



Summary report of patient experience data: Colorectal Cancer

VICS April 2025



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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.

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Abbreviations

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

Executive summary

Background:

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

Aim:

To identify the experience and perspectives of people with Colorectal Cancer and their carers who have received or are receiving care for their cancer in Victoria using results from the 2022 Victorian Cancer Patient Experience Survey (CPES) and focus groups with colorectal consumers.

Methodology

The Victorian CPES was developed by the Victorian Agency for Health Information (VAHI), in partnership Department of Health and Ipsos Public Affairs. The CPES aims to understand the cancer journey and experiences of Victorians undergoing cancer treatment at Victorian public hospitals. The CPES was first piloted in 2013 and again in 2015. This report examines responses to the 2023 CPES for Victorians who received in-patient cancer care in 2022 for colorectal cancer.

Data was also collected through eleven focus groups with colorectal patients and carers completed between January and February 2025. The focus group covered all the steps in the Colorectal Cancer Optimal Care Pathways from prevention and early detection to end-of-life care.

Findings

A total of 258 participants with colorectal cancer responded to the CPES survey in 2023, with 55% identifying as a man and 45% identifying as a woman. Almost half (49%) of participants were aged \geq 70 years at the time of the survey. Majority (91%) of participants mainly spoke English at home and 97% did not require an interpreter at their appointments, and 1 (<1%) participant indicated that they needed an interpreter, but no one talked to them about this service during appointments.

Dependent on treatment phases/modes, between 48-56% of participants reported that they felt staff asked if friends/family needed information or support (49% at time of diagnosis, 48% at time of surgery, 56% at time of radiotherapy, and 52% at time of chemotherapy) which are all similar to the statewide averages. Most participants felt they were treated with respect and dignity throughout the different phases/modes of treatment (91-100% across diagnosis, surgery, radiotherapy, and chemotherapy). A greater proportion of colorectal participants (65%) were confident in their GP's ability in managing ongoing cancer care, compared to the statewide cohort (55%).

Between 30 and 183 participants responded in the open-ended survey questions, which captured participants' experiences across all phases of their cancer treatment journey. Themes identified in the qualitative data were categorised according to the seven principles outlined in the Colorectal Optimal Care Pathway.

Patient-centred care (Principle 1) was consistently noted by participants as something they found helpful across all areas of care, specifically mentioning compassionate care and respect from staff. Participants also noted that communication and information sharing (Principle 6: Communication) from clinicians was very helpful, as well as themes related to safe and quality care (Principle 2). Care coordination (Principle 5) during follow up was found to be very helpful, specifically effective follow-up care and care coordination, and care closer to home.

Areas that participants felt required the most improvement throughout areas of cancer care were primarily related to communication and information sharing from clinicians (Principle 6: Communication), and specifically timeliness of care (Principle 5: Care coordination) during ED

admission. However, many participants did not have any suggestions for improvements and reiterated their positive experiences of care.

A total of 13 people with colorectal cancer or carers participated in focus group discussions. Six were under the age of 50, five over 50 and two older than 60. There were five male and eight female participants. Eleven consumers were diagnosed with stage III, one with stage II and one with stage IV. Focus group discussions highlighted varied experiences throughout their care journey. Participants expressed frustration with delays in diagnosis and issues with poor health literacy regarding early-onset colorectal cancer. Participants reported a need for clearer, more detailed communication from healthcare providers. While many felt included in treatment decisions, some desired more options and time to process information. Compassionate care, particularly from stoma nurses, was highly valued, though gaps remained in family support and long-term side effect management. Post-treatment, patients often felt unsure about follow-up care and who to contact for support.

Conclusion

The findings emphasise the need for systemic improvements, including enhanced general practitioner and population health education, streamlined diagnostic pathways, and better support and communication practices for colorectal cancer patients and their carers/families especially for patients with early-onset symptoms to be diagnosed earlier.

Recommendations include utilising data to promote colorectal cancer awareness, increasing access to care coordination and information support, expansion of breadth and access of supportive care services such as counselling and peer programs to carers, reduction of the stigma around colorectal cancer and greater travel support for rural, regional and remote patients.

Addressing these gaps through collaboration between healthcare providers and stakeholders will be crucial for optimising colorectal cancer care for patients and their families in Victoria.

Background

The Victorian Integrated Cancer Services (VICS) Optimal Care Summits program is an initiative of the VICS which involves the examination of tumour-specific cancer care, experience, and outcomes measures against the standards and targets set out in the Optimal Care Pathways. [1] The Victorian Cancer Plan 2024-2028 [2] defines the program as an enabler for reducing variations in clinical practice and cancer outcomes. It aims to identify data informed patterns of cancer care and outcomes, variations in care, agree priorities for reducing unwarranted variations, and deliver quality improvement initiatives to reduce prioritised variations. The program involves a mixed-methods strategic consultation approach including tumour-specific expert advisory groups, strategic consultations, statewide surveys, and relevant stakeholder engagement throughout Victoria, as well as priority initiatives that are resourced by the VICS and other cancer organisations. Across 2024-25, the program explored unwarranted variations in colorectal cancer across Victoria.

In Australia, CRC was the fourth most commonly diagnosed cancer in 2023 (58 cases per 100,000 population), with estimated all-age incidence rates of 66 per 100,000 in males and 52 per 100,000 in females.[3] The incidence rate for bowel cancer is expected to increase with age, highest for those aged 85–89 years.[3] Nevertheless emergent evidence suggests that incidence of CRC in people under 50 years of age is rising in Australia [4] with survival outcomes varying, based on the stage of disease at diagnosis.[5]

The evidence-to-practice gap remains a healthcare challenge especially in complex settings like cancer services. [6] The Optimal Care Pathways (OCPs) are 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. An important aspect of determining unwarranted variations is to explore the perspectives and experiences of colorectal cancer patients and their families to accessing and receiving care. Consumer engagement is central to high-quality patient-centred cancer service delivery. [7] Consumer involvement in cancer care is recognised as crucial with consumers encouraged to participate in policy and planning, research and service delivery. [8] The experiences and views of consumers help identify key areas that will assist in reducing the impact of cancer on all people affected and lessening disparities for those groups that have poorer cancer outcomes. [9]

The Victorian Cancer Patient Experience Survey (CPES) was developed by the Victorian Agency for Health Information (VAHI), in partnership Department of Health and Ipsos Public Affairs. The CPES aims to understand the cancer journey and experiences of Victorians undergoing cancer treatment at Victorian public hospitals. The CPES was first piloted in 2013 and again in 2015.

In 2023, the updated survey was sent out to randomly selected patients who received cancer care at a Victorian public hospital in 2022. Participants were asked to answer questions based on their 2022 experience of care. In addition, a series of focus groups were completed by the VICS Optimal Care Summits team with Victorians who had a lived experience of colorectal cancer. This report examines responses to the 2023 CPES for Victorians who received in-patient cancer care in 2022 for colorectal cancer and responses to the colorectal cancer focus groups. Results of this analysis will be used to inform the VICS Optimal Care Summit colorectal program.

Aims

To identify the experience and perspectives of people with colorectal cancer and their carers who have received or are receiving care for their cancer in Victoria using results from the 2022 Victorian CPES and focus groups.

Methodology

3.1 CPES Data

Recruitment and data collection

Victorian cancer patients were randomly selected from a stratified list of cancer consumers prepared by individual campuses and invited to complete the survey via email, SMS, or letter. Data collection occurred between 13th March and 19th May 2023. The overall response rate for the survey was 32%, indicating that caution is needed in the interpretation of these results. Raw data for the colorectal cancer cohort was provided by VAHI, which included any survey participants who answered the question “What cancer were you diagnosed with?” with “colorectal cancer” or “Other”, specifying other colorectal cancer related terms, e.g. “bowel”, “colon”, “rectal”, “anal”, “lower gastrointestinal”, “small bowel”. These data were then aggregated to reflect the percentages across multiple choice responses.

Positive response coding

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

Statistical comparisons

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

Free-text data

Free-text responses were collected for 17 survey items. Verbatim responses for each item were collated in an Excel file and common themes were identified using an inductive thematic analysis approach. As each response was open-ended, no restrictions were placed on how many themes could be used to code each response. Coded responses were then organised according to the seven principles outlined in the Colorectal Optimal Care Pathway (2nd Edition). [10] Responses that did not provide descriptions related to the experience of cancer care (e.g., when participants responded to the free-text survey item with statements like “nothing”, etc.) were coded as N/A and excluded from further analysis. Coded results were examined for themes that could provide further context to aspects of cancer care described by participants in their responses. Where relevant, steps outlined in the Colorectal Optimal Care Pathway were noted for additional context.

3.2 Focus Groups

Recruitment

Recruitment for the focus groups was carried out through several colorectal cancer related organisations and advocacy groups. The VICS Optimal Care Summits team advertised an invitation to participate via their newsletters. Eligible individuals (adults living in Victoria with experience of treatment for colorectal cancer and their carers), volunteered to participate and were put in contact with the VICS Optimal Care Summits team. Participants were given a participant information sheet which included the list of focus group questions (Appendix 1). None of the participants were known to the VICS Optimal Care Summits team prior to study recruitment. Further participants were also identified through snowball sampling and referral from the expert advisory group. This study is ethically approved, VicTRI-19783.

Question development

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

Data collection

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

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

Analysis

The transcripts were then analysed using simple thematic analysis whereby patterns of meaning were generated from the data. Quantitative data from the discussions was extracted by a VICS Optimal Summits team member and analysed descriptively using Excel.

