficulties.

## **OCP Step 6: Managing recurrent, residual or metastatic disease**

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

Formal survivorship planning and forward-looking care guidance were not discussed for the majority of participants (67%, n=8). Where survivorship information was provided (25%, n=3), it typically focused on lifestyle advice, such as exercise and diet, rather than structured survivorship pathways. Participants who reported survivorship discussions often linked these to nurse coordinators or breast care nurses (17%, n=2). Lack of clarity regarding long-term follow-up expectations and potential late effects was reported by 42% of participants (n=5). Several participants described learning about survivorship management through peer groups rather than clinicians (25%, n=3). Unanswered or 'not discussed' responses accounted for 25% (n=3).

### **Focus group participants were asked if they had the opportunity to discuss advance care planning.**

Advance care planning was reported not being discussed with most participants (67%, n=8). Explicit advance care planning discussions were reported to occur in 17% of cases (n=2), including one case where planning was clearly documented. Cultural discomfort or awareness gaps relating to advance care planning were noted in 17% of cases (n=2). Several participants reported that advance care planning 'was not discussed but not relevant' due to disease stage (25%, n=3). This highlights a lack of understanding of advance care planning. Where discussions did occur, they were typically late and situational rather than routine.

### **Focus group participants were asked if they had the opportunity to discuss palliative care with the healthcare providers.**

Palliative care was not discussed for the majority of participants (58%, n=7). An association of palliative care with end-of-life only was explicitly expressed by 33% (n=4), including participants who equated palliative care with imminent death. Cultural resistance or fear of discussing palliative care appeared in 25% (n=3), particularly where conversations about death was culturally sensitive. Understanding the overlap between pain management and palliative appeared in 17% (n=2). Early or integrated explanations of palliative care was rare (8%, n=1).

## **OCP Step 7: End-of-life care**

### **Focus group participants were asked if they were happy with the care their loved ones received.**

End-of-life or future care discussions were not discussed for most participants (67%, n=8). Brief or situational discussion occurred in 17% of cases (n=2), typically linked to escalation of illness severity. Participant-initiated questioning occurred in 8% (n=1). Themes of cultural discomfort or avoidance appeared in 25% of cases (n=3), although clinician non-initiation remained the dominant pattern. Several responses were coded as 'not applicable' or 'not relevant' due to early-stage disease (25%, n=3). Where discussions did take place, they were described as emotionally difficult but ultimately clarifying.

*'People often refuse to discuss palliative care or death... It's a curse to talk about these things before someone dies.'*

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

## **Other experiences in the cancer journey**

### **Focus group participants were asked if their cultural background influenced their understanding or experience of a cancer diagnosis and treatment.**

Participants described cultural background as what shapes their cancer experience, rather than refusal of treatment. Cultural beliefs and what illness in their culture e.g., fate, moral causation, food or behaviour explanations, and stigma narratives were reported by 50% of participants (n=6).

Collectivist family structures, which influenced how information was processed and decisions were supported were reported, were noted by 33% (n=4), including the role of family in interpreting information and providing emotional buffering during diagnosis. Health literacy and medically informed navigation, such as having a family member with a medical background or familiarity with clinicians were reported by 25% (n=3) as enabling confidence and understanding. Language and

representation gaps in health information, including the absence of CALD languages in materials, were also noted by 25% (n=3). Faith compatible with biomedical care appeared in 17% (n=2), typically framed as a form of spiritual coping rather than treatment avoidance. A smaller subset (17%, n=2) reported that cultural influence not perceived, describing suffering as universal and 'cutting across cultures.' Unanswered responses accounted for 17% of participants (n=2).

*'We are a very collectivist culture and families are close-knit.'*

### **Focus group participants were asked if their family or community's cultural beliefs or traditions supported or influenced the way decisions were made about care.**

Family and community were described as both sources of strength and sources of pressure for CALD consumers. Social support through friends, family, or organised communities was reported by 50% of participants (n=6), including practical caregiving, provision of meals, companionship, and emotional anchoring. However, cultural stigma, silence, or shame around cancer, including avoidance of disclosure, was described by 33% (n=4), particularly regarding mental health concealment and 'not talking about cancer.' Community pressure, intrusion, or the burden of managing others' reactions was reported by 25% (n=3), highlighting concerns around privacy and emotional bandwidth. Faith-based coping and meaning-making, serving as a resilience support, appeared in 25% of participants (n=3), often framed as empowerment and gratitude rather than fatalism. Peer support groups, including non-governmental organisations (NGOs) and online communities, were identified as important by 33% of participants (n=4), particularly to address loneliness and the need to speak with 'people who get it.' Harmful family or community responses, including blame, ostracism, or moral judgement, were reported by 17% (n=2). Unanswered responses accounted for 17% (n=2).