Findings

4.1 CPES Data

General findings

Age, gender, Aboriginal status, and interpreter status

A total of 258 people who participated in the Victorian CPES were diagnosed with a colorectal cancer in 2022. Two participants identified as Aboriginal, and the remaining participants did not identify as Aboriginal or Torres Strait Islander. Just over half (55%) of participants identified as male, and 45% identified as female. Almost half (49%) of participants were aged ≥ 70 years, 44% were aged 50-69 years, and 7% were aged 16-49 years. The majority of participants (91%) mainly spoke English at home, 3 (1%) participants spoke Italian, 3 (1%) spoke Greek, 3 (1%) spoke Cantonese, 3 (1%) spoke Mandarin, 2 (1%) spoke Vietnamese and 9 (4%) spoke a language not listed in the survey ("Other"). The majority of participants (97%) indicated that they did not need an interpreter at any point during their cancer care, 4 (2%) participants indicated that an interpreter was available at all/most of their appointments, 1 (<1%) indicated that an interpreter was available at some of their appointments, and 1 (<1%) indicated that they needed an interpreter but no one talked to them about this service during their appointments.

Quantitative data

Finding out what was wrong

Over one-third (39%) of participants with colorectal cancer waited less than two weeks from when they were referred by their general practitioner (GP) to when they were seen by a specialist/clinic, compared to 45% across all cancers in the state. Of these, 81% felt their doctor explained their cancer diagnosis in a way they could understand, which is similar to the statewide average (75%), and 80% were satisfied with the format in which their diagnosis was explained, compared to 73% across the state. Additionally, 79% said they were given information about treatment options, which is similar to the statewide average (74%).

Almost all participants (97%) felt that they were encouraged to ask questions regarding their diagnosis with their doctor, and 92% said that staff repeated treatment options following their diagnosis. Similarly, 93% of participants felt that they were treated with respect and dignity during diagnosis.

Questions related to being told how to access more information and being told who to contact for support yielded positive responses from only 51- 54% of the colorectal cancer cohort. In addition, only 49% of the colorectal cancer cohort said health professionals asked if family/friends need information or support during the diagnosis period. These survey items align with the statewide averages.

Deciding on treatment

Over three-quarters (80%) of participants were happy with the level of involvement they had in treatment decision making. The same number of participants (80%) of participants reported being explained the short-term side-effects of treatment before deciding on treatment. However, only 62% reported that they were explained the long-term side-effects, which is similar to the statewide average (67%). Similarly, 79% of participants reported being referred to services before commencement of treatment to address potential issues arising from treatment (e.g., reduced fertility, incontinence). The majority (91%) of participants said that they were given information regarding what would be involved with receiving the decided treatment(s).

Surgery

Majority (89%) of participants underwent surgery for treatment. Of these, 29% waited less than two weeks between being told they were ready for surgery and undergoing surgery, compared to 35% of

the statewide result. The colorectal cancer cohort experienced surgery similarly to the statewide cohort across all survey items related to surgery. For those who underwent surgery, 61% reported being fully informed regarding the costs related to surgery, and 82% reported being given acceptable information regarding what it would be like post-surgery. Similarly, 81-85% reported being given information about what it would be like immediately after surgery and management of side-effects, and 91% of participants felt their surgical staff explained things in a way they could understand.

Side-effects post-surgery were reported to be managed well for 79% of participants, and 91% felt that staff did everything they could to manage their pain. Additionally, 95% felt they were able to get staff to assist them in a timely manner. Follow up care was organised before discharge for 84% of colorectal participants, with 78% reporting they received information about managing at home, and 76% reported receiving arrangements for any services required at home.

Only 48% of participants said health professionals asked if family/friends need information or support during their surgical admission, and only 52% felt staff discussed worries and concerns they had. These results align with the statewide average. Similarly, only 38% reported being given contact details of staff at the hospital for concerns/queries.

91% of participants felt they were treated with respect and dignity during their surgical admission, and 99% rated care from the surgical teams as either "good" or "very good".

Radiotherapy

The colorectal cancer cohort experienced radiotherapy similarly to the statewide cohort across all survey items related to radiotherapy, with the exception that 56% of colorectal participants reported being told about the out-of-pocket costs associated with radiotherapy before commencement. This was lower than the statewide cohort (66%). Almost one-third (32%) of colorectal participants reported receiving radiotherapy for treatment, and of these, 61% stated they waited less than two weeks between radiotherapy mapping and beginning radiotherapy treatment.

Majority (83-93%) of participants reported being given information before the commencement of radiotherapy about how to prepare, how to manage stress/anxiety, how to manage side-effects, how they might feel at the end of treatment, and how long it might take to recover from radiotherapy. Similarly, 83% of participants felt staff checked that they understood the information about radiotherapy that was provided, and 82% felt their personal circumstances were considered when arranging appointments. Majority (96%) of participants were given a phone number to contact if they had any questions.

Majority (91-92%) of participants felt staff checked if they experienced any treatment side-effects and helped participants manage these. Similarly, 77-89% of participants said staff checked if needed help with managing their emotional state and help with travelling to and from appointments. Almost all participants (93%) said staff checked if they needed help with diet, eating, or physical movements. Despite this, only 56% of participants stated that staff asked if their family/friends needed any information of support.

All (100%) of participants felt they were treated with respect and dignity during radiotherapy, and also rated their radiotherapy care as either "good" or "very good".

Chemotherapy

Over two-thirds (70%) of all colorectal participants reported receiving chemotherapy treatment. Of these, 50% stated that they waited less than two weeks between being told they were ready for chemotherapy and commencing chemotherapy, compared to 55% for the statewide cohort. The colorectal cancer cohort experienced chemotherapy similarly to the statewide cohort across all survey items related to chemotherapy.

Regarding information provision, 72-95% of participants stated they were given information before the commencement of chemotherapy about how to prepare, how to manage stress/anxiety, how

they might feel at the end of treatment, possible side-effects, how to manage side-effects, the possibility of needing to go to ED, and how to contact Symptom and Urgent Review Clinic. Additionally, 77% of participants felt staff checked that information about chemotherapy was understood, and 71% felt their personal circumstances were taken into account when appointments were arranged.

The majority (88%) of participants had to wait less than 30 minutes at chemotherapy appointments. During treatment, 92% of participants said staff checked if they had any side-effects, and 84% felt staff managed these side-effects well. Additionally, 90% of participants said staff checked if they needed help with diet, eating and physical movements, 79% said they checked if they needed help with managing their emotional state, and 70% said they checked if they needed help with travelling to/from appointments.

Majority (99%) of participants reported that they were given a phone number to contact if they had any questions, and 90% were given a card that explained their chemotherapy treatment to show Emergency Department (ED) staff. However, only 52% said health professionals asked family/friends need information or support during chemotherapy.

Majority (98%) of participants felt that they were treated with respect and dignity during chemotherapy, and 99% rated chemotherapy care as either “good” or “very good”.

Emergency Department experience

Almost two-thirds (61%) of participants who attended ED during cancer treatment reported that they waited more than 30 minutes to be seen. Majority (79%) of participants felt their condition was well managed in the ED, which is similar to the statewide average (75%), and 80% felt that ED staff had knowledge and skills to look after them compared to 73% across the state.

Follow up care

The colorectal cancer cohort experienced follow up care similarly to the statewide cohort, with the exception that 65% of colorectal participants stated they were confident in their GP’s ability to manage their ongoing cancer care. This is higher compared to 55% of the statewide cohort. Over half (60%) of participants reported being given a written plan for 12-month follow up care. Over half (60-63%) of participants felt that staff accounted for personal circumstance when arranging follow up appointments and felt that their appointments were coordinated well to reduce travel time. Majority (82%) said that test results and other information were always available to the GP.

When participants finished treatment, 84% stated they were given information about required follow up tests and 74% reported they were provided with information about ways to stay healthy. Just over half of participants reported that they were given information about which new symptoms required investigation (56%) and how people generally feel after finishing treatment (54%). Similarly, 59% stated they were given information about how to get support for themselves and/or their family, 78% said they were given information about how often check-ups should occur, and 67% information about how to manage ongoing symptoms/side-effects.

Information received

Regarding information provision throughout their treatment journey, 61-73% of participants indicated they received enough information about possible impacts on usual activities, possible changes in energy levels, and how to possibly preserve fertility, which were similar to the statewide cohort. The majority (84%) of participants felt they could ask health professionals questions, however, only 39% said that health professionals talked to them about financial support programs. This was lower than that statewide average of 47%. Similarly, only 47% felt that they could talk to health professionals about complementary or alternative therapies to help with symptoms.

Participants reported similarly to the statewide averages regarding health professionals discussing a range of supportive services to them related to their cancer care, including social workers (89%, compared to 85% across the state), dieticians (89%, compared to 82% across the state), Cancer Helpline (88%, compared to 84% across the state), occupational therapists (83%, compared to 74%

across the state), physiotherapists (72%, compared to 75% across the state), psychologists (70%, compared to 73% across the state), and financial planner/services (51%, compared to 42% across the state). A greater proportion of colorectal participants (76%) indicated that health professionals discussed the role of a pain management specialist compared to the statewide cohort (64%). A smaller proportion of colorectal participants indicated that health professionals discussed speech therapy (60%, compared to 77% across the state) and palliative care (65%, compared to 77%).

Participants also indicated that health professionals asked participants if they needed help with a range of other activities including domestic chores (83%), family problems (71%), finances (43%), and finding support groups (67%), which were all similar to the statewide averages. However, a greater proportion of colorectal participants (77%) indicated that they were asked if they needed help with childcare, compared to the statewide cohort (67%).

Overall care

When asked about their experiences overall during their cancer care, 99% of participants rated their overall care as either “very good” or “good”, and 92% of participants rated how well their staff worked together as either “excellent” or “very good”. However, 14% of participants said that there was a time that they were so unhappy that they wanted to/did complain.

Aligning with statewide averages, 83% of participants never received conflicting information from different health professionals during cancer care, and 85% never thought a health professional was not fully informed regarding their treatment and progress. Similarly, 95% of participants never thought tests were being repeated unnecessarily, 88% never went to an appointment at which results were unavailable, and 83% never felt that health professionals were not passing on information to another. Almost all participants (99%) reported never experiencing discrimination based on racial, ethnic or cultural background.

Majority (82%) of participants said there was a health professional they could contact to address questions/concerns throughout their care, and 83% of participants felt that treatment centres were well informed about the care they had received at other sites, which aligned with the statewide averages. Similarly, 72% of participants believed that their GP was kept informed throughout their care. Only 52% of participants though stated they were given the name of the Clinical Nurse Specialist in charge of their care. Of those who were given a Clinical Nurse Specialist’s details, 60% said it was easy to get in contact with the them. Availability and accessibility of Clinical Nurse Specialists were both lower than the statewide averages (67% and 74%, respectively). However, 93% of participants said their Clinical Nurse Specialist listened carefully to them and 92% said they often received answers from Clinical Nurse Specialists that they understood, which is similar to the statewide averages.

Your health today

At the time of the survey, 49% of participants rated their health with a score equal to or greater than 81/100 compared to the statewide result of 40%. When reviewing the five areas of daily functioning, the majority of colorectal participants did not report any issues with self-care (90%) and mobility (72%). Colorectal cancer patients though did report issues with, anxiety/depression (37%), ability to perform usual activities (38%), and pain/discomfort (47%). These align with statewide averages.

Qualitative data

Qualitative data from the open-ended survey questions were present for between 30 and 183 participants, depending on the item. Each free-text response survey item captured between three and six principles from the OCP. Brief descriptions of OCP principles are described below, before results are presented by aspect of care as per the CPES. For detailed descriptions of each principle, please refer to the Optimal Care Pathway for people with colorectal cancer (2nd edition). [10]

OCP Principles

Principle 1: Patient-centred care

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

Principle 2: Safe and quality care

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

Principle 3: Multidisciplinary care

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

Principle 4: Supportive care

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

Principle 5: Care coordination

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

Principle 6: Communication

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

Principle 7: Research and clinical trials

Research and clinical trials play an important role in establishing the efficacy and safety of diagnostic, prognostic and therapeutic interventions, as well as establishing the role of psychological, supportive care and palliative care interventions (Sjoquist & Zalcborg 2013). [11]

Other

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

Aspects of care

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

Text responses that could not be coded due to a lack of clarity, or where participants noted 'N/A' were excluded from the thematic analysis (n=34). However, any responses stating 'no further comments', 'unsure' or similar were not excluded from the analysis, as these statements still provide valuable insight into patient perspectives. Where any single response could be coded with more than one theme, each individual idea was separately coded. As such, the number of themes identified in free text responses may be equal to or greater than the number of responses for the corresponding survey item. Results from the analysis are presented in line with the seven OCP steps and survey question order.

Diagnosis

Between 131 and 183 participants with colorectal cancer answered survey items related to diagnosis. Six of the seven OCP principles were identified in responses for questions related to diagnosis (Table 1). Participants indicated that the most helpful things staff did during their diagnosis related primarily to the ways that staff interacted with them (1: Patient-centred care) and the information shared with them (6: Communication). Compassionate care and respect were key to interactions that participants considered helpful, and included the care, empathy and professionalism of staff when guiding patients through their diagnosis and treatment options (Table 1). For example:

“The oncologist was very caring and compassionate sitting cross legged on the floor explaining the diagnosis and treatment options.”

Of similar importance was the mode of communication and information sharing used by staff in delivering information about the diagnosis and treatment options. In some responses, the interconnectedness of person-centred care and communication were clearly apparent:

“Explained in simple language that we could understand, used models to show where the cancer was it was very helpful. mortal [sic., moral] support was given at the time. Every help was given to help us but we accepted that I had cancer and we were now in the hands of the surgeon and the doctors we just had to hope all went well with the surgery.”

Likewise, the interconnectedness between person-centred care and safe and quality care were also noted in some responses:

“Everyone I spoke to were always friendly and supportive. I felt that I was receiving the best possible care during the entirety [sic., entirety] of my cancer journey.”

Four OCP principles were identified in responses less frequently for questions related to diagnosis, with most of these responses relating to care quality (2: Safe and quality care) and timeliness of care (5: Care coordination). For example:

“The surgery was arranged quickly at a convenient time and location. The staff were excellent.”

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

Q11. What were the most helpful things staff did during your diagnosis? (n= 183 responses)			
OCP Principle	Experience	Themes	Count
1: Patient-centred care (n=99, 42%)	Negative	Compassionate care and respect (negative)	1
	Positive	Compassionate care and respect (positive)	85
		Family/friend involvement (positive)	4
		Patient involvement (positive)	1
		Professionalism (positive)	8
2: Safe and quality care (n=25, 11%)	Negative	Care quality (negative)	2
	Positive	Care quality (positive)	19
		Clinical skills/knowledge (positive)	3
		Outcomes (positive)	1
3: Multidisciplinary care (n=1, 0%)	Positive	Multidisciplinary care (positive)	1
4: Supportive care (n=2, 1%)	Positive	Supportive care access/referrals (positive)	2
5: Care coordination (n=19, 8%)	Positive	Care coordination (positive)	4
		Follow-up care (positive)	3

		Timeliness (positive)	12
6: Communication (n=86, 36%)	Negative	Communication and information sharing (negative)	6
	Positive	Communication and information sharing (positive)	80
Other (n= 2, 1%)	Positive	Food access (positive)	1
	Negative	COVID-19	1
N/A (n= 4, 2%)	Neutral	No further comments	2
		Unsure	2
Total themes identified			238
Q12. What could be done to improve the diagnosis experience? (n= 131 responses)			
OCP Principle	Experience	Themes	Count
1: Patient-centred care (n=14, 10%)	Negative	Alternative treatment access (negative)	3
		Compassionate care and respect (negative)	2
		Family/friend involvement (negative)	2
		Patient involvement (negative)	1
		Professionalism (negative)	1
	Positive	Compassionate care and respect (positive)	4
		Professionalism (positive)	1
2: Safe and quality care (n=9, 7%)	Negative	Care quality (negative)	1
		Clinical skills/knowledge (negative)	1
		Early discharge	1
		Hospital environment (staffing)	1
		Treatment discrepancy	1
	Vic public hospital system (negative)	1	
Positive	Care quality (positive)	3	
4: Supportive care (n=4, 3%)	Negative	Supportive care access/referrals (negative)	3
	Positive	Supportive care access/referrals (positive)	1
5: Care coordination (n=6, 4%)	Negative	Follow-up care (negative)	1
		Timeliness (negative)	3
	Positive	Timeliness (positive)	2
6: Communication (n=12, 17%)	Negative	Communication and information sharing (negative)	21
	Positive	Communication and information sharing (positive)	2
Other (n=7, 5%)	Negative	Access to resources (negative)	1
		COVID-19	5
	Neutral	Public health recommendations	1
N/A (n=72, 53%)	Positive	Thanks/satisfaction	1
	Neutral	Unsure	3
		No further comments	68
Total themes identified			135

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

Most participants did not have suggestions for what could be done to improve the diagnosis experience. Where suggestions were made, these focused on communication and information sharing. Many of the suggestions described a desire for being more informed about what was happening while treatment options were being discussed. For example:

“To be given all information before needing to ask. It's my body and I want to know exactly what's happening!”

“After surgery, me or my family were not provided with any updates. This was extremely frustrating and very insensitive.”

Several responses also described a need for written information to take away, as it can be difficult to remember all the information communicated during an appointment:

“Perhaps written detail - the initial response is short, so difficult to remember the spoken details.”

The preference for more consistent communication throughout the diagnosis period was reflected in comments from five participants who described receiving little to no communication about their diagnosis prior to treatment:

“I did not receive advice until after the operation to remove a malignant lump.”

“I learnt more from the nurse at the pre operation appointment and some things that really hadn't been explained to me or had been talked about.”

“Only my surgeon explained the diagnosis & remedial treatment”

“The cancer diagnosis was never brought up by staff. I was left to deal with the shock alone - counselling would have helped me.”

“This was terrible. I was kept in the [dark] at every turn. I was refused info on myself & cancer until multi-disciplinary meeting then not told those results with outpatients apt [sic].”

One respondent also described the experience of being made to feel ‘annoying’ by staff because of their questions:

“I felt that my questions were annoying to them. They said I was the woman with 1000 questions”

Treatment decision-making

Between 110 and 140 participants with colorectal cancer answered survey items related to treatment decision-making. All seven OCP principles were found in free text describing aspects of treatment decision-making that participants found most helpful (Table 2). Participants most frequently referred to Principle 6: Communication, with clear explanations, information sharing, and responding to questions considered most helpful to treatment decision-making. A smaller proportion of participants also described engaging with staff who were helpful and who had a positive or professional attitude as helpful during treatment decision-making (Principle 1: Patient-centered care).

Less frequently referenced OCP principles included 2: Safe and quality care, 3: Multidisciplinary care, 4: Supportive care, 5: Care coordination, and 7: Research and clinical trials.