*'Religion... gives you strength... we saw it as God's will... but not the end of life.'*

### **Focus group participants were asked if they were able to get information or support in their preferred language.**

Communication experiences indicated that language alone did not determine whether patients felt informed. Interpreter inconsistency or absence, including consultations proceeding without interpreters and reliance on family members, was reported by 33% of participants (n=4), raising concerns about quality, continuity, and accountability. English proficiency or preference for English reduced language barriers for 50% of participants (n=6); however, even within this group, medical complexity and unclear explanations remained problematic. Information perceived as insufficient or requiring self-seeking was reported by 33% (n=4). System communication design issues, such as missed calls due to lack of caller ID, or one-way contact methods, were reported by 17% (n=2). CALD participants described 'medical English' as a barrier even when conversational English was strong (25%, n=3), and highlighted risks when children acted as interpreters without medical literacy. Requests for more interactive information formats such as talks, live explanations, and contextual reasoning rather than static brochures, were reported by 25% of participants (n=3).

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

*'When treatment ends, you are left with a lot of questions... I felt so lost.'*

### **Focus group participants were also asked if they found it easy to access cancer care or support services that understood or respected their cultural or language needs.**

Access to support was described as easy and respectful for a subset of participants (33%, n=4), typically those with strong English proficiency, stable eligibility, or supportive service coordination. However, system inequities for CALD consumers without existing networks were explicitly reported by 33% (n=4), where 'menu-less' systems rendered supports invisible unless patients already knew

what to request. Barriers related to visa and Medicare eligibility which restricted access, were reported by 25% (n=3), with international students and uninsured migrants describing exclusion from mainstream services.

### **Focus group participants were asked what they thought health services could do to make care more welcoming and responsive for people from different cultural or language backgrounds.**

CALD community organisations and NGOs were perceived as limited in addressing cancer-specific needs by 17% of participants (n=2), although some support for awareness or general community work was described. Public specialist centres (e.g., large comprehensive cancer services) were described as more culturally responsive and comprehensive than private care by 25% of participants (n=3), offering greater access to allied health services and proactive navigation.

*'Being paired with somebody who's been there before... same cancer... would be great.'*

Workforce cultural capability and communication training, including strategies for engaging patients with speech impairments and diverse cultural norms, was recommended by 50% of participants (n=6). Interpreter availability and quality assurance, including emergency access and interpreter accountability, was raised by 42% of participants (n=5). Navigation and peer support models, such as pairing patients with someone with lived experience, and developing structured peer groups (including online platforms), were recommended by 50% of participants (n=6).

*'There is no compliance or supervision... what's a successful interaction with an interpreter? ...Hospitals need a KPI.'*

Clearer caregiver inclusion rules and privacy guidance were suggested by 25% of participants (n=3), reflecting confusion about when and where carers can advocate. Multilingual and multimodal resources, including adoption of vetted resources from other countries and improved language coverage, were recommended by 33% of participants (n=4). CALD-tailored system design and administrative reforms, such as improvements to name and identity matching and addressing system assumptions, were raised by 25% of participants (n=3).

Social determinants and equity barriers, including visa insecurity, insecure employment, lack of Medicare, absence of social networks and class dynamics, were highlighted by 33% of participants (n=4), with many emphasising that culture and structural disadvantage shape care more than language alone. Food and culturally appropriate comfort needs were noted by 25% of participants (n=3), framed as addressing both nutrition and dignity.

*'People with advanced cancer feel unable to participate due to fear related to insecure employment... no sick leave... don't disclose.'*

## **4.3 Key findings**

The results of the Victorian CPES and focus groups highlight opportunities to improve aspects of cancer care for CALD communities across Victoria. It is important to note, however, that these may not capture all gaps in optimal cancer care experienced by CALD communities. Additionally, the methods used in this report included limited representation of CALD consumers living in rural and regional areas of Victoria and those who do not speak English.