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

Q23. What were the most helpful things staff did in relation to treatment decisions? (n=140 responses)			
OCP Principle	Experience	Themes	Count
1: Patient-centred care (n=47, 28%)	Negative	Alternative treatment access (negative)	1
		Compassionate care and respect (negative)	1
		Patient involvement (negative)	2
	Positive	Compassionate care and respect (positive)	33
		Patient involvement (positive)	5
		Professionalism (positive)	5
2: Safe and quality care (n=10, 6%)	Positive	Care quality (positive)	10
3: Multidisciplinary care (n=1, 1%)	Positive	GP experiences (positive)	1
4: Supportive care (n=1, 1%)	Positive	Supportive care access/referrals (positive)	1
5: Care coordination (n=8, 5%)	Negative	Timeliness (negative)	1
		Care coordination (positive)	3
		Timeliness (positive)	4
6: Communication (n=96, 56%)	Negative	Communication and information sharing (negative)	4
	Positive	Communication and information sharing (positive)	92
7: Research and clinical trials (n=3, 2%)	Positive	Clinical trials (access)	3
N/A (n=4, 2%)	Neutral	Unsure	3
		No further comments	1
Total themes identified			170
Q24. What could be done to improve your experience in relation to treatment decisions? (n=110 responses)			
OCP Principle	Experience	Themes	Count
1: Patient-centred care (n=11, 10%)	Negative	Alternative treatment access (negative)	3
		Compassionate care and respect (negative)	1
		Family/friend involvement (negative)	1
		Patient involvement (negative)	2
	Positive	Compassionate care and respect (positive)	1
		Family/friend involvement (positive)	1
2: Safe and quality care (n=9, 8%)	Negative	Care quality (negative)	1
		Side effect management (negative)	1
3: Multidisciplinary care	Positive	Care quality (positive)	7
		Negative	Multidisciplinary care (negative)

(n=1, 1%)			
4: Supportive care (n=3, 3%)	Negative	Supportive care access/referrals (negative)	3
5: Care coordination (n=8, 7%)	Negative	Care coordination (negative)	2
		Timeliness (negative)	4
	Positive	Care coordination (positive)	1
		Telehealth (positive)	1
6: Communication (n=19, 17%)	Negative	Communication and information sharing (negative)	17
	Positive	Communication and information sharing (positive)	1
	Neutral	Communication and information sharing (suggestions)	1
N/A (n=60, 54%)	Positive	Thanks/satisfaction	2
	Neutral	Unsure	6
		No further comments	52
Total themes identified			111

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

Most participants provided positive comments regarding their experience with treatment decision-making. Where suggestions were made, most comments described aspects of communication and information sharing (Principle 6: Communication). Specifically, participants wanted greater detail on what to expect from the treatments, including more information on possible side effects of treatment, including potential long-term side effects. For example:

“Just provide as much information about the type of treatment that a patient is to receive”

“I would like to have been informed of the ongoing consequences of treatment”

“Given more information on long-term effects & potential post-surgery complications”

Suggestions for improvement that reflected other OCP principles were less frequent, ranging from not receiving enough information in a timely manner or being offered a greater range of treatment options, to requests for increased support during treatment decision-making:

“I guess that it was the time it took from presentation with symptoms to a definitive diagnosis that bothered me more than anything else.”

“Maybe offer a few more options, the Dr suggested one option as the best option but did not talk much about alternative options.”

“After the surgery and the follow up treatment I would have liked to talk to somebody about the different moods you go through and how I could support my wife in dealing with the situation.”

Surgery

Between 109 and 145 participants with colorectal cancer answered survey items related to surgery. Themes related to five of the OCP Principles were highlighted as helpful during a hospital stay for surgery (Principles 1, 2, 4, 5, and 6, see Table 3). Overwhelmingly, participants highlighted the importance of good quality staff, responsive care, attention to detail, effective pain-management and staff who were helpful and had a positive or professional attitude (1: Patient-centred care, and 2: Safe and quality care). Participants also highlighted communication and information sharing as helpful during their surgical stay (Principle 6: Communication). For example:

“Explained clearly what to expect. Mostly got this [from] nurses as surgeons seem to have less of a social persona. For example the Stoma nurses filled in all the blanks to upcoming treatments to expect with sincerity and compassion. They were all INCREDIBLE!!”

Less frequent responses included having access to supportive care (Principle 4: Supportive care) and timeliness of care (Principle 5: Care coordination).

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

Q50. What were the most helpful things staff did while you were in hospital for surgery? (n=145 responses)			
OCP Principle	Experience	Themes	Count
1: Patient-centred care (n=64, 34%)	Negative	Compassionate care and respect (negative)	1
	Mixed	Compassionate care and respect (mixed)	1
	Positive	Compassionate care and respect (positive)	58
		Family/friend involvement (positive)	2
		Professionalism (positive)	2
2: Safe and quality care (n=80, 43%)	Negative	Care quality (negative)	1
		Hospital environment (negative)	2
		Hospital environment (staffing)	3
		Pain management (negative)	1
	Mixed	Care quality (mixed)	2
	Positive	Care quality (positive)	59
		Clinical skills/knowledge (positive)	2
		Medication management (positive)	1
4: Supportive care (n=8, 4%)	Positive	Supportive care access/referrals (positive)	8
5: Care coordination (n=3, 2%)	Negative	Timeliness (negative)	1
	Positive	Follow-up care (positive)	1
		Timeliness (positive)	1
6: Communication (n=27, 15%)	Positive	Communication and information sharing (positive)	27
N/A (n=4, 2%)	Positive	Thanks/satisfaction	2
	Neutral	No further comments	2
Total themes identified			186
Q51. What could be done to improve your surgery experience? (n=109 responses)			
OCP Principle	Experience	Themes	Count
1: Patient-centred care (n=8, 6%)	Negative	Alternative treatment access (negative)	1
		Compassionate care and respect (negative)	4
	Positive	Compassionate care and respect (positive)	2
		Professionalism (positive)	1
2: Safe and quality care (n=39, 31%)	Negative	Care quality (negative)	5
		Clinical skills/knowledge (negative)	4
		Early discharge	1

		Hospital environment (negative)	7
		Hospital environment (staffing)	4
		Pain management (negative)	4
	Mixed	Care quality (mixed)	1
	Positive	Care quality (positive)	13
4: Supportive care (n=2, 2%)	Negative	Supportive care access/referrals (negative)	2
5: Care coordination (n=8, 6%)	Negative	Care closer to home (negative)	2
		Care coordination (negative)	1
		Follow-up care (negative)	1
	Positive	Timeliness (negative)	2
	Positive	Follow-up care (positive)	2
6: Communication (n=16, 13%)	Negative	Communication and information sharing (negative)	14
	Positive	Communication and information sharing (positive)	1
	Neutral	Communication and information sharing (suggestions)	1
Other (n=5, 4%)	Negative	Access to resources (negative)	2
		Food access (negative)	1
		COVID-19	2
N/A (n=47, 38%)	Positive	Thanks/satisfaction	2
	Neutral	Unsure	1
		No further comments	44
Total themes identified			125

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

Roughly a third of responses to the item asking for suggestions for improvements to the surgery experience indicated no further comments (Table 3). Aspects of surgical care that participants indicated could be improved most frequently discussed providing more information to patients and ensuring information is communicated in a way patients can understand. Other responses reiterated positive experiences of their care quality without providing additional suggestions for improvement (Principle 2: Safe and quality care), or suggested greater access to resources, including supportive care or follow up care, and dissatisfaction from experiences sharing a room with other inpatients while on the ward.

Radiotherapy

Between 33 and 53 participants with colorectal cancer answered survey items related to radiotherapy (Table 4). Aspects of radiotherapy considered most helpful by participants included themes related compassionate care and respect, quality care, and communication and information sharing (Principles 1: Patient-centred care, 2: Safe and quality care, and 6: Communication, respectively). Themes related to compassionate care and respect focused on staff helping patients feel comfortable and supported and taking the time to explain information and respond to questions.

“They explained the treatment, side effects current & ongoing after treatment stopped. They listened when I had questions, were quick to help with medications etc. to address side effects”

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

“Explain procedure, encourage & made me feel I was the only person for the day (When I knew there were large numbers)”

“Always did their best. Showed ultimate patience with me even though at times I hadn't had enough to drink or timed it wrong”.

“I thought they went beyond reasonable efforts to manage my treatment.”

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

Q74. What were the most helpful things staff did during your radiotherapy? (n=53 responses)			
OCP Principle	Experience	Themes	Count
1: Patient-centred care (n=27, 44%)	Positive	Compassionate care and respect (positive)	26
		Professionalism (positive)	1
2: Safe and quality care (n=18, 30%)	Positive	Care quality (positive)	16
5: Care coordination (n=4, 7%)	Positive	Care coordination (positive)	2
		Follow-up care (positive)	1
		Timeliness (positive)	1
6: Communication (n=12, 20%)	Positive	Communication and information sharing (positive)	12
Total themes identified			61
Q75. What could be done to improve your radiotherapy experience? (n=33 responses)			
OCP Principle	Experience	Themes	Count
1: Patient-centred care (n=1, 3%)	Positive	Compassionate care and respect (positive)	1
2: Safe and quality care (n=4, 11%)	Negative	Hospital environment (staffing)	1
	Positive	Care quality (positive)	3
3: Multidisciplinary care (n=2, 6%)	Negative	Clinical information sharing (negative)	1
	Positive	Multidisciplinary care (positive)	1
4: Supportive care (n=1, 3%)	Negative	Supportive care access/referrals (negative)	1
6: Communication (n=2, 6%)	Negative	Communication and information sharing (negative)	1
	Neutral	Communication and information sharing (suggestions)	1
Other (n=2, 6%)	Negative	Food access (negative)	1
		COVID-19	1
N/A (n=23, 66%)	Positive	Thanks/satisfaction	3
	Neutral	Unsure	1
		No further comments	19
Total themes identified			35

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

Very few comments were provided that identified areas for improvement to the radiotherapy experience, with most responses either indicating no further comments or reiterating satisfaction with the radiotherapy experience. Where provided, recommendations centred on improving clinical information sharing between departments (Principle 2: Multidisciplinary care), and recommendations for improving communication with patients (Principle 6: Communication).

Chemotherapy

Between 61 and 102 participants with colorectal cancer answered survey items related to chemotherapy. Responses describing what participants found most helpful during chemotherapy aligned primarily with Principle 1: Patient-centred care, Principle 2: Safe and quality care, and Principle 6: Communication (Table 5). Across all aspects of chemotherapy, responses focused almost exclusively on interpersonal experiences with staff. Participants considered engaging with friendly, respectful, and professional staff who had a positive attitude and receiving clear and direct explanations that allowed participants to feel informed as the most helpful parts of their chemotherapy experiences. Responses also often described the empathy and support provided by staff, and themes related to safe and quality care centred on the ability of staff to do their job well, and their responsiveness to patient needs. For example:

“They were understanding, friendly, respectful at all times. They explained treatment & side effects, listened when I had questions, brought me coffee! They’re all legends & I will always be very grateful to them & very appreciative of their help & care.”

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

Q99. What were the most helpful things staff did during your chemotherapy? (n=102 responses)			
OCP Principle	Experience	Themes	Count
1: Patient-centred care (n=52, 36%)	Negative	Alternative treatment access (negative)	1
	Positive	Compassionate care and respect (positive)	45
		Patient involvement (positive)	1
		Professionalism (positive)	5
2: Safe and quality care (n=40, 28%)	Negative	Care quality (negative)	1
		Side effect management (negative)	1
	Mixed	Care quality (mixed)	2
	Positive	Care quality (positive)	23
		Clinical skills/knowledge (positive)	3
		Medication management (positive)	1
Side effect management (positive)	9		
	4: Supportive care (n=2, 1%)	Positive	Supportive care access/referrals (positive)
5: Care coordination (n=16, 11%)	Positive	Care closer to home (positive)	3
		Care coordination (positive)	2
		Follow-up care (positive)	7
		Timeliness (positive)	4
6: Communication (n=25, 17%)	Positive	Communication and information sharing (positive)	25
Other (n=7, 5%)	Negative	Food access (negative)	1
		COVID-19	1
	Positive	Access to resources (positive)	1
		Food access (positive)	4

N/A (n=2, 1%)	Neutral	Unsure	1
		No further comments	1
Total themes identified			144
Q100. What could be done to improve your chemotherapy experience? (n=61 responses)			
OCP Principle	Experience	Themes	Count
1: Patient-centred care (n=8, 12%)	Negative	Compassionate care and respect (negative)	1
		Family/friend involvement (negative)	1
		Patient involvement (negative)	1
	Positive	Compassionate care and respect (positive)	3
		Professionalism (positive)	2
2: Safe and quality care (n=13, 19%)	Negative	Hospital environment (negative)	2
		Side effect management (negative)	2
	Mixed	Care quality (mixed)	3
	Positive	Care quality (positive)	5
		Hospital environment (positive)	1
3: Multidisciplinary care (n=1, 1%)	Negative	Clinical information sharing (negative)	1
5: Care coordination (n=6, 9%)	Negative	Care closer to home (negative)	1
		Care coordination (negative)	1
		Timeliness (negative)	2
	Positive	Care closer to home (positive)	1
		Follow-up care (positive)	1
6: Communication (n=5, 7%)	Negative	Communication and information sharing (negative)	3
	Positive	Communication and information sharing (positive)	2
Other (n=2, 3%)	Negative	COVID-19	1
	Neutral	Public health recommendations	1
N/A (n=34, 49%)	Positive	Thanks/satisfaction	5
	Neutral	Unsure	1
		No further comments	28
Total themes identified			69

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

Significantly fewer responses provided suggestions for how chemotherapy care could be improved, with almost half of all responses to the question about improvements indicating 'no further comments'. Where discussed, the greatest proportion of responses relating to opportunities for improvement focused on mixed experience of care quality, including the management of side effects, ensuring staff have a positive attitude, and a mixed experience with staff communication and information sharing (Principles 2, 1, and 6, respectively).

ED experiences

Items related to ED experiences were answered by between 34 and 46 participants with colorectal cancer (Table 6). Aspects of care participants considered most helpful in their ED experiences

focused on attentiveness of staff, (Principle 2: Safe and quality care), clear and direct communication (Principle 6: Communication), and compassionate and respectful care by ED staff (Principle 1: Patient-centred care). Two participants described mixed experiences in care quality by ED staff:

“Making sure I’m ok, all care was excellent. The one incident that was unfortunate is having 2 doctors having a very active discussion over whether I should be admitted up to a ward or not. So I was placed in the overnight stay room and the next day I was admitted and stayed 5-6 days.”

“After more than 40 hours in a small ‘half room’ (not a treatment cubicle) with very little contact from treatment staff - no food/water - I was finally taken to a cubicle and provided some attention a nurse asked if there was anything I wanted. I responded, in tears, that I needed help and someone to check my situation and get me into a ward. They actually did something about it as they called [someone...] and I was in a ward not too long after. This nurse actually listened to me!”

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

Q107. What were the most helpful things staff did during your Emergency Department visit? (n=46 responses)			
OCP Principle	Experience	Themes	Count
1: Patient-centred care (n=8, 15%)	Positive	Compassionate care and respect (positive)	8
2: Safe and quality care (n=22, 42%)	Negative	Care quality (negative)	2
		Hospital environment (negative)	1
	Mixed	Care quality (mixed)	2
	Positive	Care quality (positive)	14
		Clinical skills/knowledge (positive)	1
Positive	Pain management (positive)	2	
	Positive	Clinical information sharing (positive)	3
		Multidisciplinary care (positive)	2
3: Multidisciplinary care (n=5, 10%)			
5: Care coordination (n=4, 8%)	Negative	Timeliness (negative)	1
	Positive	Care closer to home (positive)	1
		Timeliness (positive)	2
6: Communication (n=8, 15%)	Positive	Communication and information sharing (positive)	8
Other (n=3, 6%)	Positive	Access to resources (positive)	1
	Negative	COVID-19	2
N/A (n=2, 4%)	Positive	Thanks/satisfaction	1
	Neutral	Unsure	1
Total themes identified			52
Q108. What could be done to improve the Emergency Department experience for cancer patients? (n=34 responses)			
OCP Principle	Experience	Themes	Count
2: Safe and quality care (n=7, 19%)	Negative	Hospital environment (negative)	3
		Hospital environment (staffing)	3
	Positive	Clinical skills/knowledge (positive)	1
5: Care coordination (n=16, 43%)	Negative	Care coordination (negative)	3
		Timeliness (negative)	13

6: Communication (n=3, 8%)	Negative	Communication and information sharing (negative)	2
	Neutral	Communication and information sharing (suggestions)	1
Other (n=2, 5%)	Negative	COVID-19	2
N/A (n=9, 24%)	Positive	Thanks/satisfaction	1
	Neutral	Unsure	1
		No further comments	7
Total themes identified			37

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

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

“Not leave me sitting in a chair for many hours”

“Less wait times”

“Waiting times”

“Reduce the waiting time to see a doctor (not withstanding the pressures that Emergency departments are under).”

“Waited 12 hours to see a Dr.”

Follow-up care

Aspects of follow-up care considered most helpful primarily related to Principle 6: Communication, and Principle 1: Patient-centred care (Table 7). Participants emphasised the importance of clear communication of information and advice, and the caring and friendly approach used by staff.

Participants also found having follow up plans after treatment and access to hospital in the home services helpful (Principle 5: Care coordination). Less frequent responses related to Principle 2: Safe and quality care, Principle 3: Multidisciplinary care, and Principle 4: Multidisciplinary care. Themes related to these principles included having confidence in the knowledge and abilities of staff, and effective communication between medical professionals, including facilitating access to supportive care needs when required:

“Blood tests, CT scans are always followed up”

“Very good co-ordination between the specialists/hospital & gp, all care was great.”

“Arrange support and specialists to manage nutrition and anxiety.”

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

Q120. What were the most helpful things staff did during your follow-up care? (n=87 responses)			
OCP Principle	Experience	Themes	Count
1: Patient-centred care (n=22, 22%)	Negative	Compassionate care and respect (negative)	1
	Positive	Compassionate care and respect (positive)	21
2: Safe and quality care	Positive	Care quality (positive)	7

(n=10, 10%)		Clinical skills/knowledge (positive)	3
3: Multidisciplinary care (n=3, 3%)	Positive	Clinical information sharing (positive)	1
		GP experiences (positive)	1
		Multidisciplinary care (positive)	1
4: Supportive care (n=5, 5%)	Positive	Supportive care access/referrals (positive)	5
5: Care coordination (n=32, 32%)	Negative	Care coordination (negative)	1
	Positive	Care closer to home (positive)	7
		Care coordination (positive)	9
		Follow-up care (positive)	11
		Telehealth (positive)	2
		Timeliness (positive)	2
6: Communication (n=25, 25%)	Positive	Communication and information sharing (positive)	25
N/A (n=3, 3%)	Neutral	Unsure	1
		No further comments	2
Total themes identified			100
Q121. What could be done to improve the follow-up experience for cancer patients? (n=70 responses)			
OCP Principle	Experience	Themes	Count
1: Patient-centred care (n=3, 4%)	Negative	Alternative treatment access (negative)	1
		Compassionate care and respect (negative)	2
2: Safe and quality care (n=3, 4%)	Negative	Hospital environment (staffing)	1
		Side effect management (negative)	1
	Positive	Care quality (positive)	1
3: Multidisciplinary care (n=1, 1%)	Negative	Clinical information sharing (negative)	1
4: Supportive care (n=4, 6%)	Negative	Supportive care access/referrals (negative)	4
5: Care coordination (n=14, 19%)	Negative	Care closer to home (negative)	2
		Care coordination (negative)	6
		Follow-up care (negative)	1
		Telehealth (negative)	1
		Timeliness (negative)	4
6: Communication (n=13, 18%)	Negative	Communication and information sharing (negative)	8
	Positive	Communication and information sharing (positive)	1
	Neutral	Communication and information sharing (suggestions)	4
Other (n=2, 3%)	Negative	Access to resources (negative)	1
		COVID-19	1
N/A (n=32, 44%)	Positive	Thanks/satisfaction	6
	Neutral	Unsure	3

	No further comments	23
Total themes identified		72

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

Just under half of participants did not have additional comments related to what could be done to improve the follow-up experience for cancer patients (Table 7). Where suggestions were provided, responses primarily related to Principle 5: Care coordination and Principle 6: Communication. Limited responses were provided that related to Principles 1-4. Suggestions for improvements included improving access to clinical information such as test results, or information about appointments, and increased access to supportive care services. One respondent noted how helpful they found the patient portal, but that they had not been advised about it by staff:

“Advise patients about the patient portal app. We stumbled upon it and found it to be very helpful because it gave us access to the surgeon’s notes.”