### **Communication and understanding of information**

Communication emerged as a consistent theme across both data sources. In the CPES, 75% of CALD respondents reported that their cancer diagnosis was explained in a way they could understand, and 95% felt encouraged to ask questions. However, focus group discussions suggested that understanding was often incomplete during early stages of care. Only 42% of participants reported clear understanding of their diagnosis, while others required repeated

explanations or independent research. Many participants relied on family members or bilingual relatives to support interpretation of information.

### **Navigation and coordination across the care pathway**

Treatment initiation was generally timely once a diagnosis was made, with 50% of focus group participants starting treatment within 2 weeks and 25% within 6 weeks. However, earlier stages of the care pathway were more variable. Around 42% of participants reported delays in seeking help for symptoms, and 33% described undergoing multiple consultations before being referred for investigation. After treatment, transitions between specialist care and primary care were sometimes unclear. While 67% of CPES respondents reported receiving a written follow-up plan, 42% of focus group participants described confusion regarding follow-up responsibilities.

### **Information provision and survivorship preparation**

Most survey respondents reported receiving information about treatment and side effects, with 77–95% indicating key information was provided prior to treatment. However, focus group participants frequently described insufficient preparation for the long-term impacts of treatment. Over half (58%) reported only partial understanding of treatment processes and approximately one third (33%) indicated that they were not adequately prepared for permanent or late side effects.

### **Supportive care and psychosocial needs**

Supportive care services were accessed by many participants but were not consistently embedded across the care pathway. In focus groups, 58% of participants reported receiving referrals to services such as social work, psychology or physiotherapy, while 33% described unmet supportive care needs. CPES results also indicated opportunities to strengthen discussion of broader support needs, with only 41% of CALD respondents reporting that staff inquired about financial concerns and 59% reporting discussion about support groups.

### **Equity barriers and social determinants of health**

Participants highlighted that structural factors often influenced their cancer experience. Around 75% described difficulty transitioning back to everyday life following treatment, and 58% reported disruption to work or study. Some participants also described challenges related to visa status, financial insecurity or limited support networks, which could affect access to care and recovery after treatment.

## **5. Implications**

The findings of this report highlight several opportunities to improve CALD cancer care across Victoria. While many participants expressed gratitude for the expertise and compassion of their treating teams, they identified gaps in CALD cancer care that point to the need for targeted improvements to deliver more equitable and patient-centred care. These include:

- Strengthening interpreter and bilingual communication support
- Improving workforce cultural capability and communication training
- Enhancing patient navigation and care coordination roles
- Improving access to multilingual and culturally tailored information
- Strengthening survivorship care planning and integration with GPs
- Embedding supportive care earlier and more consistently across the pathway
- Addressing structural equity barriers affecting CALD patients.

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

## 6. Appendices

### Appendix 1: Demographic information form and focus group discussion points

#### 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
Which health services did you have the majority of your treatment?	
What type of cancer have you or your loved one been diagnosed with? <input type="checkbox"/> Yes <input type="checkbox"/> No	
How long ago were you or your loved one diagnosed [insert cancer type] 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?	-----
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?

<b>17. Did you receive or were you offered a referral for palliative care?</b>

**End-of-life care (if applicable):**

<b>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)</b>
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**General Questions:**

<b>19. Your experience:</b>
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<b>How has your cultural background influenced your understanding or experience of your (or your loved one's) cancer diagnosis and treatment?</b>
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<b>20. Family and community:</b>
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<b>How have your family or community's cultural beliefs or traditions supported you, or influenced the way you've made decisions about care?</b>
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<b>21. Communication and language:</b>
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<b>Were you able to get information and support in your preferred language? Have you had any challenges talking with your healthcare team or understanding what was happening?</b>
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<b>22. Accessing support:</b>
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<b>Have you found it easy to access cancer care or support services that understand or respect your cultural or language needs?</b>
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<b>23. Improving care:</b>
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<b>What do you think health services could do to make care more welcoming and responsive for people from different cultural or language backgrounds?</b>
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## 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)

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