Additional comments made in survey

All principles except for Principle 7: Research and clinical trials were discussed by participants across the four survey items for additional comments (Table 8), with response numbers ranging from 30-94 depending on the item. Responses describing experiences colorectal cancer patients had regarding information they received or would like to have received primarily described positive experience of care quality and communication and information sharing (Principles 2: Safe and quality care, and 6: Communication). Where specific suggestions were made for opportunities for improved information sharing, these included better information about and/or access to support services:

“More information on Centrelink payments available.”

“Would like to have been informed about travel allowance.”

“I would like to be able to contact somebody when I am feeling down and worried about things and how and give my wife support with dealing with the care she gives me while working full time I try to look at life with a positive outlook but sometimes I feel down and wish I could talk to someone when I feel that way not often but now and again.”

One respondent also highlighted concerns with how much information was delivered at a single time, highlighting the importance of ensuring communication approaches are tailored to the patient:

“Actually, my problem was more with the deluge of information and with treatment and outcomes on my mind I found that some things became snowed under ...”

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

“Confusion between departments - radiology and outpatients colorectal clinic on several occasions when organizing tests and appointment times.”

“On all doctors not passing on information, not sure which specialist where making decisions, shoved from one doctor to the next. All on many occasions.”

Responses also discussed when appointments and/or meetings had to proceed without the required test results:

“3 monthly review appointment was done without inform tram ct scan, as if could not be found. Most disappointing.”

“GP has had to chase up test results. When I went to hospital for aborted ablation information did not get passed to medical oncologist appropriately”

“After blood tests - which were regular - the results often had not been received by both the oncologist & the gp”

Participants also described instances where problems or repeated testing were caused by a lack of multidisciplinary information sharing. For example:

“Having to stop taking my regular medications without consultation with my Rheumatologist, and now trying to control Psoriatic Arthritis and Psoriasis flare.”

“Radiation was not informed that a cafiter [sic. catheter] was fitted during treatment. Super pubic cafiter [sic. catheter] they did not remove it before discharging me & had no record of it.”

Thirty participants indicated there was a time they were so unhappy with their treatment that they wanted to or did complain about it. Broadly, dissatisfaction and cause for complaint were reflections of poor experiences with a health professional and/or the quality of care provided by a particular staff member, the timeliness of care, or a lack of communication from staff (Principles 2, 5 and 6, respectively). For example:

“Very poor interaction and care by one chemotherapy nurse was reported”

“After being informed of a release day, I had to wait hours to find out what time I'd be released therefore unable to arrange with family to be picked up at a certain time.”

“I have repeatedly had to enquire, request and beg for appointments for follow ups and procedures”

Few responses described problems with Principles 1: Patient-centred care, 3: Multidisciplinary care, 4: Supportive care, and no responses identified themes related to Principle 7: Research and clinical trials. However, one particular response highlighted a serious issue with unprofessional behaviour by a staff member:

“The NUM of the oncology department. Discussed me & my treatment with another patient. She then said one day I would leave the department & drop dead because I was using cryotherapy to treat cold sensitivity from oxaliplatin this was very traumatic...”

Roughly two thirds of the general comments about the care experiences of colorectal cancer patients focused on reiterating positive experiences across their cancer treatment journey:

“All staff were excellent care was wonderful service could not have been improved. Wonderful experience in a difficult time.”

“For the vast majority of my time while being treated in this case I have nothing but praise for the medical AND ancillary staff who attended to my care and made me feel that I was the major reason for them being there.”

Where negative experiences were discussed, these generally related to communication and information sharing issues, problems with care coordination, mixed experiences of care quality, the negative impact of COVID-19 on cancer care, and problems related to long-term side effects. For example:

“Post operative support other than stoma nurse was extremely poor. Directly after surgery child not notified about the outcomes. Had to wait for weeks for an appointment. Surgeon did not call to confirm all went well etc.”

“I was not informed I would require clexane injections for 1 month at home until day of discharge.”

“Better post-surgery info about complications, long-term effects life changes [needed]”

Table 8: Additional free-text questions

Q128. If you would like to make any other comments about your experiences regarding information you received or would like to have received, please use the space below. We would like to know about them. (n=47 responses)			
OCP Principle	Experience	Themes	Count
1: Patient-centred care (n=3, 5%)	Negative	Compassionate care and respect (negative)	1
	Positive	Compassionate care and respect (positive)	1
		Professionalism (positive)	1
2: Safe and quality care (n=17, 30%)	Negative	Clinical skills/knowledge (negative)	1
		Hospital environment (staffing)	1
		Pain management (negative)	1
	Mixed	Care quality (mixed)	1
	Positive	Care quality (positive)	13
3: Multidisciplinary care (n=2, 4%)	Negative	Clinical information sharing (negative)	1
		Multidisciplinary care (negative)	1
4: Supportive care (n=11, 20%)	Negative	Supportive care access/referrals (negative)	5
	Positive	Supportive care access/referrals (positive)	6
5: Care coordination (n=2, 4%)	Negative	Care coordination (negative)	1
	Positive	Care closer to home (positive)	1
6: Communication (n=12, 21%)	Negative	Communication and information sharing (negative)	3
	Positive	Communication and information sharing (positive)	9
Other (n=1, 2%)	Positive	Food access (positive)	1
N/A (n=8, 14%)	Positive	Thanks/satisfaction	3
	Neutral	No further comments	5
Total themes identified			56
Q131. If you experienced any of the things listed in the previous question, could you please provide us with information about what happened and when it happened (n=51 responses)			
OCP Principle	Experience	Themes	Count
1: Patient-centred care (n=3, 5%)	Negative	Alternative treatment access (negative)	2
		Compassionate care and respect (negative)	1
2: Safe and quality care	Negative	Care quality (negative)	1

(n=4, 7%)		Side effect management (negative)	1
		Treatment discrepancy	1
	Mixed	Care quality (mixed)	1
3: Multidisciplinary care (n=21, 38%)	Negative	Clinical information sharing (negative)	16
		GP experiences (negative)	1
		Multidisciplinary care (negative)	2
	Positive	Multidisciplinary care (positive)	2
5: Care coordination (n=6, 11%)	Negative	Care coordination (negative)	3
		Timeliness (negative)	2
	Positive	Care closer to home (positive)	1
6: Communication (n=5, 9%)	Negative	Communication and information sharing (negative)	5
Other (n=1, 2%)	Negative	COVID-19	1
N/A (n=15, 27%)	Positive	Thanks/satisfaction	1
	Neutral	No further comments	14
Total themes identified			55

Q142. If yes, what was the issue you wanted to complain about? (n=30 responses)

OCP Principle	Experience	Themes	Count
1: Patient-centred care (n=6, 18%)	Negative	Compassionate care and respect (negative)	3
		Professionalism (negative)	3
2: Safe and quality care (n=12, 35%)	Negative	Care quality (negative)	6
		Clinical skills/knowledge (negative)	3
		Medication management (negative)	1
		Treatment discrepancy	1
	Mixed	Care quality (mixed)	1
3: Multidisciplinary care (n=2, 6%)	Negative	Clinical information sharing (negative)	2
4: Supportive care (n=1, 3%)	Negative	Supportive care access/referrals (negative)	1
5: Care coordination (n=7, 21%)	Negative	Care coordination (negative)	2
		Timeliness (negative)	5
6: Communication (n=5, 15%)	Negative	Communication and information sharing (negative)	5
Other (n=1, 3%)	Negative	Food access (negative)	1
Total themes identified			34

Q157. If you would like to make any other comments about your care experiences during your treatment, please use the space below. We would like to know about them. (n=94 responses)

OCP Principle	Experience	Themes	Count
1: Patient-centered care (n=12, 10%)	Negative	Family/friend involvement (negative)	1
	Positive	Compassionate care and respect (positive)	8
		Family/friend involvement (positive)	1
		Professionalism (positive)	2
2: Safe and quality care	Negative	Care quality (negative)	2

(n=45, 38%)		Hospital environment (negative)	1
		Hospital environment (staffing)	1
		Management of complaints (negative)	1
		Side effect management (negative)	2
		Treatment discrepancy	2
	Mixed	Care quality (mixed)	2
	Positive	Care quality (positive)	32
		Outcomes (positive)	1
Side effect management (positive)		1	
3: Multidisciplinary care (n=2, 2%)	Negative	Clinical information sharing (negative)	1
	Positive	GP experiences (positive)	1
4: Supportive care (n=2, 2%)	Positive	Supportive care access/referrals (positive)	2
5: Care coordination (n=10, 9%)	Negative	Care closer to home (negative)	2
		Care coordination (negative)	4
		Follow-up care (negative)	1
		Timeliness (negative)	2
	Positive	Care closer to home (positive)	1
6: Communication (n=7, 6%)	Negative	Communication and information sharing (negative)	6
	Positive	Communication and information sharing (positive)	1
Other (n=4, 3%)	Negative	Access to resources (negative)	1
		COVID-19	3
N/A (n=35, 30%)	Positive	Thanks/satisfaction	25
	Neutral	No further comments	10
Total themes identified			117

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

4.2 Focus Groups

Thirteen people with colorectal cancer or carers participated in the focus group discussions.

Demographics

Table 9 below shows the demographic data provided by focus group participants. More than half of the participants were female (62%, n=8) and one participant reported being of Aboriginal or Torres Strait Islander descent (8%). Almost half of the participants were younger than 50 (47%, n=6), and just over a third were between 50 – 60 years old (38%, n=5), and two were above 60 years old. Just over half of the participants reported living in metropolitan regions (54%, n=7). Almost two thirds (61%) of participants reported being diagnosed with stage III colorectal cancer with three participants (23%) having late stage colorectal cancer.

Table 9. Colorectal cancer focus group demographic information

Gender	n = 13	Percentage
Women	8	62%
Men	5	38%
Total	13	100%
Age	n = 13	Percentage
Younger than 50	6	47%
50 - 60	5	38%
61 - 70	2	15%
Total	13	100%
Stage/Grade	n = 13	Percentage
I	0	0%
II	1	8%
III	8	61%
IV	3	23%
N/A	1	8%
Total	13	100%
Region	n = 13	Percentage
Metropolitan	7	54%
Regional	6	46%
Total	13	100%
Aboriginal Background	n = 9	Percentage
Yes	1	8%
No	12	92%
Total	13	100%

OCP Step One: Prevention and early detection

Focus group participants were asked if they were aware of colorectal prior to their diagnosis. Almost a quarter of participants, (23%, n=3) reported being unaware of colorectal cancer prior to their diagnosis. Most participants reported they were aware of risk factors such as smoking, alcohol and processed meat consumption, and obesity linked to cancer but that they were not directly aware of their link to colorectal cancer.

Some participants (31%, n=4) reported their willingness to receive medical advice but may have been considered too young to be diagnosed with cancer.

“I remember directly asking my GP at one stage, you know, given my grandpa had bowel cancer and my both my parents have regular colonoscopies. Like, is that something I should be thinking about? And they sort of said well, no because he was like 60 when he was diagnosed.”

Most participants (77%, n=10) were aware of the National Bowel Cancer Screening Program. However, some of them believed they did not fit into the age group requirement.

“I suppose I was loosely aware of various national screening programs, probably more so in the typical female cancer space. I was aware of cervical cancer screening and the Victorian breast screening program but in terms of being given a target of sort of explicit information prior to my diagnosis, I wasn't. I kind of assumed that most of my clinicians considered me too young to be needing to know that.”

OCP Step Two: Presentation, initial investigations and referral

Focus group participants were asked how long it took them to see a health professional after noticing an initial symptom. Many participants reported initially attributing their symptoms to unrelated conditions such as haemorrhoids, postpartum changes, thyroid issues, celiac disease, or even stress from moving to a different country. Symptoms like fatigue, changes in bowel habits, and rectal bleeding were often dismissed or linked to more common, non-cancerous conditions.

The timelines to consult a health professional about symptoms ranged from being seen immediately to 12 months. The majority of participants (70%, n=9) took less than one month to discuss their symptoms with a health professional. 15% of participants (n=2) reported the discovery of their cancer as a result of an emergency medical situation with alarming symptoms such as unbearable pain, extreme bleeding and bowel rupture occurring.

“I didn't really know how sick I was or how bad it was until I went to hospital. Nothing was different for me before I had just a pain in the guts.”

Focus groups explored if participants felt that all their symptoms were appropriately investigated. Some participants stated they were initially diagnosed with conditions like Irritable Bowel Syndrome (IBS) or diverticulitis before colorectal cancer (CRC) was considered. Some participants reported that delays in referral occurred because GPs prioritised ruling out more common conditions first. Some GPs also dismissed symptoms such as frequent toilet visits, rectal bleeding, and pain as infections rather than potential cancer indicators.

“So while I was in there, they identified I had C. diff, but something else was going on...they detected that I had a tumour in my rectum and that I needed a colonoscopy.”

OCP Step Three – Diagnosis, staging and treatment planning

Focus groups explored how long from the investigation of their symptoms did it take for participants to receive a cancer diagnosis. On average, participants reported it took about 2.9 months for them to receive their diagnosis. Just over a third of participants (38%, n=5) reported having their diagnostic investigations within the two-week timeframe provided by the colorectal cancer OCP. [1] One participant reported their diagnosis was eighteen months long after their diagnostic investigation.

“Common [symptoms] are common”

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

Many participants described their diagnosis as a big shock, traumatic and quite devastating. This often led to information being explained by oncologists to be unheard. Some participants noted the importance of having a second opinion which provided them with clarity. A few participants reported the need to be able to note take and refer back to the information once they had some time to reflect.

“I was obviously shocked and quite upset about it. You can Google whatever you like and get all the answers you like and the answers that I got from that weren't very favourable. So, I just went and took each day by day and yeah, but a huge shock. “

Having a support person enabled some participants to rely on them and be on this journey with someone rather than alone.

“Another valuable point here is that I made contact with someone who had just gone through the process of diagnosis and treatment for colorectal cancer and their advice and information was very helpful.”

“I had a very supportive friend who was knowledgeable about cancer and the treatment system.”

OCP Step Four – Treatment

Focus group participants were asked how long it took for them to begin active treatment after their diagnosis. Over a third of participants (38%, n=5) reported having their diagnosis after investigations of symptoms to be more than one month which is greater than the OCPs recommendation. One of these participants reported that it took over three months to be diagnosed.

Participants were also asked about their experiences of the treatments they received. Approximately a quarter (23%, n=3) reported of post-treatment complications. Complications were reported to include wound discharge, nausea and loss of appetite.

“I get it, but it's kind of been explained to us before having chemo that this wouldn't happen and that you need to be away from people. So, it was kind of just like very much felt pushed to the side. I just don't understand how that you're in their care already. But you know, it's our time to clock off. So, see you later.”

Over three quarter of participants (77%, n=10) reported undergoing (77%) chemotherapy, 69% (n=9) stated they had surgery, 54% radiotherapy (n=7) and 23% (n=3) reported having an ileostomy procedure.

One participant discussed their experience with finding their treatments confronting but felt they were reassured, especially regarding their stoma. They also reflected on the experience of their partner and how overwhelming the treatment process was for them.

Experience of travel was also discussed with the focus group participants. More than half of the participants (62%, n=8) reported that they did have to travel long distances to receive their care. This ranged from 20 minutes to one hour. Some participants however reported travelling significant distances to receive treatment, with some travelling over 100kms and others travelling just under two hours.

“But on the on the occasions when [family] wasn't there, like when I was having friends and stuff take me in and when you're being hooked up to chemo at 8:00 AM and on a good day not being released till 6:00 PM trying to find parking and [hospital] parking is hideously expensive. If you went in, like so many times in a week two-week period you could get a discounted parking, but you still had to like to go and line up to get the discounted parking which is just another thing to remember, another thing to do.”

Participants reported that support by family, friends, colleagues and community were imperative in enabling them to receive their treatment.

“Fortunately, I knew that I had people around me who cared for me, and I had this wonderful extra special supportive person who was right there throughout the process.”

The focus group participants were asked about their experience of clinical trials. Most participants(62%, n=8) reported they were aware or were made aware of any clinical trials by their health professional. Less than a quarter (23%, n=3) stated they had a brief discussion about clinical trials but believed they were ineligible.

Two consumers (15%) noted that the trial nurses were excellent, caring and easy to contact. They

were able to provide clear explanations of the process. However, there were implications with one consumer regarding a complication they experienced resulting in ED admittance. They reported experiencing a great lack of support when this occurred especially as a participant of the trial and due to not meeting emergency care requirements for a trial complication.

Fertility implications were also explored with over half of participants (54%, n=7) stating that fertility information had been provided to them. All participants who did not receive any fertility information believed it to not be applicable to their personal circumstances. One participant reported a lack of communication regarding fertility implications.

“Yeah, I think it was just real poor communication with me about why I was having these additional appointments scheduled and poor communication between the two hospitals and the online appointment scheduling platform. So it was that disconnect, and it wasn't until I had finished treatment and finally was able to turn up to one of these appointments that they're like, oh yeah, because you had chemo and because you did fertility preservation. We have the option of tracking your hormone levels because you're at risk of early menopause.”

Over half of participants (69%, n=9) reported having access to a stoma nurse or clinical nurse consultant. Almost all these participants had high praise for the service they provided including supporting them with their colostomy, being the point of contact, and managing their treatment concerns.

“Nothing was too much trouble. She was very special, and I've told her that many times and I'm sure she has many patients telling her that. But, you know, mine's really from my heart.”

Focus group participants were asked about their supportive care needs and referrals they may have received. Supportive care was reported as being limited by participants. Only one participant (11%) reported being able to participate in a local ten-week rehabilitation program after their treatment. Participants highlighted the gaps in supportive care service available during their cancer journey.

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

Approximately a third of participants (31%, n=4) reported not having supportive care services offered or discussed with them. Most participants that did receive supportive care referrals stated that they utilised psychology, counselling, and dietitian services most frequently.

“Looking back it does seem like I was facing the need to access a broad range of services and information at a time when I was really struggling with everything”

OCP Step Five – Care after initial treatment and recovery

Focus group participants were asked about the health professionals that were involved in their care after finishing active treatment. Less than half (46%, n=6) of the participants were in touch with their oncologist, and small proportions with other medical professionals including their surgeon (38%, n=5) and GP (23%, n=3). A few participants also reported being in contact with allied health professionals including an exercise physiologist (15%, n=2) dietitian (31%, n=4). One consumer continued to see their nurse and another remains involved with their psychologist. Just under a quarter of participants (23%, n=3) reported still undergoing active treatment.

“The dietitian was more helpful for me because...she was talking a language and really tailoring information that I needed in a way [that] free resources through Cancer Australia can't do.”

One participant (8%) reflected on the importance to her of being supported to seek second opinions and the rapport and trust that it built with her care team.

“If you're getting a feeling that maybe it's not a good fit with the with a particular clinician, then it's okay to get a second opinion or get a third opinion and find the person that fits with you, because I think it's really critically important. We've had to have a lot of very difficult conversations, and we've had to be not deliberately critical but ask the critical questions and you know sometimes be the squeaky wheel. Each of them have all welcomed that, none of them have shunned away from me asking hard questions or me challenging or me finding alternative opinions from the outside.”

A common theme between all participants was the psychological aspect of living with their diagnosis.

“You also don't know what you need and when you need it. Nobody also says that the psychological element is almost harder at times than the physical element of this disease.”

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. All participants reported that their GPs were consistently kept in the loop regarding their care. A small proportion (15%, n=2) felt that after diagnosis, the role of their GP had diminished and they preferred to go directly to their oncologist or surgeon to receive updates about the progress.

“I have a great GP, but to be really frank, I don't see her much. Almost everything needs to be run past my oncologist She's copied into all of my reports and scans. And she knows how I'm going. But in terms of taking any of this on, I don't think she'd feel particularly comfortable. And she's a great GP, I think she too has been on a steep learning curve as well.”

Participants were asked about their experience with transitioning back into day-to-day life after finishing active treatment. Just over half of the participants (33%, n=7) reported they felt supported but a key theme raised was the need for supportive return to work policies. Participants also highlighted the importance of understanding the financial costs of care, especially for patients diagnosed at a younger age with greater family and work commitments.

“The financial situation is not something discussed particularly for younger patients. I don't think enough focus is given to that and I think as Australia continues to see this increase in in young onset cancers across the board, we are going to actually have to deal with this because it's not only toxic to the individual, but it's toxic to society more broadly and the system. I've been asked more than once to try and convince other young women to go forward with treatment, [but] they've got a partner that needs to work or they're a single parent. They can't see their way through the financial element of going through active chemotherapy.”

While some participants report that their workplace was very supportive, they acknowledged that they had to work and endure work while undergoing treatment or recovery.

“You still do day to day life anyway, just kind of got to get on with it.”

OCP Step Six – Managing recurrent, residual or metastatic disease

Focus group participants were asked if they had the opportunity to discuss their prognosis with their healthcare providers. Just over a third of participants (38%, n=5) asked about their prognosis. Some participants felt that the discussion of prognosis was irrelevant to them. They reported that due to personal circumstances they did not want to discuss prognosis. One participant (8%) however, stated (8%) that they did not receive any information about their prognosis and eventually had to ask.

"I'm actually very grateful that my oncologist didn't sit down and say oh, well, you know, X percent of people will survive this. He knew that I knew, and I knew that he knew we were both doing the reading. We both knew how terrible and bleak the literature was. But he never discussed it because he used to keep saying the guideline isn't written for you. The guideline isn't taking into account how healthy you are outside of everything else."

Focus group participants were also asked about advance care planning and making future decisions with them. Approximately a third of participants (33%, n=4) reported having informal or formal conversations regarding advance care planning.

OCP Step Seven – End-of-life care

23% of consumers and one carer reported utilisation of palliative care. These were often used for pain management as a result of treatment or recovery.

Other experiences in their cancer journey

Participants shared their perspectives on the accessibility, communication, and quality of information provided throughout their cancer journeys. Some participants reported receiving diverse types of information—verbal, written, and video-based however this varied.

The amount of information given at diagnosis can be overwhelming and difficult to process. Shock from the diagnosis can result in difficulty retaining important details. Having written information is crucial, as it allows patients to review it later when they are in a better state of mind. When a support person is unavailable to take notes, it becomes even harder to retain and prioritise information.

"I think there's a still a heavy reliance on verbal information. In a time when cognitively, people are not going to be best able to receive the information because either they're stressed or have anxiety."

Participants reflected on the fact that non-English speakers may struggle with the complexity of medical terminology and explanations. Pamphlets and hospital-provided materials are not always relevant to individual cases, making it difficult to find the most useful information.

"I have a bit of a medical background, but I have a lot of friends and colleagues who have great backgrounds, so I was able to use their knowledge. But I feel that if I was a non-English speaking person, I'm not sure how well, even through an interpreter, some of the things would be understood."

The importance of peer groups and support people were highlighted. Participants reflected on peer groups helping them share experiences, ask questions, and gain a better understanding of their journey. They also discussed the role of support people who attended appointments, took notes, asked important questions, kept records and helped navigate the pathway.

"Once again I was greatly helped by my support person attending all appointments with me, asking good questions and keeping a record of the diagnostic and treatment process in a notebook."

Participants were asked if the cancer care system recognised their unique needs. Six consumers (46%) reported that their unique needs were met and three consumers (23%) reported that this question was not applicable to their circumstances. Of those that believed their needs were unmet, two (15%) were due to being overlooked given their age, one was due to the travel and distance barrier. Another participant also believed that their experience as a colorectal nurse led their care

team to assume that they already knew everything about their treatment and recovery journey which was untrue.

“With increased diagnosis of bowel cancer in younger patients, more effort and time needs to be spent in recognising that survivorship phase and what support people need during treatment and beyond into survivorship, to live well with cancer and that’s something that I have mentioned with Bowel Cancer Australia as well, about whether there’s opportunities there to provide support.”

Many of the focus group participants identified the stigma around having colorectal cancer and how it has become a barrier for people to talk about and be screened for it. Health literacy and awareness were highlighted as key drivers for improvement.

“There needs to be a acknowledgement [of] the extra difficulties with colorectal cancer and a stigma that’s around it. No one likes talking about poo or bottoms.”

Key findings

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

Key findings include:

- **Patient experience and support** – Participants generally reported positive experiences, with most feeling respected and treated with dignity throughout their cancer journey. Compassionate care, particularly from stoma nurses, was highly valued. However, gaps remained in family support, long-term side effect management, and access to appropriate post-treatment care.
- **Communication and health literacy** – While many participants found clinician communication helpful, others expressed a need for clearer, more detailed information about their diagnosis and treatment options. Poor health literacy regarding early-onset colorectal cancer contributed to delayed diagnoses, with some participants feeling unprepared for their care journey. Many wished for more time to process information and make informed decisions.
- **Care coordination and timeliness** – Effective follow-up care and coordination were highly valued, particularly when care was provided closer to home. However, delays in diagnosis and emergency department admissions were a key concern and patients often feeling uncertain about who to contact for support post-treatment.
- **Confidence in ongoing care** – A higher proportion of colorectal cancer patients (65%) reported confidence in their GP’s ability to manage their ongoing cancer care compared to the statewide average (55%), suggesting positive engagement with primary care in the long term.
- **Psychosocial support needs** – Emotional and psychological support for patients and their family was often inadequate, with limited access to counselling and support services.
- **Areas for improvement** – The most commonly cited areas requiring improvement included better communication from healthcare providers, improved health literacy efforts, timeliness of care coordination, and more structured follow-up support after treatment. While some participants identified gaps, others reiterated their positive experiences and had no suggestions for change.

Implications

The findings of this report highlight several opportunities to enhance colorectal cancer care in Victoria. While many participants reported positive experiences, the identified gaps in communication, care coordination, and psychosocial support indicate the need for targeted improvements to ensure equitable and patient-centred care.

A stronger focus on health literacy and communication strategies is essential to address patient concerns about unclear information and delayed diagnoses, particularly for early-onset colorectal cancer. In addition, care coordination must be strengthened to reduce delays in diagnosis, emergency department admissions, and post-treatment follow-up. Enhancing integrated care pathways between hospitals, primary care, and community services will ensure patients receive timely, seamless, and well-coordinated care. Additionally, addressing uncertainty around follow-up care by providing clear guidance on support services and contact points will improve patient confidence in ongoing care management.

Access to psychosocial and family support should be considered, as emotional and psychological care remains an unmet need. Cancer services should prioritise facilitating pathways to increase access to counselling, peer support, and resources for patients and their families to manage the long-term impacts of treatment. Stoma care teams were highly valued, suggesting that similar supportive models could be extended across other aspects of colorectal cancer care.

Given the limited representation of rural, regional, and culturally diverse populations in the survey, further research and targeted strategies are required to ensure equity in care delivery. Expanding support services and accessibility for these populations will help address disparities in cancer care experiences.

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

Appendix

Appendix 1: Discussion Points for the Focus Group

Demographic Information Form

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

Prevention and early detection:

- | |
|---|
| 1. Were you given any information before your diagnosis about cancer prevention and/or early detection (weight, smoking, exercise, screening programs)? |
| 2. Were you aware of the national screening program? (e.g. NBCSP) |

Presentation:

- | |
|---|
| 3. From your initial symptoms, how long did it take for you to see a health professional about these? |
| 4. Did you feel your symptoms were investigated timely and appropriately? |

Diagnosis:

- | |
|---|
| 5. How long from initial presentation of symptoms or a positive screening result did it take you to receive a cancer diagnosis? |
| 6. What was your experience with receiving your cancer diagnosis and considerations with beginning the treatment journey? |

Treatment:

- | |
|---|
| 7. How long from diagnosis did it take for you to begin active treatment? |
| 8. What types of treatment did you receive? What was your experience with each of these treatments? (Prompt: surgery, chemotherapy, radiotherapy) |
| 9. Did you have to travel to receive care? What was your experience with this if you did? |
| 10. What has been your experience with receiving information about clinical trials? |
| 11. Were fertility implications of your treatment discussed with you? |
| 12. Were you able to access a colorectal clinical nurse consultant and/or stoma nurse? |
| 13. 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:

- | |
|---|
| 14. Did you have any contact with health professionals after finishing treatment? (Prompt: doctors, cancer nurses, dietitians, physios, etc) |
| 15. Was your GP informed about your cancer care? What was your experience of care between your GP and specialist care? |
| 16. 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:

17.	Did you have an opportunity to ask about your prognosis?
18.	Did anyone discuss advance care planning or making future medical decisions with you?
19.	Did you receive or were you offered a referral for palliative care?

End-of-life care (if applicable):

20.	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)
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General Questions:

21.	Were you given information about your cancer diagnosis, treatment, care and recovery in a way that suited you (e.g. verbal, written, video)?
22.	Were you involved in discussions and how did you find the level of communication?
23.	People with cancer come from a range of diverse backgrounds, did you feel like the cancer care system recognised your unique needs?
24.	Are there any improvements you would like to see in the care provided to people with colorectal cancer and their families?

Table 10: 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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